

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

England & Wales · Charity number 1155577

## Details

---

|                |                                                         |
|----------------|---------------------------------------------------------|
| Other names    | IAPO                                                    |
| Status         | Registered                                              |
| Legal form     | Charitable company                                      |
| Company number | <a href="#">08495711</a>                                |
| Registered     | 2014-01-30                                              |
| Register       | <a href="#">View on the Charity Commission register</a> |

## Contact

---

|         |                                                                        |
|---------|------------------------------------------------------------------------|
| Address | Canopi<br>Unit A<br>Arc House<br>82 Tanner Street<br>London<br>SE1 3GN |
| Phone   | 02072508280                                                            |
| Email   | <a href="mailto:info@iapo.org.uk">info@iapo.org.uk</a>                 |
| Website | <a href="http://www.iapo.org.uk">www.iapo.org.uk</a>                   |

## Activities

---

**Objects:** THE OBJECTS OF THE ASSOCIATION ARE THE PROMOTION OF THE RELIEF OF SICKNESS AND PRESERVATION AND PROTECTION OF HEALTH FOR THE PUBLIC BENEFIT THROUGH FOSTERING PATIENT-CENTRED HEALTHCARE WORLDWIDE AND IN PARTICULAR BY DEVELOPING THE CAPACITY OF PATIENTS? ORGANISATIONS.

**Activities:** IAPO is a global alliance representing patients of all nations across all disease areas and promoting patient-centred healthcare across the world.

## Classification

---

- **How:** Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Charities Or Voluntary Bodies, The General Public/mankind

## Geography

---

- Afghanistan
- Akrotiri
- Albania
- Algeria
- American Samoa
- Andorra
- Angola
- Anguilla
- Antarctica
- Antigua And Barbuda
- Argentina
- Armenia
- Aruba
- Australia
- Austria
- Azerbaijan
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia
- Bosnia And Herzegovina
- Botswana
- Brazil
- British Indian Ocean Territory
- British Virgin Islands
- Brunei
- Bulgaria
- Burkina Faso

- Burma
- Burundi
- Cambodia
- Cameroon
- Canada
- Cape Verde
- Cayman Islands
- Central African Republic
- Chad
- Chile
- China
- Christmas Island
- Cocos (KEELING) ISLANDS
- Colombia
- Comoros
- Congo
- Congo (Democratic Republic)
- Cook Islands
- Costa Rica
- Croatia
- Cuba
- Cyprus
- Czech Republic
- Denmark
- Dhekelia
- Djibouti
- Dominica
- Dominican Republic
- East Timor
- Easter Island
- Ecuador
- Egypt
- El Salvador
- Equatorial Guinea
- Eritrea

- Estonia
- Eswatini
- Ethiopia
- Falkland Islands
- Faroe Islands
- Fiji
- Finland
- France
- French Guiana
- French Polynesia
- Gabon
- Georgia
- Germany
- Ghana
- Gibraltar
- Greece
- Greenland
- Grenada
- Guadeloupe
- Guam
- Guatemala
- Guernsey
- Guinea
- Guinea-bissau
- Guyana
- Haiti
- Honduras
- Hong Kong
- Hungary
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland

- Isle Of Man
- Israel
- Italy
- Ivory Coast
- Jamaica
- Japan
- Jersey
- Jordan
- Kazakhstan
- Kenya
- Kiribati
- Kosovo
- Kuwait
- Kyrgyzstan
- Laos
- Latvia
- Lebanon
- Lesotho
- Liberia
- Libya
- Liechtenstein
- Lithuania
- Luxembourg
- Macau
- Macedonia
- Madagascar
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Martinique
- Mauritania
- Mauritius

- Mayotte
- Mexico
- Micronesia
- Moldova
- Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
- Mozambique
- Namibia
- Nauru
- Nepal
- Netherlands
- New Caledonia
- New Zealand
- Nicaragua
- Niger
- Nigeria
- Niue
- Norfolk Island
- North Korea
- Northern Ireland
- Northern Mariana Islands
- Norway
- Occupied Palestinian Territories
- Oman
- Pakistan
- Palau
- Panama
- Papua New Guinea
- Paraguay
- Peru
- Philippines
- Pitcairn, Henderson, Ducie And Oeno Islands

- Poland
- Portugal
- Puerto Rico
- Qatar
- Romania
- Russia
- Rwanda
- Réunion
- Saint Barthélemy
- Saint Helena
- Saint Pierre And Miquelon
- Saint Vincent
- Samoa
- San Marino
- Saudi Arabia
- Scotland
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Sint Maarten
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Georgia And South Sandwich Islands
- South Korea
- South Sudan
- Spain
- Sri Lanka
- St Kitts And Nevis
- St Lucia
- Sudan

- Suriname
- Svalbard And Jan Mayen
- Sweden
- Switzerland
- Syria
- São Tomé And Príncipe
- Taiwan
- Tajikistan
- Tanzania
- Thailand
- The Bahamas
- The Gambia
- Togo
- Tokelau
- Tonga
- Trinidad And Tobago
- Tunisia
- Turkey
- Turkmenistan
- Turks And Caicos Islands
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United States
- United States Virgin Islands
- Uruguay
- Uzbekistan
- Vanuatu
- Venezuela
- Vietnam
- Wallis And Futuna
- Yemen
- Zambia
- Zimbabwe

- Throughout England And Wales

## Finances

| Period end | Income   | Expenditure | Assets   | Employees |
|------------|----------|-------------|----------|-----------|
| 2024-12-31 | £595,120 | £619,759    | £520,603 | 3         |
| 2023-12-31 | £620,727 | £608,257    | £545,242 | 3         |
| 2022-12-31 | £582,642 | £399,126    | £532,772 | 3         |
| 2021-12-31 | £380,706 | £270,656    | -        | -         |
| 2020-12-31 | £509,091 | £436,449    | £239,207 | 3         |

## Trustees

| Name                               | Role | Appointed  |
|------------------------------------|------|------------|
| Agron Bytyqi                       |      | 2024-12-04 |
| Dr Sita Ratna Devi Duddi MBBS, MBA |      | 2024-12-04 |
| Dr Wael Kamel Ali Ali Mazrouh      |      | 2025-11-15 |
| Fernanda Souza de Carvalho         |      | 2023-12-06 |
| Flavia Kyomukama                   |      | 2023-12-06 |
| Orajitt Bumrungskulswat            |      | 2020-12-15 |
| Paul Albert Sumat Mendoza          |      | 2022-02-26 |
| Prof Lara Claire Bloom             |      | 2022-02-26 |
| Vasiliki Rafaela Vakouftsi         |      | 2024-12-04 |

**INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

England & Wales - Charity number 1155577

---

# Accounts

---



**International Alliance of  
Patients' Organizations**

Company registration number (England and Wales): 08495711

Charity registration number (England and Wales): 1155577

## **International Alliance of Patients' Organizations**

**(Incorporated as a Company Limited by Guarantee  
and not having a Share Capital)**

---

### **Annual Report and Financial Statements for the Year Ended in December 2024**

## Contents

---

|                                                                                                                                        |    |
|----------------------------------------------------------------------------------------------------------------------------------------|----|
| Reference and Administrative Details of The Charity, Its Trustees and Advisers                                                         | 3  |
| Trustees' Report for the Year Ended 31 December 2024                                                                                   | 4  |
| Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31st December 2024 | 30 |
| Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the Year Ended 31 December 2024                | 32 |
| Balance Sheet as at 31 December 2024                                                                                                   | 33 |
| Notes to the Financial Statements for the Year Ended 31 December 2024                                                                  | 35 |

## Reference and Administrative Details of the Charity, its Trustees and Advisers

|                                                        |                                                                                                                                                                                                                                                                                                                                                                                             |
|--------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Company number</b>                                  | 08495711 (England and Wales)                                                                                                                                                                                                                                                                                                                                                                |
| <b>Charity number</b>                                  | 1155577 (England and Wales)                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Registered office</b>                               | International Alliance of Patients' Organizations<br>Canopi, 82 Tanner Street, London, SE1 3GN, UK                                                                                                                                                                                                                                                                                          |
| <b>Governing Board members<br/>(Board of Trustees)</b> | Ellos Ellard Lodzeni<br>Professor Lara Claire Bloom<br>Adebisi Omolola Bright (Resigned 4 Dec 2024)<br>Orajitt Bumrungskulswat<br>Anthony John Holland (Resigned 4 Dec 2024)<br>Flavia Kyomukama<br>Paul Albert Sumat Mendoza<br>Fernanda Souza de Carvalho<br>Mr. Agron Bytyqi (Joined 4 Dec 2024)<br>Dr. Ratna Devi (Joined 4 Dec 2024)<br>Vasiliki-Rafaela Vakouftsi (Joined 4 Dec 2024) |
| <b>Chief Executive</b>                                 | Daniela Espindula Mothci                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Bankers</b>                                         | NatWest Bank Plc<br>PO Box 12258<br>1 Princes Street<br>LONDON<br>EC2R 8BP                                                                                                                                                                                                                                                                                                                  |
| <b>Independent auditor</b>                             | Knox Cropper LLP<br>65 Leadenhall Street<br>London<br>EC3A 2AD                                                                                                                                                                                                                                                                                                                              |
| <b>Website</b>                                         | <a href="http://www.iapo.org.uk">www.iapo.org.uk</a>                                                                                                                                                                                                                                                                                                                                        |

## Trustees' Report for the Year Ended 31 December 2024

The directors, who are also the trustees of the charity, are pleased to present their report together with the financial statements of the charity for the year ended 31 December 2024 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

IAPO Trading Limited (company number 08863190) was dormant and was dissolved in July 2024.

The trustees have complied with the duty to have due regard to guidance issued by the Charity Commission and have adopted the Statement of Recommended Practice for charities (SORP) (FRS 102 second edition effective 1 January 2019).

### Aims and objectives of the organisation

The objects of the International Alliance of Patients' Organizations (IAPO), as set out in the articles of association, are the promotion of the relief of sickness and preservation and protection of health for the public benefit through fostering patient-centred healthcare worldwide and in particular by developing the capacity of patients' organisations.

IAPO is a unique global alliance representing patients of all nationalities, across all disease areas, and promoting patient-centred healthcare around the world. IAPO brings a global patient voice to healthcare decision-making based on the belief that patients' voices are amplified and heard effectively when patients' organisations are linked, can share best practices and practical strategies, and are connected with resources. Our members are patients' organisations working at the international, regional, national and local levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability.

IAPO was first established in 1999 in the Netherlands as a Dutch Stichting and subsequently deregistered, registering in England and Wales as a company limited by guarantee on 19 April 2013 and a charity on 30 January 2014. IAPO has a membership of nearly 300 organisations across 71 countries covering 51 diseases groups. IAPO is a non-State Actor in official relations with the World Health Organization (WHO) and has a memorandum of understanding with the International Council of Nurses (ICN), International Hospital Federation (IHF), International Pharmaceutical Federation (FIP), World Medical Association (WMA), International Society for Quality in Health Care (ISQua), The Professional Society for Health Economics and Outcomes Research (ISPOR), The Union for International Cancer Control (UICC), and with many other Non-State Actors.

### IAPO's vision and mission

IAPO's **vision** is that patients throughout the world are at the centre of healthcare.

IAPO's **mission** is to help build patient-centred healthcare worldwide by:

## Trustees' Report for the Year Ended 31 December 2024

- ❖ Realizing active partnerships with patients' organisations, maximizing their impact through capacity building
- ❖ Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
- ❖ Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives

### IAPO's activities include:

- ❖ Advocacy at global level on relevant aspects of healthcare policy to influence international health agendas and policies
- ❖ Providing membership services, including capacity building and shared learning, to its members, who are patient-led organisations across the world
- ❖ Empowering its members to undertake their own advocacy at regional and national meetings
- ❖ Providing opportunities for stakeholders from across the health sector to meet and work together to advance patient involvement in health services and decision-making
- ❖ Research on emerging areas of interest to patients' organisations and to underpin the evidence base for showing the importance of patient involvement to public health.

### Structure

The organisation is a charitable company limited by guarantee, incorporated on 19 April 2013 and registered as a charity on 31 January 2014. The company was established articles of association which define the objects and powers of the company and its governance arrangements. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

All assets and liabilities from the International Alliance of Patients Organizations and its predecessor not-for-profit structure registered in the Netherlands, were transferred to the new UK incorporated charity on 1 February 2014. IAPO Netherlands was (voluntarily) dissolved from the Netherlands Trade Register with effect from 31 May 2015, executed on 21 October 2015.

### Appointment and induction of Governing Board

Every member of the IAPO Governing Board is elected by IAPO's members, through a process defined in the [articles of Association](#), [by-laws](#) and [election code of conduct](#). Every year, in advance of the annual general meeting (AGM), the number of vacancies on the Board is notified to all members, who may then nominate someone from their organisations (a Board member or senior staff member) to IAPO's

### Trustees' Report for the Year Ended 31 December 2024

Governing Board. The full list of nominees is sent to all members in advance of the AGM; members may vote by post or proxy or in person at the AGM.

Governing Board members serve for a maximum of two terms subject to the retirement by rotation clause; once their term of service is complete, they or anyone from their organisation cannot be re-elected to the Board for at least a year. All new members of the Board receive induction including core information about the work and history of the organisation, and conversations with the Chief Executive Officer and the Chair.

All Governing Board members sign a code of conduct when they are appointed to the Board. All staff and Governing Board members are required to declare any relevant conflict of interests or conflict of loyalties at every Board meeting, or between meetings if applicable. The Governing Board have no beneficial interest in the charitable company or its trading subsidiary. No Governing Board member receives any remuneration, but some receive reimbursement for essential travel or similar expenses.



Trustees' Report for the Year Ended 31 December 2024



Governance

The International Alliance of Patients' Organizations has a Board of Trustees and Directors overseeing its governance and direction, supported by a secretariat headed by the Chief Executive Officer.

| Board of Trustees/Directors    |              |                |                  |
|--------------------------------|--------------|----------------|------------------|
| Name                           | Position     | Country        | Dates            |
| Mr. Ellos Ellard Lodzeni       | Chair        | Malawi         |                  |
| Prof. Lara Claire Bloom        | Vice Chair   | United Kingdom |                  |
| Mr. Paul Albert Mendoza        | Secretary    | Philippines    |                  |
| Mrs. Orajitt Bumrungruskulswat | Board Member | Thailand       |                  |
| Ms. Flavia Kyomukama           | Treasurer    | Uganda         |                  |
| Ms. Fernanda Souza de Carvalho | Board Member | Brazil         |                  |
| Mr. Agron Bytyqi               | Board Member | Kosovo         | Since 4 Dec 2024 |
| Dr. Ratna Devi                 | Board Member | India          | Since 4 Dec 2024 |
| Vasiliki-Rafaela Vakouftsi     | Board Member | Greece         | Since 4 Dec 2024 |



## Trustees' Report for the Year Ended 31 December 2024

### Public benefit

The Governing Board confirms that they have considered the guidance contained in the Charity Commission's general guidance on public guidance when reviewing the charity's aims and objectives. They consider that the activities carried out, summarised in the Achievements and Performance section of this report, provide benefit to the public.

IAPO's objects are the promotion of the relief of sickness and the preservation and protection of health for the public benefit. IAPO pursues this through fostering patient-centred healthcare worldwide and, in particular, by developing the capacity of patients' organisations.

In setting our objectives and planning our activities trustees have given consideration to the Charity Commission's general guidance on public benefit (PB1, PB2 and PB3) and have taken these into account in making all decisions. We have not departed from the guidance in 2024.

IAPO's services are open to all people and our membership reflects a diverse group of patients' organisations representing patients with communicable and non-communicable diseases, including patients with diseases that are stigmatised in many societies.

IAPO had 278 members comprising umbrella groups and single organisations in 2024 who directly represented views of over 1 million patients in 72 countries across 54 disease areas. The services the charity provides are designed to build the capacity of patients' organisations, allowing them to better assist the needs of patients and carers (and their own member patient organisations in some cases) from across the world.

Access to IAPO's website is freely available to the public. Currently it is in English, with some sections in Spanish. The website contains a wide range of information on IAPO's activities and on patient-centred healthcare, which is of benefit to the public, particularly those who wish to set up local patients' organisations.

By improving access to information, training and other capacity building programmes for patients and their representative organisations, IAPO improves access to healthcare itself. By raising awareness and through capacity building and education, we increase access to acceptable services that respect patients' preferences, values, rights and needs.

IAPO has a wealth of evidence, gained from patients' organisations worldwide, which demonstrates that patient involvement in patients' care leads to better health outcomes and lower costs for the whole of society. The charity works with patients' organisations that are not for profit and non-governmental organisations who demonstrate commitment to improving patient-centred healthcare which is reflected in the charity's membership criteria.

## Trustees' Report for the Year Ended 31 December 2024

### Chair's Report for the Financial Year 1st January to 31st December 2024

The year 2024 marked a significant period of transition for our organisation, laying the groundwork for a new strategic direction.

The appointment of Dani Mothci as the new CEO in August 2023 followed by the celebrations of our 25<sup>th</sup> anniversary in 2024, triggered a pivotal moment of realignment of goals, and strengthening of our governance and operations.

Throughout the year, we remained deeply committed to supporting our member organisations, to engaging with the World Health Organization through our status of Non-State Actor in official relations with them, and fulfilling our obligations to both longstanding and newly established partners and funders. These relationships have been vital to sustaining our mission, and we are grateful for the continued trust and support from our community. At the same time, we laid the foundation for a renewed and resilient future: one built on collaboration, shared values, and strengthened partnerships.

A major area of focus in 2024 was strengthening our governance. We dedicated time and resources to ensure that our structures and practices reflect the highest standards of accountability, transparency, and effectiveness. This work positions us to respond more effectively to the challenges and opportunities ahead.

To support our growing ambitions, we expanded our team by hiring a new administration officer, helping to improve our day-to-day operations and internal coordination. Alongside this, we invested in operational improvements, including streamlining internal processes and adopting new digital tools to enhance efficiency and collaboration.

We also launched a new impact strategy, including a new vision, mission and strategic framework: FACE – facilitation, advocacy, collaboration and empowerment. The impact strategy sets a clear direction for the coming years, supported by a refreshed brand identity that reflects this exciting new chapter. These developments have helped articulate our mission and values more clearly, both internally and externally.

Finally, and most importantly, we made a conscious effort to deepen our engagement with our member organisations, ensuring their voices, perspectives, and experiences are at the heart of everything we do. Their active involvement has been instrumental in shaping our initiatives, and we remain committed to working with and for our global patient organisation community.

As we look ahead, we do so with a renewed sense of purpose, a strengthened foundation, and deep gratitude for the resilience and dedication of our board members, staff, member organisations, partners, and supporters.



**Ellos Ellard Lodzeni**  
**Chair of IAPO Governing Board**

## Trustees' Report for the Year Ended 31 December 2024

### Achievements and Performance

In 2024, IAPO continued its journey of collaboration, advocacy and innovation to advance patient-centred healthcare globally. This report presents our 2024 highlights organized according to the IAPO Strategic Plan 2022-2024.

#### Goal 1: **EMPOWER**

Empower members with cutting- edge knowledge and advocacy skills to enhance the reach, efficacy, and impact of our membership in bringing about a Patient-Centred (PC) and Pandemic Prepared (PP) Universal Health Coverage (UHC).

 In 2024, IAPO proudly celebrated its [25th anniversary](#), reflecting on the quarter century journey we have been on as an alliance championing patient-centred healthcare globally. To mark this milestone, we launched our [new impact strategy](#) to guide our efforts through 2025 and beyond. This includes an updated vision and mission, as well as IAPO's new FACE – a strategic framework standing for **F**acilitation, **A**dvocacy, **C**ollaboration and **E**mpowerment.

- **Vision:**  
A world where health systems are shaped by the unique needs and preferences of the people and communities they represent.
- **Mission:**  
Mobilise and support patient organisations around the world, empowering them to play an active role in decision-making processes shaping the global health landscape.
- **FACE strategic framework:**  
Facilitation  
Advocacy  
Collaboration  
Empowerment

 As part of our **25th anniversary celebrations**, we also launched a special 4-episode web series titled [‘IAPO Turns 25’](#) spotlighting the voices of our global membership. Each of the 4 episodes featured members exploring a pillar of our new FACE framework and sharing what these pillars mean to them and their communities.

## Trustees' Report for the Year Ended 31 December 2024

- ◆ We celebrated [Patient Solidarity Day \(PSD\)](#) on 9 December 2024 under the theme 'The Power of Community', which highlighted the collective strength of the IAPO patient organisation community built over the last 25 years. PSD 2024 showcased this community as a powerful testament to what can be achieved when patient organisations come together to take control of their journeys, amplify their voices, and advocate for healthcare systems that prioritise the needs of patients and communities.
  - To mark PSD 2024, IAPO members contributed with video testimonials, sharing their perspectives on the strengths of the global patient organisation community. These insights were brought together as [a special playlist on IAPO's YouTube channel](#), showcasing diverse and compelling interpretations of this concept from different regions around the world.
- ◆ Through the [Personalised Cancer Care Alliance \(PCC Alliance\)](#), IAPO hosted a [capacity-building workshop](#) in **Morocco**, bringing together 18 patient advocates from the country. The workshop served as a platform for exchanging ideas, forging collaborations, and laying the groundwork for initiatives aimed at integrating the personalised approach to cancer care in Morocco.
- ◆ Additionally, through the **PCC Alliance**, we hosted a **second regional capacity-building workshop in Dubai** for cancer patient organisations from countries of the Gulf Confederation (GCC), where we also had the participation of the WHO Office for the Eastern Mediterranean Region. The workshop culminated in a collaborative roadmap translating the action points agreed by the group to advance personalised cancer care.
- ◆ As part of IAPO's efforts to advance social participation in healthcare, we co-hosted a webinar with the Civil Society Engagement Mechanism for UHC2030 (CSEM) and Frontline Aids, titled ["What's next? Follow-up on the resolution on social participation for universal health coverage: Translating global commitments into national action"](#). The webinar was a moment for participants to share valuable insights, lessons learned, and strategies for sustaining political support for social participation at both global and national levels.
- ◆ As a member of the World Skin Health Coalition, IAPO joined the ["Not Just My Skin" campaign](#): a collaborative effort to raise global awareness about the significant impact of skin diseases and conditions on patients, people with lived experience and communities. The campaign addressed the urgent need for timely diagnosis, access to care and affordable treatment, and mental health support for people with skin conditions, advocating for the prioritisation of these critical issues by health policy leaders worldwide. The campaign was a massive success and acted as a spark that ignited a global movement to act for better and more equitable skin healthcare.

## Trustees' Report for the Year Ended 31 December 2024

- ❖ As part of our involvement in the Global Patient Think Tank (GPTT), a group of patient representatives from across the globe convened by Roche, **IAPO co-created and launched the [UHC Compass](#)**. The compass was designed by patients, for patients, to support local leaders and communities in advancing decision-making and progress toward universal health coverage (UHC) on the ground. In addition to providing accessible knowledge on UHC, the UHC Compass offers self-assessment resources and case studies to help patient organisations develop their capabilities in playing an active role in decision-making processes in health.
- ❖ As a founding and steering committee member of the [African Medicines Agency Treaty Alliance \(AMATA\)](#), IAPO together with its partners finalised the **AMATA Toolkit**. This toolkit aims to support AMATA members and their networks in advocating for the operationalisation of the African Medicine Agency, a continental regulatory body which will ensure timely access to quality medicines that are safe and effective for all patients in Africa.
- ❖ IAPO joined global health stakeholders in celebrating the annual [World Patient Safety Day](#) (WPSD), a WHO-led initiative observed yearly on 17 September. Through the 2024 theme of "Improving diagnosis for patient safety," we actively promoted the campaign among our members and wider network, raising awareness about the critical importance of correct and timely diagnosis in ensuring patient safety and improving health outcomes.
  - As part of the global celebration of WPSD 2024, IAPO joined a webinar panel hosted by [Joint Commission International](#), titled "**Diagnostic Safety: The Multidisciplinary Approach**". Representing the patient perspective, we highlighted the importance of a patient-centred, collaborative approach to diagnostic safety underscoring how multidisciplinary cooperation is essential to achieving accurate and timely diagnoses that protect and empower patients.
  - IAPO also marked WPSD 2024 by **co-creating a global social media campaign** in collaboration with GS1 Healthcare, the European Association of Hospital Pharmacists (EAHP), the International Hospital Federation (IHF), and the International Society for Quality in Health Care (ISQua). This joint effort aimed to raise awareness and promote patient safety worldwide, reinforcing the importance of coordinated action across the healthcare community.

## Trustees' Report for the Year Ended 31 December 2024

-  IAPO participated in the **PEOF Virtual Session "Catalyzing Change: Using the WHO Resolution on Social Participation in health to achieve real patient-driven impact,"** where we discussed how patient voices can shape more inclusive health policies and systems for universal health coverage. The session was a unique opportunity to co-create actionable plans to advance the WHO resolution on social participation and drive meaningful change in health systems worldwide.
-  We advanced the **Patient Academy** website by collaborating on additional modules, involving patients in creating videos, and fostering engagement through social media awareness posts. The vision of the Patient Academy is to create communities of empowered patients who take ownership of the management of their medical condition through customized health information.
-  We launched a **new toolkit** on biosimilar medicines, titled **"Toolkit to Become an Informed Patient: Deciphering the World of Biosimilar Medicines."** This toolkit was created to empower and equip patient organisations with essential insights into the science, regulatory landscape, and benefits of biosimilars.
-  We launched an **AI-based application** called **EczemaLess App**, aiming to support patients in tracking and managing Atopic Dermatitis. The app also assists patients in setting up a care routine and tracking trigger factors, as well as providing insights and educational videos to raise awareness about this condition.

## Strategy Goal 2: DRIVE RESEARCH

Co-create evidence in support of healthcare that is PC, PP and a UHC that strengthens patient involvement in clinical research and global health institutes.

-  IAPO conducted the **Unmet Patient Needs Research**, where we co-designed a survey with IAPO members to gather valuable insights about unmet health-related needs from the perspective of patients and people with lived experience. The research project deliverables consist of a comprehensive analytical report and a set of advocacy briefs to be launched in 2025.
-  We launched the report of our commissioned research project **"Improving Breast Cancer in the Middle East and Africa"** at an online panel discussion where we highlighted its key findings and potential as an advocacy tool featuring the involvement of patient representatives.
-  We continued our support to the **international research project EOLinPlace** both as part of the **Patient Advisory Group** and as the project's patient representative. Through IAPO board member

## Trustees' Report for the Year Ended 31 December 2024

Flavia Kyomukama, we participated in the work retreat advising and contributing to the development of the International Classification of Dying Places. This project is hosted by the University of Coimbra and is the largest study of international time trends in place of death and the first showing a rise of home deaths in the COVID-19 pandemic across countries.

- IAPO also continued to participate as a member of the **BMJ Group International Patient and Public Advisory Panel**, advising within the different working groups, including the ones on Patient Safety and Healthcare Sustainability.

### Strategy Goal 3: **SHAPE LAW, POLICY, STANDARDS**

Apply the empowered patient community and evidence created to shape the institutional, law, policy, practice, and standards framework for healthcare that is PC, PP and a UHC at global, regional, and national levels.

- As part of our role as a Non-State Actor in official relations with the WHO, we developed and submitted our final report on the **IAPO-WHO Triennial Collaboration Plan (2022-2024)** for review by the WHO Executive Board, as well as our **new plan for the next three years of the collaboration (2025-2027)**. Both the final report and the **IAPO-WHO Triennial Collaboration Plan (2025-2027)** were approved and our status as Non-State Actor in official relations with the WHO was renewed for the next three years.
- We participated in the [World Patient Safety Day 2024 Global Consultation](#) 'Improving diagnostic safety and implementing the Global Patient Safety Action Plan 2021-2030', to discuss the strategies for enhancing diagnostic processes and reducing diagnostic errors and reflecting on the progress and challenges in implementing the Global Patient Safety Action Plan 2021-2030. On the occasion, we joined working groups and integrated the panel "How stakeholders can accelerate the implementation of the Global Patient Safety Action Plan" as representatives of patient and civil society organisations.
- In collaboration with The Synergist, we jointly hosted the [side event](#) "**Leveraging patient organisations as key partners in the delivery of Universal Health Coverage**" on the side-lines of the 77th World Health Assembly (WHA77) in Geneva. The event brought together 80 participants and discussed the importance of social participation in the delivery of universal health coverage, highlighting patient organisations' fundamental role in shaping patient-centred health systems.

## Trustees' Report for the Year Ended 31 December 2024

- ❖ As a member of the Global Self-Care Coalition, IAPO participated in the [1st Global Self-Care Summit](#), titled 'Self-Care in Action: Empowering Health and Well-Being', on the side-lines of WHA77 in Geneva. The event highlighted the relevance of self-care in achieving global health goals, including the health-related SDG targets, universal health coverage, NCD prevention and control, and improving access and quality of primary health care.
- ❖ IAPO joined the speaker panel of the side event "[Uniting Voices for Action on Women Cancer in the Eastern Mediterranean Region](#)", promoted by the NCD Alliance on the side-lines of WHA77. This session catalysed efforts around women's cancers in the region and galvanized the EMR political commitment in ensuring women's cancer remains a central focus on the agenda of the upcoming UN High-Level Meeting on Non-communicable Diseases in 2025.
- ❖ IAPO delivered statements at the WHO Regional Committee meetings as follows:
  - In August 2024, IAPO delivered a [statement](#) on **Agenda item 18.1 of the 74th Session of WHO Regional Committee for Africa**. In alignment with the resolution on social participation for universal health coverage, health, and well-being, IAPO urged Member States from the African region to fully commit to its implementation. We also joined the **African Medicines Agency Treaty Alliance (AMATA)**, in delivering a statement at the same regional meeting calling upon the African Union Member States who have not yet ratified the African Medicines Agency Treaty to do so urgently, to enable the operationalization of a strong continental regulatory system with the ultimate objective of improving public health, patient safety and the quality of life for all people in Africa.
  - In October 2024, IAPO delivered a [statement](#) on **Agenda item 8.2 of the 77th Session of the WHO Regional Committee for South-East Asia**. IAPO's statement urged Member States to fully commit to the resolution on social participation for universal health coverage, health, and well-being, stressing that engaging patients, communities, and people with lived experience in policy design and implementation is key to accelerating progress toward safe, quality, equitable, and people-centred healthcare policies across South-East Asia.
  - In October 2024, IAPO delivered a [statement](#) on **Agenda item 9 of the 74th Session of the WHO Regional Committee for Europe**. IAPO's statement called on Member States to commit fully to the resolution on social participation for universal health coverage, health, and well-being, emphasising that involving patients, communities, and people with lived experience in policy design and implementation is essential to advancing safe, quality, equitable, and people-centred healthcare policies throughout Europe.

## Trustees' Report for the Year Ended 31 December 2024

- ◆ IAPO co-authored an [editorial for the BMJ in July](#), highlighting the resolution on social participation for universal health coverage, health and well-being. Titled **"World leaders unite to embed social participation in health systems"** and published in the BMJ's patient-led issue **"Patient Partnership: Time for patients to have a seat at every table,"** the editorial delves into the critical role of social participation as a pressing need and fundamental right in health policy design and practices while discussing strategies to amplify the patient voice across all levels of healthcare systems.
- ◆ As a founding partner of the [International Consensus Framework for Ethical Collaboration](#), IAPO attended a roundtable meeting in May to mark the **10th Anniversary of the Framework**. At the meeting, partners discussed the importance and timeliness of these principles in building ethical and trustful partnerships aimed at delivering greater patient benefits. An outcome of this session was the agreement to review the framework, modernise its language and introduce a fifth principle on upholding the responsible use of health data and technology.
- ◆ To further celebrate the [10th Anniversary of the International Consensus Framework for Ethical Collaboration](#) as well as **Global Ethics Day**, IAPO joined other founding partners including International Council of Nurses (ICN), International Federation of Pharmaceutical Manufacturers and Associations (IFPMA), International Pharmaceutical Federation (FIP), and World Medical Association (WMA), [in publishing a joint op-ed](#), where we reflected on progress made under the Framework over the last decade and announced our commitment to ensuring it is fit-for-purpose to address unfolding new realities, including the impact of new innovations on patients' lives.
- ◆ IAPO joined a coalition of patient groups, informal carers (Eurocarers), and palliative care professionals from the International Association for Hospice and Palliative Care (IAHPC) and the International Children's Palliative Care Network (ICPCN) in issuing [a statement on home support for patients with advanced diseases and their families](#). The statement urged governments to enhance home support for patients with advanced diseases and their families who prefer to receive care and pass away at home whenever feasible. This call came in response to findings from the [EOLinPlace](#) research project, the largest study to date on international time trends in place of death, where IAPO serves as the patient representative and participates in the Patient Advisory Group.
- ◆ IAPO continued to be part of the [Global Patient Think Tank \(GPTT\)](#), a diverse group of patient community representatives from across the globe, convened by Roche. The GPTT has come together to ensure the patient community voice is integrated into the global movement for universal health coverage, including policy discussion, inclusion into national design, governance and implementation, and at the primary healthcare level.

## Trustees' Report for the Year Ended 31 December 2024

---

- ❖ IAPO spoke at the [6th Global Ministerial Summit on Patient Safety in Chile](#), a platform that plays a vital role in driving forward the patient safety agenda, shaping policies, and catalysing action to ensure safer and more effective healthcare delivery worldwide.
- ❖ As a founding member of the African Medicines Agency Treaty Alliance (AMATA), IAPO joined the alliance in publishing a [statement during the 37th African Union Summit](#), in February 2024. The statement urged Member States to expedite the ratification and operationalisation of the African Medicines Agency Treaty to ensure timely access to quality medicines for all patients in Africa.
- ❖ In response to the revision of the **Declaration of Helsinki**, which has long stood as a foundational text in medical research ethics, shaping the ethical principles that govern human participation in clinical research, IAPO – through our board member Prof. Lara Bloom – published an [article](#) to contextualise the history of the Declaration, analyse the implications of its latest revision, and emphasize the need for patient centricity in research ethics.
- ❖ IAPO continued to be a member of the [WHO Civil Society Commission \(CSO\)](#) and applied to join the **working group “CSO engagement strategy”**, which together with the WHO Secretariat will co-develop the **WHO Civil Society Engagement Strategy 2025-2028**.



### IAPO's Annual General Meeting

We held our Annual General Meeting in December 2024, where we celebrated IAPO's 25<sup>th</sup> anniversary by unveiling our new impact strategy for 2025 and beyond and introducing our new FACE framework designed to guide our efforts in empowering patient organisations to drive meaningful change globally. We also unveiled our new brand identity as a first step in our rebranding process which will culminate in the launch of a new website. We also launched a special four-episode web series titled '[IAPO Turns 25](#)' featuring our global membership. We also announced the newly elected and re-elected Governing Board Members.

## Trustees' Report for the Year Ended 31 December 2024

### Communications

#### Newsletter & mailing

IAPO maintained its newsletter subscription of over 12,000 subscribers, who receive our announcements, campaigns and monthly newsletter covering all IAPO-related news and updates, including initiatives such as our congresses, member activities, advocacy news and information. We also added to the newsletter a section on relevant updates about the World Health Organization (WHO), including new policy documents and guidelines, important dates and advocacy campaigns. We also used several mailing campaigns to disseminate and promote important IAPO initiatives and events throughout the year.

#### X (formerly Twitter)

The IAPO secretariat continued to operate the following X accounts: [@IAPOvoice](#), [@PatientSolidarityDay](#), [@AfricanAmata](#), [@PCCAlliance](#).

#### Facebook

We continued to operate the following Facebook accounts: [IAPOvoice](#), [International Alliance of Patients' Organizations](#), [Patient Solidarity Day](#), [Personalised Cancer Care Alliance](#).

#### LinkedIn

IAPO also continued to operate the following LinkedIn accounts: [International Alliance of Patients' Organizations](#), [African Medicines Agency Treaty Alliance \(AMATA\)](#), [Personalised Cancer Care Alliance](#).

#### YouTube

We continued to operate IAPO's YouTube channel – [@IAPOPatientVoice](#) – which is currently composed of 235 videos.

#### Website



[www.iapo.org.uk](http://www.iapo.org.uk)

IAPO's website continues to be the main source of information for all IAPO's activities, initiatives and events, as well as an important promotion and dissemination channel.

#### UHC Compass landing page



[www.tinyurl.com/uhccompass](http://www.tinyurl.com/uhccompass)

## Trustees' Report for the Year Ended 31 December 2024

In 2024, IAPO co-created and launched the **UHC Compass**, an evolving resource to support local leaders and communities in advancing decision-making and progress toward universal health coverage in their countries. The UHC compass can be accessed as a stand-alone landing page or through the IAPO website.

### Rebranding

As part of our celebrations to mark IAPO's 25th Anniversary in 2024, we developed and launched a new logo as the starting point of our wider rebranding, which will culminate in the launch of our new website in 2025.

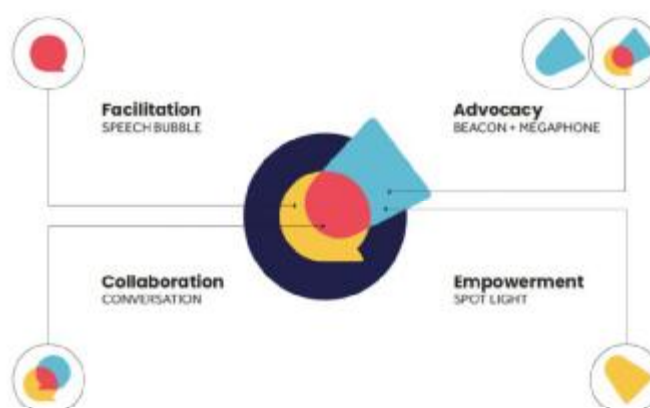
Besides marking the anniversary, a new branding system was needed for several reasons. The old logo had an outdated design with limited colour palette and unclear figures, was not accessible whenever applied to different backgrounds, and ultimately did not link with the IAPO's impact strategy for 2025 and beyond.

The new logo combines the concepts of 'communicate' through the yellow speech bubble, 'empower' through the blue beacon. Both shapes combined result in the multi-colour megaphone standing for the concept of 'amplify'. Altogether, our new icon translates IAPO's support and mobilisation to our IAPO membership and the wider global patient organisation community.

Below are some of the different uses of our new logo when applied against a white background:



Here are the links between the new logo concept and IAPO's FACE framework:



Trustees’ Report for the Year Ended 31 December 2024

Membership

IAPO continued to strengthen its member network in 2024 supporting its 278 members. IAPO is currently implementing software to streamline the entire membership management, from outreach to invoicing and engagement. As of 31st December 2024, IAPO members were:

| Region                        |     |
|-------------------------------|-----|
| African members               | 43  |
| Eastern Mediterranean members | 10  |
| European members              | 96  |
| Latin American members        | 67  |
| North American members        | 24  |
| South-East Asian member       | 14  |
| Western Pacific members       | 24  |
| TOTAL                         | 278 |

| Membership Type |     |
|-----------------|-----|
| Full            | 99  |
| Associate       | 37  |
| Network         | 142 |
| Affiliate       | 0   |
| TOTAL           | 278 |

## Trustees' Report for the Year Ended 31 December 2024

### Risk Management

A risk register is prepared by the CEO and presented annually to the Board to discuss ensuring that there are effective and adequate risk management and internal control systems in place to manage the major risks to which the Charity is exposed. IAPO prepares the risk register by understanding the risk environment and its operations and then identifies the key risks. The CEO and the Treasurer then undertake a thorough analysis and evaluation of the risks identified before coming up with a treatment for the risks.

Risks are identified under headings of Financial, Funding, Governance, Operational and Personnel, and mitigation actions detailed.

IAPO aims to diversify its funding by approaching international trust funds, international development agencies and large programmes to raise non-industry partner funding.



## Trustees' Report for the Year Ended 31 December 2024

### Financial Review

#### Financial position at the end of the period

Incoming resources for the year amounted to £595,120 (2023: £620,727), which was higher than the previous year due to a strategic increase in research and special projects funded by our partners.

Expenditure in 2024 was £619,759 (2023: £608,257). Expenditure is also higher than the previous year, in line with the fact that we increased our output in research and Special Projects.

#### Reserves Policy

The IAPO Board approved a reserves policy in September 2014, with a target level of free reserves of 6-12 months' running costs. 6 months running cost is c.£132,280. This policy was set with due regard to guidance from Charity Commission (CC19 – Charity Reserves) and is reviewed annually.

The level of unrestricted reserves, as at 31st December 2024 is £240,564. This is within the target in the reserves policy, and will be monitored by the Board of Trustees.

#### Going Concern

The trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. Our current partners and funders have been very receptive to new proposals and wish to continue working with IAPO until the foreseeable future.

#### IAPO funding transparency

The Governing Board members declare relevant conflicts of interests and conflicts of loyalty at each Board meeting and between meetings. A register of interests is maintained.

Reference to IAPO's code of conduct and policy regulating IAPO's relationship with, and independence from, sponsors can be found at [www.iapo.org.uk/consensus-framework-ethical-collaboration](http://www.iapo.org.uk/consensus-framework-ethical-collaboration) and [www.iapo.org.uk/healthcare-industry-partners](http://www.iapo.org.uk/healthcare-industry-partners).

The overall proportion of industry to non-industry income for the year was approximately 99%.

## Trustees' Report for the Year Ended 31 December 2024

### Pension arrangements

IAPO operates an occupational pension scheme, and also operates a policy of contributions directly into staff members' chosen personal pension schemes, with no obligation for staff to make personal contributions. The issue of pension deficit, which would apply to an occupational scheme, does not therefore arise.



## Trustees' Report for the Year Ended 31 December 2024

### Future Plans

IAPO's Strategy for 2022-2024 is listed at:

<https://www.iapo.org.uk/sites/default/files/files/IAPO%20Strategy%202023-2024%20Draft.pdf>

Our vision, mission and tactical plans are adapted to build back better a patient-centred, pandemic prepared universal health coverage by 2030.

#### Vision 2022-2024

To ensure through global solidarity and national action that every patient enjoys healthcare that is:

-  Patient-centred (PC) (broader definition)
-  Pandemic prepared (PP)
-  A Universal Health Coverage (UHC)

#### Mission 2022-2024

-  Empower our members with cutting edge knowledge and advocacy skills in bringing about PC & PP UHC 2030.
-  Work with our membership, alliances, partners, and other stakeholders to drive research and policy development activity that establishes the evidence base needed in support of PC & PP UHC 2030 and strengthen patient involvement and co-creation in research.
-  Motivate the empowered patient community into using the evidence base created to shape the institutional, law, policy, practice, and standards framework needed for PC & PP UHC 2030 at global, regional (APEC, AU and EU etc) and national levels.

#### Tactical Plan 2022-2024

To attain PC (Broader Definition) and PP UHC 2030 it is important that IAPO advocates the delivery of:

-  Safe Healthcare
-  Quality Healthcare
-  Accessible Healthcare. Access is across four areas.
-  Non-Discriminatory Healthcare
-  Physically Accessible Healthcare
-  Information Accessibility
-  Affordable Healthcare
-  Acceptable Healthcare: Culturally Competent and Patient-Centred (Broader Definition)

## Trustees' Report for the Year Ended 31 December 2024

In addition to the above, IAPO is collaborating closely with the WHO Work Plan 13 and ensuring that the WHO flagship Global Patient Safety Action Plan 2022-2030 is translated and implemented into national patient safety institutional, legislative, policy, practice and standards through patient and family engagement and co-creation/coproduction.



## Trustees' Report for the Year Ended 31 December 2024

### Statement of Trustees' Responsibilities

The trustees (who are also the directors of the company for the purposes of company law) are responsible for preparing the trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial period which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including income and expenditure, of the charitable company for that period.

In preparing those financial statements, the trustees are required to:

- ❖ select suitable accounting policies and then apply them consistently;
- ❖ observe the methods and principles in the Charities SORP;
- ❖ make judgements and estimates that are reasonable and prudent;
- ❖ state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- ❖ prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable charity will continue in business.

The trustees are responsible for keeping proper accounting records, which disclose with reasonable accuracy at any time, the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

### Statement as to disclosure to our auditors

In so far as the trustees are aware at the date of approving this report:

- ❖ there is no relevant audit information, being information needed by the auditor in connection with preparing their report, of which the charity's auditor is unaware; and
- ❖ the trustees having made enquiries of fellow directors and the group's auditor that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a director in order to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

## Trustees' Report for the Year Ended 31 December 2024

### Reappointment of auditors

A proposal to reappoint Knox Cropper as the charity's statutory auditors will be put to members at our forthcoming annual general meeting.

Approved and authorised for issue by the Governing Board on 21 July 2025 and signed on their behalf by:



**Ellos Ellard Lodzeni**  
**Chair of IAPO Governing Board**



## Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31st December 2024

### Opinion

We have audited the financial statements of International Alliance of Patients' Organization for the year ended 31 December 2024 which comprise the Statement of Financial Activities (including the Income and Expenditure Account), the Balance Sheet and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- ◆ Give a true and fair view of the state of the charitable company's affairs as at 31 December 2024 and of its income and expenditure, for the period then ended;
- ◆ Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- ◆ Have been prepared in accordance with the requirements of the Companies Act 2006.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The other information comprises the information included in the Trustees' Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information.

## Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31st December 2024

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

### Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- ◆ The information given in the Trustees' Report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- ◆ The directors' report, included within the Trustees' Report, has been prepared in accordance with applicable legal requirements.

### Matters on which we are Required to Report by Exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- ◆ Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- ◆ The financial statements are not in agreement with the accounting records and returns; or
- ◆ Certain disclosures of Trustees' remuneration specified by law are not made; or
- ◆ We have not received all the information and explanations we require for our audit; or

## Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31st December 2024

- ◆ The trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Trustees' Report.

### Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

### Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- ◆ The Charitable Company is required to comply with both company law and charity law and, based
- ◆ The Charitable Company is required to comply with both company law and charity law and, based on our knowledge of its activities, we identified that the legal requirement to accurately account for restricted funds was of key significance.
- ◆ We gained an understanding of how the charitable company complied with its legal and regulatory framework, including the requirement to properly account for restricted funds,

## Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31st December 2024

through discussions with management and a review of the documented policies, procedures and controls.

- ◆ The audit team, which is experienced in the audit of charities, considered the charitable company's susceptibility to material misstatement and how fraud may occur. Our considerations included the risk of management override.
- ◆ Our approach was to check that all restricted income was properly identified and separately accounted for and to ensure that only valid and appropriate expenditure was charged to restricted funds. This included reviewing journal adjustments and unusual transactions.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

### Use of our report

This report is made solely to the charitable company's trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Liv Burrell (Senior Statutory Auditor)  
For and on behalf of Knox Cropper LLP (Statutory Auditor)  
65 Leadenhall Street  
London  
EC3A 2AD  
July 31, 2025

## Statement of Financial Activities (incorporating an income and expenditure account) for the Year Ended 31 December 2024

|                                                 |                                  |                     |                   | <b>Total<br/>2024</b> | <b>Total<br/>2023</b> |
|-------------------------------------------------|----------------------------------|---------------------|-------------------|-----------------------|-----------------------|
|                                                 | <b>N<br/>o<br/>t<br/>e<br/>s</b> | <b>Unrestricted</b> | <b>Designated</b> | <b>Restricted</b>     |                       |
|                                                 |                                  | <b>£</b>            | <b>£</b>          | <b>£</b>              |                       |
|                                                 |                                  |                     |                   | <b>(year)</b>         | <b>(year)</b>         |
|                                                 |                                  |                     |                   | <b>£</b>              | <b>£</b>              |
| <b>Income from charitable activities:</b>       |                                  |                     |                   |                       |                       |
| Membership                                      |                                  | 193                 | -                 | -                     | 193                   |
| Healthcare Industry Partners                    |                                  | 81,336              | -                 | -                     | 81,336                |
| APPC congress                                   |                                  | -                   | -                 | -                     | -                     |
| GPC congress                                    |                                  | -                   | -                 | -                     | -                     |
| Special Projects                                |                                  | -                   | -                 | 488,499               | 488,499               |
| Other charitable activities                     |                                  | 25,092              | -                 | -                     | 25,092                |
| <b>Total</b>                                    | <b>2</b>                         | <b>106,621</b>      | <b>-</b>          | <b>488,499</b>        | <b>595,120</b>        |
| <b>Expenditure on charitable Activities:</b>    |                                  |                     |                   |                       |                       |
| Charitable activities:-                         |                                  |                     |                   |                       |                       |
| • Capacity building, advocacy and collaboration |                                  | (97,206)            | -                 | -                     | (97,206)              |
| • Asia Pacific Patients Congress                |                                  | -                   | -                 | -                     | -                     |
| • Global Patients Congress                      |                                  | -                   | -                 | -                     | -                     |
| • Special projects                              |                                  | -                   | -                 | (522,553)             | (522,553)             |
| <b>Total</b>                                    | <b>3</b>                         | <b>(97,206)</b>     | <b>-</b>          | <b>(522,553)</b>      | <b>(619,759)</b>      |
| <b>Net income/(expenditure)</b>                 |                                  | <b>9,415</b>        | <b>-</b>          | <b>(34,054)</b>       | <b>(24,639)</b>       |
| Transfers                                       |                                  | -                   | -                 | -                     | -                     |
| <b>Net movement in funds</b>                    |                                  | <b>9,415</b>        | <b>-</b>          | <b>(34,054)</b>       | <b>(24,639)</b>       |
| <b>Reconciliation of funds:</b>                 |                                  |                     |                   |                       |                       |
| Funds brought forward                           |                                  | <b>231,149</b>      | <b>(21,351)</b>   | <b>335,444</b>        | <b>545,242</b>        |
| <b>Total funds carried forward</b>              |                                  | <b>240,564</b>      | <b>(21,351)</b>   | <b>301,390</b>        | <b>520,603</b>        |

All transactions are derived from continuing activities.

All recognised gains and losses are included in the Statement of Financial Activities.

**Balance Sheet as at 31 December 2024**

|                                                       | Notes | <b>2024<br/>£</b> | <b>2023<br/>£</b> |
|-------------------------------------------------------|-------|-------------------|-------------------|
| <b>Fixed assets</b>                                   | 6     | -                 | -                 |
| <b>Current assets</b>                                 |       |                   |                   |
| Debtors                                               | 7     | 56,885            | 6,868             |
| Cash in hand and in bank                              |       | 507,451           | 690,597           |
|                                                       |       | 564,336           | 697,465           |
| <b>Creditors: amounts falling due within one year</b> | 8     | (43,733)          | (152,223)         |
| <b>Net current assets</b>                             |       | 520,603           | 545,242           |
| <b>Net assets</b>                                     |       | <b>520,603</b>    | <b>545,242</b>    |
| <b>Funds</b>                                          |       |                   |                   |
| Unrestricted Funds                                    |       | 240,564           | 231,149           |
| Designated Funds                                      |       | (21,351)          | (21,351)          |
| Restricted Funds                                      |       | 301,390           | 335,444           |
| <b>Total Funds</b>                                    | 9     | <b>520,603</b>    | <b>545,242</b>    |

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

These financial statements were approved and authorised for issue by the Governing Board on 21 July 2025 and signed on their behalf by:



Ellos Ellard Lodzeni  
**Chair**



Ms. Flavia Kyomukama  
**Treasurer**

Registered company number: 08495711 (England and Wales)

The notes on pages 35 to 45 form part of these financial statements.

## Cash flow statement as of December 2024

|                                                             | 2024                     | 2023             |                            |
|-------------------------------------------------------------|--------------------------|------------------|----------------------------|
| <b>Cashflows from operating activities</b>                  |                          |                  |                            |
| Surplus/(deficit) for the financial year                    | (24,639)                 | 12,470           |                            |
| Adjustments for:                                            |                          |                  |                            |
| Depreciation Charge                                         | -                        | -                |                            |
| (Increase)/Decrease in debtors                              | (50,017)                 | 1,247            |                            |
| Increase/(Decrease) in creditors                            | (108,490)                | 51,313           |                            |
|                                                             | (183,146)                | 65,030           |                            |
| <b>Net increase/(decrease) in cash and cash equivalents</b> | (183,146)                | 65,030           |                            |
| Cash at 1 January 2024                                      | 690,597                  | 625,567          |                            |
| Cash at 31 December 2024                                    | 507,451                  | 690,597          |                            |
| <b>A) Components of cash and cash equivalents</b>           |                          |                  |                            |
| Cash at bank and in hand                                    | 507,451                  | 690,597          |                            |
| <b>B) Analysis of changes in net debt</b>                   |                          |                  |                            |
|                                                             | <b>At 1 January 2024</b> | <b>Cashflows</b> | <b>At 31 December 2024</b> |
| <b>Cash and cash equivalents</b>                            | 690,597                  | (183,146)        | 507,451                    |
|                                                             | 690,597                  | (183,146)        | 507,451                    |

## Notes to the Financial Statements for the Year Ended 31 December 2024

### 1. Accounting Policies

#### 1.1 Accounting convention

The financial statements of the charitable company, which is a public benefit entity under FRS102, have been prepared in accordance with the 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (SORP) (FRS102 second edition - effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

The financial statements are presented in Sterling (£).

IAPO Trading Limited (company number 08863190) was dormant and was dissolved in July 2024.

#### Statement on going concern

After reviewing the charity's forecasts and projections, the directors have reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. The charity therefore continues to adopt the going concern basis in preparing its financial statements.

#### 1.2 Company status

The parent charity is a company limited by guarantee. The directors of the company are the trustees named on page 1. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

#### 1.3 Incoming resources

All incoming resources are included in the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable certainty.

#### 1.4 Expenditure

All expenditure is included on an accruals basis and is inclusive of all VAT, which cannot be reclaimed, and is reported as part of the expenditure to which it relates:

- ◆ Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

## Notes to the Financial Statements for the Year Ended 31 December 2024

-  Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.
-  All costs are allocated between expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, other costs are apportioned on the basis staff time incurred.

The core elements of charitable expenditure are as follows:

**Capacity Building:** Realising active partnerships with patients' organisations, maximising their impact through capacity building.

**Advocacy:** Advocating internationally with a strong patients' voice on the relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies.

**Collaboration:** Building cross-sector alliance and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives.

### 1.5 Funds

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Designated funds are funds which are 'ring-fenced' to be used for the specific purpose of the congress.

Restricted funds are funds, which are to be used in accordance with specific restrictions imposed by the donor. The aim and use of the restricted fund is set out in the notes of the financial statements.

### 1.6 Tangible fixed assets and depreciation

Capital expenditure on items costing £1,000 or higher are recorded as tangible fixed assets. Tangible fixed assets are stated at historical cost less depreciation.

Depreciation is provided to reflect the useful estimated economic life of computer equipment assets at a rate of 33% per annum (reducing balance method).

## Notes to the Financial Statements for the Year Ended 31 December 2024

### 2. Incoming resources

|              | OTHER         | Healthcare<br>Industry<br>Partners | Projects       | Total                 |
|--------------|---------------|------------------------------------|----------------|-----------------------|
|              | £             | £                                  | £              | £                     |
| IFPMA        | -             | 43,113                             | -              | <b>43,113</b>         |
| GSK          | -             | 38,223                             | -              | <b>38,223</b>         |
| Projects     | -             | -                                  | 488,499        | <b>488,499</b>        |
| Other income | 25,285        | -                                  | -              | <b>25,285</b>         |
|              | <u>25,285</u> | <u>81,336</u>                      | <u>488,499</u> | <u><b>595,120</b></u> |

### Income Resources comparative

|              | OTHER          | Healthcare<br>Industry<br>Partners | Projects       | Total                 |
|--------------|----------------|------------------------------------|----------------|-----------------------|
|              | £              | £                                  | £              | £                     |
| GSK          | -              | 39,584                             | -              | <b>39,584</b>         |
| IFPMA        | -              | 44,354                             | -              | <b>44,354</b>         |
| Projects     | -              | -                                  | 410,197        | <b>410,197</b>        |
| Other income | 126,592        | -                                  | -              | <b>126,592</b>        |
|              | <u>126,592</u> | <u>83,938</u>                      | <u>410,197</u> | <u><b>620,727</b></u> |

## Notes to the Financial Statements for the Year Ended 31 December 2024

### 3. Congress Support 2024

| APPC congress | GPC congress | Total    |
|---------------|--------------|----------|
| £             | £            | £        |
| -             | -            | -        |
| -             | -            | -        |
| -             | -            | -        |
| <u>-</u>      | <u>-</u>     | <u>-</u> |
| <u>-</u>      | <u>-</u>     | <u>-</u> |

There was no congress held in 2024 but IAPO is holding the GPC in November 2025 in the Philippines.

### Congress Support 2023

|                         | APPC congress | GPC congress  | Total                 |
|-------------------------|---------------|---------------|-----------------------|
|                         | £             | £             | £                     |
| ROCHE PHARMA HOLDING    | 32,309        | 39,220        | <b>71,529</b>         |
| NOVARTIS                | -             | 11,679        | <b>11,679</b>         |
| BIOMARIN PHARMACEUTICAL | -             | 31,246        | <b>31,246</b>         |
|                         | <u>32,309</u> | <u>82,145</u> | <u><b>114,454</b></u> |

## Notes to the Financial Statements for the Year Ended 31 December 2024

### 4. Expenditure on Charitable Activities

|                                                      | Staff Costs    | Other Costs    | Support Costs  | Total                 |
|------------------------------------------------------|----------------|----------------|----------------|-----------------------|
| <b>Capacity Building, advocacy and collaboration</b> | 22,870         | -              | 74,113         | <b>96,983</b>         |
| <b>Congress</b>                                      | -              | -              | -              | -                     |
| <b>Special Projects</b>                              | 86,235         | 325,757        | 110,784        | <b>522,776</b>        |
| <b>Total</b>                                         | <u>109,105</u> | <u>325,757</u> | <u>184,897</u> | <u><b>619,759</b></u> |

### Expenditure on Charitable Activities Comparative

|                                                      | Staff Costs    | Other Costs    | Support Costs | Total                 |
|------------------------------------------------------|----------------|----------------|---------------|-----------------------|
| <b>Capacity Building, advocacy and collaboration</b> | 86,326         | -              | 65,952        | <b>152,278</b>        |
| <b>Congress</b>                                      | 7,008          | 86,288         | 4,397         | <b>97,693</b>         |
| <b>Special Projects</b>                              | 63,071         | 277,628        | 17,587        | <b>358,286</b>        |
| <b>Total</b>                                         | <u>156,405</u> | <u>363,916</u> | <u>87,936</u> | <u><b>608,257</b></u> |

### 5. Analysis of support costs

|                                    | Capacity Building, advocacy and collaboration | Congress | Special Projects | Total                 |
|------------------------------------|-----------------------------------------------|----------|------------------|-----------------------|
| <b>Rent and Rates</b>              | 3,000                                         | -        | 4,500            | <b>7,500</b>          |
| <b>Other Office Costs</b>          | 30,149                                        | -        | 44,839           | <b>74,988</b>         |
| <b>Legal and Professional Fees</b> | 35,772                                        | -        | 53,657           | <b>89,429</b>         |
| <b>Audit Fees</b>                  | 5,192                                         | -        | 7,788            | <b>12,980</b>         |
| <b>Total</b>                       | <u>74,113</u>                                 | <u>-</u> | <u>110,784</u>   | <u><b>184,897</b></u> |

Over 80% of the charity's total resources—including activities, staff time, and professional expertise — were dedicated to supporting our projects and ensuring the achievement of our deliverables.

## Notes to the Financial Statements for the Year Ended 31 December 2024

### *Analysis of support costs comparative*

|                                        | Capacity<br>Building,<br>advocacy and<br>collaboration | Congress     | Special<br>Projects | Total         |
|----------------------------------------|--------------------------------------------------------|--------------|---------------------|---------------|
| <b>Rent and Rates</b>                  | 5,321                                                  | 355          | 1,419               | <b>7,095</b>  |
| <b>Other Office Costs</b>              | 38,300                                                 | 2,553        | 10,213              | <b>51,066</b> |
| <b>Legal and Professional<br/>Fees</b> | 17,750                                                 | 1,184        | 4,733               | <b>23,667</b> |
| <b>Audit Fees</b>                      | 4,581                                                  | 305          | 1,222               | <b>6,108</b>  |
| <b>Total</b>                           | <b>65,952</b>                                          | <b>4,397</b> | <b>17,587</b>       | <b>87,936</b> |

## 6. Trustees and staff remuneration

The trustees received no remuneration. The Charity also paid £25,373 on behalf of Trustees to allow them to fulfil their duties (2023: £22,056).

### *Staff remuneration and numbers*

|                    | Total<br>2024<br>£ | Total<br>2023<br>£ |
|--------------------|--------------------|--------------------|
| Wages and salaries | 109,105            | <b>125,376</b>     |
| Social Security    | 4,633              | <b>13,167</b>      |
| Pension costs      | 1,154              | <b>660</b>         |
|                    | <b>114,892</b>     | <b>139,203</b>     |

The average number of full and part-time employees during the year was 3. 1 individual employee received emoluments in excess of £60,000 (2023: 1 in the band £60,001 to £70,000). Key management personnel costs amounted to £66,391 (2023: £74,315).

## Notes to the Financial Statements for the Year Ended 31 December 2024

### 7. Operating Surplus

Operating surplus is stated after charging.

|                                         | Total<br>2024 | Total<br>2023 |
|-----------------------------------------|---------------|---------------|
|                                         | £             | £             |
| Auditors Remuneration                   | 5,550         | 5,550         |
| Depreciation of Assets                  | -             | -             |
| Operating Lease Charges (office rental) | 7,500         | 7,095         |

### 8. Fixed Assets

|                       | Computer<br>equipment<br>£ |
|-----------------------|----------------------------|
| <b>Cost</b>           |                            |
| Brought forward       | 4,169                      |
| Carried forward       | 4,169                      |
| <b>Depreciation</b>   |                            |
| Brought forward       | 4,169                      |
| Charge for the year   | -                          |
| Carried forward       | 4,169                      |
| <b>Net book value</b> |                            |
| At 31 December 2024   | -                          |
| At 31 December 2023   | -                          |

There are no charges or securities held over any fixed assets. All fixed assets are held in the charity and none in the trading subsidiary. Depreciation was nil was in the previous period.

## Notes to the Financial Statements for the Year Ended 31 December 2024

### 9. Debtors

|                | 2024<br>£     | 2023<br>£           |
|----------------|---------------|---------------------|
| Debtors        | 50,000        | -                   |
| Prepayments    | 6,885         | <b>6,868</b>        |
| Accrued income | -             | -                   |
|                | <u>56,885</u> | <u><b>6,868</b></u> |

### 10. Creditors: amount falling due within one year

|                 | 2024<br>£     | 2023<br>£             |
|-----------------|---------------|-----------------------|
| Creditors       | -             | -                     |
| Deferred income | 21,512        | <b>113,590</b>        |
| Accruals        | 22,221        | <b>38,633</b>         |
|                 | <u>43,733</u> | <u><b>152,223</b></u> |

### 11. Analysis of net assets between funds

|                        | Unrestricted<br>Fund<br>£ | Designated<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total Funds<br>£      |
|------------------------|---------------------------|--------------------------|--------------------------|-----------------------|
| Current assets         | 262,946                   | -                        | 301,390                  | <b>564,336</b>        |
| Current liabilities    | (22,382)                  | (21,351)                 | -                        | <b>(43,733)</b>       |
| As at 31 December 2024 | <u>240,564</u>            | <u>(21,351)</u>          | <u>301,390</u>           | <u><b>520,603</b></u> |

## Notes to the Financial Statements for the Year Ended 31 December 2024

### Analysis of net assets between funds comparative

|                        | Unrestricted Fund<br>£ | Designated Funds<br>£ | Restricted Funds<br>£ | Total Funds<br>£ |
|------------------------|------------------------|-----------------------|-----------------------|------------------|
| Current assets         | 231,149                | -                     | 466,316               | <b>697,465</b>   |
| Current liabilities    | -                      | (21,351)              | (130,872)             | <b>(152,223)</b> |
|                        | <hr/>                  | <hr/>                 | <hr/>                 | <hr/>            |
| As at 31 December 2023 | 231,149                | (21,351)              | 335,444               | <b>545,242</b>   |
|                        | <hr/>                  | <hr/>                 | <hr/>                 | <hr/>            |

The deficit in the designated fund is due to timing difference between the time we held the event and the time we received the income.

### 12. Movement in funds 2024

|                            | At 31 December 2023<br>£ | Incoming Resources<br>£ | Resources Expended<br>£ | Transfers<br>£ | At 31 December 2024<br>£ |
|----------------------------|--------------------------|-------------------------|-------------------------|----------------|--------------------------|
| <u>Unrestricted fund</u>   | <b>231,149</b>           | 106,621                 | (97,206)                | -              | <b>240,564</b>           |
| <u>Designated Funds: -</u> |                          |                         |                         |                |                          |
| APPC congress              | <b>33,978</b>            | -                       | -                       | -              | <b>33,978</b>            |
| GPC congress               | <b>(9,617)</b>           | -                       | -                       | -              | <b>(9,617)</b>           |
| Africa congress            | <b>(22,241)</b>          | -                       | -                       | -              | <b>(22,241)</b>          |
| Latin Congress             | <b>(23,471)</b>          | -                       | -                       | -              | <b>(23,471)</b>          |
| <u>Restricted funds: -</u> |                          |                         |                         |                |                          |
| Special projects *         | <b>335,444</b>           | 488,499                 | (522,553)               | -              | <b>301,390</b>           |
|                            | <hr/>                    | <hr/>                   | <hr/>                   | <hr/>          | <hr/>                    |
|                            | <b>545,242</b>           | <b>595,120</b>          | <b>(619,759)</b>        | <b>-</b>       | <b>520,603</b>           |
|                            | <hr/>                    | <hr/>                   | <hr/>                   | <hr/>          | <hr/>                    |

## Notes to the Financial Statements for the Year Ended 31 December 2024

### Movements in funds comparative

|                            | At 31<br>December<br>2022<br>£ | Incoming<br>Resources<br>£ | Resources<br>Expended<br>£ | Transfers<br>£ | At 31<br>December<br>2023<br>£ |
|----------------------------|--------------------------------|----------------------------|----------------------------|----------------|--------------------------------|
| <u>Unrestricted fund</u>   | <b>287,351</b>                 | 96,076                     | (152,278)                  | -              | <b>231,149</b>                 |
| <u>Designated Funds: -</u> |                                |                            |                            |                |                                |
| APPC congress              | <b>2,367</b>                   | 32,309                     | (698)                      | -              | <b>33,978</b>                  |
| GPC congress               | <b>5,233</b>                   | 82,145                     | (96,995)                   | -              | <b>(9,617)</b>                 |
| Africa congress            | <b>(22,241)</b>                | -                          | -                          | -              | <b>(22,241)</b>                |
| Latin Congress             | <b>(23,471)</b>                | -                          | -                          | -              | <b>(23,471)</b>                |
| <u>Restricted funds: -</u> |                                |                            |                            |                |                                |
| PREFER                     | <b>29,296</b>                  | -                          | -                          | (29,296)       | -                              |
| Special projects *         | <b>254,237</b>                 | 410,197                    | (358,286)                  | 29,296         | <b>335,444</b>                 |
|                            | <b>532,772</b>                 | <b>620,727</b>             | <b>(608,257)</b>           | -              | <b>545,242</b>                 |

## Notes to the Financial Statements for the Year Ended 31 December 2024

### 13. SOFA - Comparative

|                                                 | Notes    | Unrestricted<br>£ | Designated<br>£ | Restricted<br>£  | Total<br>2023<br>(year)<br>£ |
|-------------------------------------------------|----------|-------------------|-----------------|------------------|------------------------------|
| <b>Income from charitable activities:</b>       |          |                   |                 |                  |                              |
| Membership                                      |          | 2,767             | -               | -                | 2,767                        |
| Healthcare Industry Partners                    |          | 83,938            | -               | -                | 83,938                       |
| APPC congress                                   |          | -                 | 32,309          | -                | 32,309                       |
| GPC congress                                    |          | -                 | 82,145          | -                | 82,145                       |
| Africa congress                                 |          | -                 | -               | -                | -                            |
| Latin congress                                  |          | -                 | -               | -                | -                            |
| Special Projects                                |          | -                 | -               | 410,197          | 410,197                      |
| Other charitable activities                     |          | 9,371             | -               | -                | 9,371                        |
| <b>Total</b>                                    | <b>2</b> | <b>96,076</b>     | <b>114,454</b>  | <b>410,197</b>   | <b>620,727</b>               |
| <b>Expenditure on charitable Activities:</b>    |          |                   |                 |                  |                              |
| Charitable activities:-                         |          |                   |                 |                  |                              |
| • Capacity building, advocacy and collaboration |          | (152,278)         | -               | -                | (152,278)                    |
| • Asia Pacific Patients Congress                |          | -                 | (698)           | -                | (698)                        |
| • Global Patients Congress                      |          | -                 | (96,995)        | -                | (96,995)                     |
| • Africa Patients Congress                      |          | -                 | -               | -                | -                            |
| • LatAm Patients Congress                       |          | -                 | -               | -                | -                            |
| • Special projects                              |          | -                 | -               | (358,286)        | (358,286)                    |
| <b>Total</b>                                    | <b>3</b> | <b>(152,278)</b>  | <b>(97,693)</b> | <b>(358,286)</b> | <b>(608,257)</b>             |
| <b>Net income/(expenditure)</b>                 |          | <b>(56,202)</b>   | <b>16,761</b>   | <b>51,911</b>    | <b>12,470</b>                |
| Transfers                                       |          | -                 | -               | -                | -                            |
| <b>Net movement in funds</b>                    |          | <b>(56,202)</b>   | <b>16,791</b>   | <b>51,911</b>    | <b>12,470</b>                |
| <b>Reconciliation of funds:</b>                 |          |                   |                 |                  |                              |
| Funds brought forward                           |          | <b>287,351</b>    | <b>(38,112)</b> | <b>283,533</b>   | <b>532,772</b>               |
| <b>Total funds carried forward</b>              |          | <b>231,149</b>    | <b>(21,351)</b> | <b>335,444</b>   | <b>545,242</b>               |

### 14. Related Party Transactions

There were no related party transactions other than reimbursement of Trustee expenses as detailed in Note 6 (2023: nil)

# Thank You

---



The International Alliance of Patients' Organizations is registered in England and Wales as charity n° 1155577 and company limited by guarantee n° 08495711.



## Address

Registered office: Canopi, 82 Tanner Street, London, SE1 3GN, UK.



## Website

[www.iapo.org.uk](http://www.iapo.org.uk)



**INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

England & Wales - Charity number 1155577

---

# Accounts

---



International Alliance of  
Patients' Organizations

Company registration number (England and Wales): 08495711

Charity registration number (England and Wales): 1155577

# International Alliance of Patients' Organizations

(Incorporated as a Company Limited by Guarantee  
and not having a Share Capital)

---

Annual Report and Financial Statements  
for the year ended 31 December 2023

## Contents

---

|                                                                                                                                                          |           |
|----------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
| <b>Reference and Administrative Details of the Charity, Its Trustees and Advisers</b>                                                                    | <b>3</b>  |
| <b>Trustees' Report for the Year Ended 31 December 2023</b>                                                                                              | <b>4</b>  |
| <b>Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31<sup>st</sup> December 2023</b> | <b>21</b> |
| <b>Statement of Financial Activities (Incorporating An Income And Expenditure Account) for the Year Ended 31 December 2023</b>                           | <b>24</b> |
| <b>Balance Sheet as at 31 December 2023</b>                                                                                                              | <b>25</b> |
| <b>Cash Flow statements for the year ended 31 December 2023</b>                                                                                          | <b>26</b> |
| <b>Notes to the Financial Statements for the Year Ended 31 December 2023</b>                                                                             | <b>27</b> |

## Reference and Administrative Details of the Charity, its Trustees and Advisers

---

|                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                       |
|------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Company number</b>                                                  | 08495711 (England and Wales)                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Charity number</b>                                                  | 1155577 (England and Wales)                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Registered office</b>                                               | International Alliance of Patients' Organizations<br>Hounslow House, 7 Bath Road, Hounslow TW3 3EB, UK                                                                                                                                                                                                                                                                                                |
| <b>Governing Board members<br/>(Board of Trustees)</b>                 | Professor Lara Claire Bloom<br>Adebisi Omolola Bright<br>Orajitt Bumrungskulswat<br>Anthony John Holland<br>Flavia Kyomukama (appointed 6 Dec 2023)<br>Ellos Ellard Lodzeni (Chair from 6 Dec 2023)<br>Neda Milevska-Kostova (resigned 6 Dec 2023; Chair until then)<br>Paul Albert Sumat Mendoza<br>Fernanda Souza de Carvalho (appointed 6 Dec 2023)<br>Rosalia Liliana Tieri (resigned 6 Dec 2023) |
| <b>Chief Executive<br/>Interim Chief Executive<br/>Chief Executive</b> | Kawaldip Sehmi (to 1 Aug 2023)<br>Daniela Espindula Mothci (4 Aug-31 Nov 2023)<br>Daniela Espindula Mothci (from 1 Dec 2023)                                                                                                                                                                                                                                                                          |
| <b>Bankers</b>                                                         | NatWest Bank Plc<br>PO Box 12258<br>1 Princes Street<br>LONDON<br>EC2R 8BP                                                                                                                                                                                                                                                                                                                            |
| <b>Independent auditor</b>                                             | Knox Cropper LLP<br>65 Leadenhall Street<br>London<br>EC3A 2AD                                                                                                                                                                                                                                                                                                                                        |
| <b>Website</b>                                                         | <a href="http://www.iapo.org.uk">www.iapo.org.uk</a>                                                                                                                                                                                                                                                                                                                                                  |



## Trustees' Report for the Year Ended 31 December 2023

---

The directors, who are also the trustees of the charity, are pleased to present their report together with the financial statements of the charity for the year ended 31 December 2023 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

Results for the trading subsidiary, IAPO Trading Limited (company number 08863190) are not consolidated on the grounds that it was dormant and not material to the group.

The trustees have complied with the duty to have due regard to guidance issued by the Charity Commission and have adopted the Statement of Recommended Practice for charities (SORP) (FRS 102 second edition effective 1 January 2019).

### Aims and objectives of the organisation

The objects of the International Alliance of Patients' Organizations (IAPO), as set out in the articles of association, are the promotion of the relief of sickness and preservation and protection of health for the public benefit through fostering patient-centred healthcare worldwide and in particular by developing the capacity of patients' organisations.

IAPO is a unique global alliance representing patients of all nationalities, across all disease areas, and promoting patient-centred healthcare around the world. IAPO brings a global patient voice to healthcare decision-making based on the belief that patients' voices are amplified and heard effectively when patients' organisations are linked, can share best practices and practical strategies, and are connected with resources. Our members are patients' organisations working at the international, regional, national and local levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability.

IAPO was first established in 1999 in the Netherlands as a Dutch Stichting and subsequently deregistered, registering in England and Wales as a company limited by guarantee on 19 April 2013 and a charity on 30 January 2014. IAPO has a membership of nearly 300 organisations across 71 countries covering 51 diseases groups. IAPO is a non-State Actor in official relations with the World Health Organization (WHO) and has a memorandum of understanding with the International Council of Nurses (ICN), International Hospital Federation (IHF), International Pharmaceutical Federation (FIP), World Medical Association (WMA), International Society for Quality in Health Care (ISQua), The Professional Society for Health Economics and Outcomes Research (ISPOR) and The Union for International Cancer Control (UICC). and with many other Non-State Actors.

### IAPO's vision and mission

IAPO's vision is that patients throughout the world are at the centre of healthcare.

IAPO's mission is to help build patient-centred healthcare worldwide by:

- ◆ Realizing active partnerships with patients' organisations, maximizing their impact through capacity building
- ◆ Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
- ◆ Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives

## Trustees' Report for the Year Ended 31 December 2023

---

### *IAPO's activities include:*

- ◆ Advocacy at global level on relevant aspects of healthcare policy to influence international health agendas and policies
- ◆ Providing membership services, including capacity building and shared learning, to its members, who are patient-led organisations across the world
- ◆ Empowering its members to undertake their own advocacy at regional and national meetings
- ◆ Providing opportunities for stakeholders from across the health sector to meet and work together to advance patient involvement in health services and decision-making
- ◆ Research on emerging areas of interest to patients' organisations and to underpin the evidence base for showing the importance of patient involvement to public health.

### Structure

The organisation is a charitable company limited by guarantee, incorporated on 19 April 2013 and registered as a charity on 31 January 2014. The company was established articles of association which define the objects and powers of the company and its governance arrangements. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

All assets and liabilities from the International Alliance of Patients Organizations and its predecessor not-for-profit structure registered in the Netherlands, were transferred to the new UK incorporated charity on 1 February 2014. IAPO Netherlands was (voluntarily) dissolved from the Netherlands Trade Register with effect from 31 May 2015, executed on 21 October 2015

### Appointment and induction of Governing Board

Every member of the IAPO Governing Board is elected by IAPO's members, through a process defined in the [articles of Association](#), [by-laws](#) and [election code of conduct](#). Every year, in advance of the annual general meeting (AGM), the number of vacancies on the Board is notified to all members, who may then nominate someone from their organisations (a Board member or senior staff member) to IAPO's Governing Board. The full list of nominees is sent to all members in advance of the AGM; members may vote by post or proxy or in person at the AGM.

Governing Board members serve for a maximum of two terms subject to the retirement by rotation clause; once their term of service is complete, they or anyone from their organisation cannot be re-elected to the Board for at least a year. All new members of the Board receive induction including core information about the work and history of the organisation, and conversations with the Chief Executive Officer and the Chair.

All Governing Board members sign a code of conduct when they are appointed to the Board. All staff and Governing Board members are required to declare any relevant conflict of interests or conflict of loyalties at every Board meeting, or between meetings if applicable. The Governing Board have no beneficial interest in the charitable company or its trading subsidiary. No Governing Board member receives any remuneration, but some receive reimbursement for essential travel or similar expenses.

## Trustees' Report for the Year Ended 31 December 2023

### Governance

The International Alliance of Patients' Organizations has a Board of Trustees and Directors overseeing its governance and direction, supported by a secretariat headed by the Chief Executive Officer.

| Board of Trustees/Directors |                        |                 |                  |
|-----------------------------|------------------------|-----------------|------------------|
| Name                        | Position               | Country         | Dates            |
| Dr. Neda Milevska-Kostova   | Chair                  | North Macedonia | Until 6 Dec 2023 |
| Mr. Ellos Ellard Lodzeni    | Vice Chair, then Chair | Malawi          |                  |
| Mrs. Orajitt Bumrunskulswat | Secretary              | Thailand        |                  |
| Professor Lara Claire Bloom | Treasurer              | United Kingdom  |                  |
| Mrs. Adebisi Omolola Bright | Board Member           | Nigeria         |                  |
| Dr. Anthony John Holland    | Board Member           | United Kingdom  |                  |
| Ms. Flavia Kyomukama        | Board Member           | Uganda          | From 6 Dec 2023  |
| Paul Albert Mendoza         | Board Member           | Philippines     |                  |
| Fernanda Souza de Carvalho  | Board Member           | Brazil          | From 6 Dec 2023  |
| Mrs. Rosalia Liliana Tieri  | Board Member           | Argentina       | Until 6 Dec 2023 |



## Trustees' Report for the Year Ended 31 December 2023

---

### Public benefit

The Governing Board confirms that they have considered the guidance contained in the Charity Commission's general guidance on public guidance when reviewing the charity's aims and objectives. They consider that the activities carried out, summarised in the Achievements and Performance section of this report, provide benefit to the public.

IAPO's objects are the promotion of the relief of sickness and the preservation and protection of health for the public benefit. IAPO pursues this through fostering patient-centred healthcare worldwide and, in particular, by developing the capacity of patients' organisations.

In setting our objectives and planning our activities trustees have given consideration to the Charity Commission's general guidance on public benefit (PB1, PB2 and PB3) and have taken these into account in making all decisions. We have not departed from the guidance in 2023.

IAPO's services are open to all people and our membership reflects a diverse group of patients' organisations representing patients with communicable and non-communicable diseases, including patients with diseases that are stigmatised in many societies.

IAPO had 278 members comprising umbrella groups and single organisations in 2023 who directly represented views of over 1 million patients in 72 countries across 54 disease areas. The services the charity provides are designed to build the capacity of patients' organisations, allowing them to better assist the needs of patients and carers (and their own member patient organisations in some cases) from across the world.

Access to IAPO's website is freely available to the public. Currently it is in English, with some sections in Spanish. The website contains a wide range of information on IAPO's activities and on patient-centred healthcare, which is of benefit to the public, particularly those who wish to set up local patients' organisations.

By improving access to information, training and other capacity building programmes for patients and their representative organisations, IAPO improves access to healthcare itself. By raising awareness and through capacity building and education, we increase access to acceptable services that respect patients' preferences, values, rights and needs.

IAPO has a wealth of evidence, gained from patients' organisations worldwide, which demonstrates that patient involvement in patients' care leads to better health outcomes and lower costs for the whole of society. The charity works with patients' organisations that are not for profit and non-governmental organisations who demonstrate commitment to improving patient-centred healthcare which is reflected in the charity's membership criteria.

## Trustees' Report for the Year Ended 31 December 2023

---

### Chair's Report for the Financial Year 1st January to 31st December 2023

2023 was a year of significant achievements for IAPO, as well as a time for realignment with new leadership approaches, sustainable engagement strategies, and strengthened partnerships.

We navigated difficult times after the unexpected passing of our dear colleague and IAPO's CEO Kawaldip Sehmi in August 2023. Dani Mothci, who has brilliantly led the membership role at IAPO since 2016, transitioning to partnership engagement director at the end of 2022, became IAPO's CEO. This leadership change brought new ideas, enthusiasm and commitment, while ensuring IAPO's sustainability and reliability.

The tireless efforts of the new CEO together with IAPO board members and staff were instrumental in steering IAPO in 2023. I am incredibly proud of our accomplishments and how we served our community towards a healthier future for all with patients at the centre.

We are deeply grateful to our almost 300 member organisations, our partners and collaborators for their generous support in 2023, which enabled us to achieve our objectives and stay aligned with our strategic goals. A special thank you to our industry partners who have supported IAPO through sponsorship, educational grants, and research projects. Without this, we could not have achieved the impact we had.

In 2023, we were proud to hold our flagship Global Patient Congress in May in Geneva, Switzerland marking its 10<sup>th</sup> anniversary. We also held several online and in-person events on different topics, drove research, and led advocacy initiatives aimed at supporting the global patient community to advance patient-centred, safe, affordable and accessible healthcare worldwide. We also made significant investments in the core of the organisation - its governance, staff, operations, and communication - to enhance its effectiveness, innovation, and sustainability.

I believe that our collective efforts this year created an even greater and stronger organisation which is bringing exciting possibilities ahead based on four pillars: building a stronger organisation, fostering effective and sustainable relationships, having a stronger regional presence, and supporting IAPO member patient organisations. This is to ensure that we continue our mission and deliver better and more outcomes to our members and all patients around the world.

In 2024, IAPO is celebrating a silver jubilee having attained twenty five (25) years working with and mobilizing patients' organisations from all regions of the world, representing all disease areas. 25 years on and our mission to help build patient-centred healthcare worldwide continues as solid as it can be, and central to all we do at IAPO.

In closing, I must pay tribute to Dani Mothci, my predecessor as chair (until 6 December 2023) Neda Milevska-Kostova, and all Board and Secretariat members who in their shock and grief, still kept IAPO functioning and are making it stronger.



Ellos Lodzeni  
Chair of the Board IAPO

## Trustees' Report for the Year Ended 31 December 2023

---

### Achievements and Performance

In 2023, IAPO embarked on a journey of collaboration, advocacy and innovation to advance patient-centred healthcare globally organised according to the three goals of IAPO Strategic Plan 2022-2024:

#### Goal 1: EMPOWER

Empower members with cutting-edge knowledge and advocacy skills to enhance the reach, efficacy, and impact of our membership in bringing about a Patient-Centred (PC) and Pandemic Prepared (PP) Universal Health Coverage (UHC).

- ◆ We hosted our [10th Global Patients Congress](#) at the Maison Internationale des Associations in Geneva, Switzerland, as a hybrid event during the weekend before the [76th World Health Assembly \(WHA76\)](#) with the theme “Innovative patient partnerships at the heart of global health advancement”.



### GPC 2023 brought together

**1206** delegates from

**111** countries,



including IAPO's global membership

**42**

speakers discussing and sharing their experiences to promote global health through innovative, collaborative and meaningful relationships in

**8**

capacity-building sessions

## Trustees' Report for the Year Ended 31 December 2023

---

- ◆ We launched the [African Patients Village](#), a patient-led multi-stakeholder arena that explores the power of togetherness to address current health challenges and promote patient-centred sustainable and resilient health systems in Africa. The first edition of the village was held on the sidelines of the [73rd session of the World Health Organization \(WHO\) Regional Committee for Africa](#) in Gaborone, Botswana, and it focused on two topics:

- > E-health solutions co-designed through public-private-patient organisations collaborations
- > The multistakeholder engagement in support of the efforts to ensure access to safe medical products is institutionalized through the recently established [African Medicines Agency Treaty Alliance \(AMATA\)](#).

- ◆ As part of our ongoing activities related to the [African Medicines Agency Treaty Alliance \(AMATA\)](#), we held the [3rd webinar of the AMATA webinar series with Chimwemwe Chamdim](#), the African Medicines Regulation Harmonization Programme Head.

The webinar highlighted significant progress in operationalizing the agency and shared insights on the African Medicines Agency's (AMA) role in harmonizing medicine regulations across Africa.

- ◆ In collaboration with [BETTEReHEALTH](#), we held the webinar ["eHealth: Assuring better health services, healthcare access and health literacy for the benefit of patient safety and health"](#), where we discussed the use and implementation of eHealth-related solutions for patient health and safety.

The webinar emphasized the importance of eHealth solutions in empowering patients with comprehensive and readily available information about their medication, enabling informed decision-making and improved self-management. Participants acknowledged the potential of eHealth platforms to enhance medication adherence by providing reminders, educational resources, and personalized support to patients, thereby promoting better health outcomes.

- ◆ We advanced the [Patient Academy website](#) by collaborating on additional modules, involving patients in creating videos, and fostering engagement through social media awareness posts.

The vision of the Patient Academy is to create communities of empowered patients who take ownership of the management of their medical condition through customized health information.

- ◆ IAPO joined [GS1](#), [IHF](#), [EAHP](#) and [ISQUA](#) on an awareness and celebration campaign spanning over 6 days on social media to mark [World Patient Safety Day 2023](#), where each organisation shared their views on the best way to engage with patients to advance patient safety globally.

## Trustees' Report for the Year Ended 31 December 2023

---

As part of the commemoration, IAPO participated as one of the speakers at the [WHO Global Conference](#) entitled “[Engaging Patients for Patient Safety](#)”, which was instrumental in amplifying the patient voice and advocating for patient-centred approaches to healthcare safety.

We remain committed to collaborating with stakeholders worldwide to ensure that patient safety remains a top priority in healthcare systems globally.

- ◆ We joined other health stakeholders from all over the world to celebrate [Patient Solidarity Day \(PSD\) 2023](#) under the theme “[Expert patients - the indispensable voice](#)”. On PSD 2023, we celebrated the strength, resilience, and knowledge of expert patients who have taken control of their health journeys and contributed to health systems strengthening in various ways.

IAPO’s PSD 2023 also included a tribute to the remarkable life and contributions of our departed Kawaldip Sehmi, the former IAPO CEO.

- ◆ To mark [World Antimicrobial Awareness Week \(WAAW\)](#), IAPO and IAPO Patients for Patient Safety Observatory and its AMR Patient Alliance released [a call for cross-sectoral collaboration](#) to address the growing threat of Antimicrobial Resistance (AMR) ahead of the 2024 High-Level Political Declaration.

- ◆ We had the privilege of joining a hybrid session titled “[Confronting Antimicrobial Resistance in Healthcare](#)” and “[Cancer and Cardiovascular Disease Advocacy – The Power of Changing Complex Scenarios in Favour of Health Care](#)” at the [Global Forum Frontiers of Health 2023](#).

Hosted by the [Side by Side Brazilian Institute](#), the event brought together key stakeholders, including IAPO member Fernanda de Carvalho, and representatives from the Observatory and the AMR Patient Alliance. These sessions discussed the far-reaching implications of AMR for patient care, treatment outcomes, and healthcare systems worldwide, and the vital role of advocacy in the fight against cancer and cardiovascular diseases (CVD) in driving positive change and improving healthcare outcomes for individuals affected by these diseases.

- ◆ We were honoured to participate in the [Global Self-Care Federation Event](#) alongside our esteemed partners from the [United for Self-Care Coalition](#).

At the WHA76 Side Event titled “[Self-Care: A Foundational Component of Health System Sustainability](#),” IAPO had the opportunity to highlight the crucial role of self-care practices in primary healthcare. We emphasized how these practices not only enhance patient safety but also contribute significantly to the achievement of Universal Health Coverage.

## Trustees' Report for the Year Ended 31 December 2023

---

- ◆ We were also honoured to join the [Global Patient Think Tank \(GPTT\)](#), a multinational group of patient and community representatives calling for the inclusion of the patient voice in both global UHC policy decision-making and national-level UHC design, implementation and governance. IAPO's participation in this initiative underscores our commitment to further integrate the patient perspective in UHC initiatives.
- ◆ We integrated the advisory committee of the [International Experience Exchange with Patient Organisations \(IEEPO\)](#), a global platform of engagement for the patient community and other healthcare stakeholders, to co-create and collaborate, and to be strong partners with an equal voice in the dialogue to transform the future of healthcare together.

### Goal 2: DRIVE RESEARCH

Co-create evidence in support of healthcare that is PC, PP and a UHC that strengthens patient involvement in clinical research and global health institutes.

- ◆ As part of our strategy to drive research, IAPO commissioned the Swedish Institute of Health Economics (IHE) to develop the research project [Improving Breast Cancer Care in the Middle East and Africa](#), by working on a comparative assessment of the disease burden and the economic burden of breast cancer, as well as of early detection and treatment of the disease. The Policy Report and an Advocacy Toolkit will be launched in 2024.
- ◆ We continued our support as part of the [Advisory Group](#) and as a patient representative of the international research project [EOLinPlace](#). This project is hosted by the University of Coimbra and is the largest study of international time trends in place of death and the first showing a rise of home deaths in the COVID-19 pandemic across countries.
- ◆ IAPO also continued to participate as a member of the [BMJ Patient Advisory Panel](#), advising within the different working groups, including the ones on Patient Safety and Healthcare Sustainability.

### Goal 3: SHAPE LAW, POLICY, STANDARDS

Apply the empowered patient community and evidence created to shape the institutional, law, policy, practice, and standards framework for healthcare that is PC, PP and a UHC at global, regional, and national levels.

- ◆ Following on the important statements put forward in previous years, IAPO delivered two statements at the [76th World Health Assembly \(WHA76\)](#): one on [Agenda Item 13.1 - Universal Health Coverage](#) and the other on [Agenda Item 13.2 - Political declaration of the third high-level meeting of the General Assembly on the prevention and control of non-communicable diseases, and mental health](#).

## Trustees' Report for the Year Ended 31 December 2023

---

- ◆ [The Personalised Cancer Care Alliance \(PCCA\)](#), set up by IAPO in 2022, held the [WHA76 Side Event “Amana upon our shoulders – Call to adoption and integration of personalised cancer care in the WHO Eastern Mediterranean Region”](#), which addressed the care and suffering of cancer patients in the region through advocating for personalised cancer care

- ◆ We also released a [Call to Action](#) for the adoption and integration of personalised cancer care in the WHO Eastern Mediterranean Region.

- ◆ The PCCA also held the [Roundtable “Uniting Voices for Participatory Patient-Centred Healthcare - The 5 Ps Framework”](#) on the sidelines of the [70th Session of the WHO Regional Committee for the Eastern Mediterranean](#) in Cairo, Egypt.

The roundtable brought together key health stakeholders (patients, WHO, academia, healthcare providers, and industry) to discuss ways of including the patient's voice within the healthcare system and continuum of care towards better outcomes and true patient-centred healthcare.

- ◆ We joined the [United for Self-Care Coalition at the WHA76](#) in advocating for the integration of self-care in health systems. Together, we developed an [open letter](#) urging Member States to prioritize self-care as a critical component of the healthcare continuum, particularly in the context of managing the burden of NCDs and realizing Universal Health Coverage.

- ◆ IAPO endorsed the [Statement on substandard and falsified medical products \(Agenda item 152.7\)](#) delivered by the International Pharmaceutical Students' Federation (IPSF), on behalf of the [African Medicines Agency Treaty Alliance \(AMATA\)](#), at the 152nd session of the Executive Board at the World Health Organization in Geneva.

The statement emphasized the critical importance of combating substandard and falsified medical products.

IAPO fully supports the draft list of prioritized activities outlined in the statement, particularly the objective to strengthen the capacity of national/regional regulatory authorities for the prevention, detection, and response to substandard and falsified medical products.

- ◆ As part of our activities within the [Global Coalition for Circulatory Health \(GCCH\)](#), we collaborated on the [76th World Health Assembly](#) statements as well as on the [GCCH white paper for circulatory health and UHC](#).

The GCCH is an alliance that brings together international, regional and national stakeholders in circulatory health to drive the urgent action needed to combat heart disease and stroke.

## Trustees' Report for the Year Ended 31 December 2023

---

- ❖ As a founding member of the [Fight the Fakes \(FTF\) Alliance](#), we continued to be a partner in marking eight years since it was first set up as a grassroots advocacy campaign. In 2023 we were part of the Executive Board together with seven other Non-State Actors in official relations with the WHO.

We joined the [Fight the Fakes week campaign](#) where we raised awareness of the dangers of substandard and falsified medicines for patient safety under the theme 'Africa Together Against Substandard and Falsified Medicines' and the Call to Action 'Africa – Speak Up – Stand Up'.

- ❖ We collaborated with the [Africa Civil Society Organizations Working Group on Pandemic Preparedness and Response \(ACSOWGPR\)](#) to elevate the patient voice in pandemic planning and response efforts.

Co-convened by Pandemic Action Network and PATH, [ACSOWGPR](#) aims to strengthen collective civil society advocacy to shape decision-making and implementation in response to COVID-19 and future health threats.

Together, we work towards a more inclusive and effective pandemic response.

- ❖ IAPO participated in the [UN High-level Meeting on Universal Health Coverage at UNGA78](#), held in New York. The meeting focused on expanding the ambition for health and well-being in a post-COVID world, aiming to review the implementation of the 2019 Political Declaration and identify solutions to accelerate progress towards Universal Health Coverage by 2030.

Our participation underscored the importance of a primary healthcare approach in engaging and empowering patients and communities. We also highlighted primary health care as essential for ensuring holistic and integrated health care, contributing to social justice and yielding long-lasting impact on population health and socioeconomic growth



### IAPO's Annual General Meeting

We held our Annual General Meeting in December 2023 where we announced the newly elected and re-elected [Governing Board Members](#) and presented further updates on [IAPO's new leadership and strategic direction for 2024 and beyond](#).

## Trustees' Report for the Year Ended 31 December 2023

---

### Communications

#### *Newsletter*

We doubled our newsletter subscription number from 5900 to 12070 subscribers who receive our monthly newsletter which covers all IAPO's news and updates on initiatives such as our congresses, member activities, patient-centred advocacy news and information. We continue to encourage more patient organisations to submit articles for publication.

#### *Twitter*

[@IAPOvoice](#) , [@PatientSolidarityDay](#), [@AfricanAmata](#), [@PCCAlliance](#)

#### *Facebook*

We operate [IAPOvoice](#), [International Alliance of Patients' Organizations](#), [African page](#), [Patient Solidarity Day](#), [Personalised Cancer Care Alliance](#)

#### *LinkedIn*

[International Alliance of Patients' Organizations](#), [Metrodora Awards](#), [Personalised Cancer Care Alliance](#).

#### *Website*



[www.iapo.org.uk](http://www.iapo.org.uk)

IAPO's website continues to be the main source of information for all IAPO's activities and its dissemination. We have seen an increase in the number of page views: with over 105,000 page views in 2023 compared to 82,100 in 2022.

## Trustees' Report for the Year Ended 31 December 2023

### Membership

IAPO continued to strengthen its member network in 2023 supporting its 278 members. IAPO is currently implementing software to streamline the entire membership management, from outreach to invoicing and engagement. As of 31st December 2023, IAPO members were:

| Region                        |            |
|-------------------------------|------------|
| African members               | 43         |
| Eastern Mediterranean members | 10         |
| European members              | 96         |
| Latin American members        | 67         |
| North American members        | 24         |
| South East Asian member       | 14         |
| Western Pacific members       | 24         |
| <b>TOTAL</b>                  | <b>278</b> |

| Membership Type |            |
|-----------------|------------|
| Full            | 99         |
| Associate       | 37         |
| Network         | 142        |
| Affiliate       | 0          |
| <b>TOTAL</b>    | <b>278</b> |

### Risk Management

A risk register is prepared by the CEO and presented annually to the Board to discuss ensuring that there are effective and adequate risk management and internal control systems in place to manage the major risks to which the Charity is exposed. IAPO prepares the risk register by understanding the risk environment and its operations and then identifies the key risks. The CEO and the Treasurer then undertake a thorough analysis and evaluation of the risks identified before coming up with a treatment for the risks.

Risks are identified under headings of Financial, Funding, Governance, Operational and Personnel, and mitigation actions detailed.

Discussions are underway regarding IAPO's fundraising strategy where we aim to reduce reliance upon the pharmaceutical companies. IAPO aims to diversify its funding by approaching international trust funds, international development agencies and large programmes to raise non-industry partner funding.

## Trustees' Report for the Year Ended 31 December 2023

---

### Financial Review

#### *Financial position at the end of the period*

Incoming resources for the year amounted to £620,727 (2022: £582,642), which was higher than the previous year due to a strategic increase in research and special projects funded by our partners.

Expenditure in 2023 was £608,257 (2022: £399,126). Expenditure is also higher than the previous year, in line with the fact that we increased our output in research and Special Projects.

#### *Reserves Policy*

The IAPO Board approved a reserves policy in September 2014, with a target level of free reserves of 6-12 months' running costs for 6 months. 6 months running cost is c.£76,139. This policy was set with due regard to guidance from Charity Commission (CC19 – Charity Reserves) and is reviewed annually.

The level of unrestricted reserves, as at 31<sup>st</sup> December 2023 is £231,149. This is within the target in the reserves policy, and will be monitored by the Board of Trustees.

#### *Going Concern*

The trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. Despite the unfortunate passing of IAPO's chief executive generating a change in management the board took time to contact all funders and commit to fulfilling and meeting current projects, events and current collaborative works. Our current partners and funders have been very receptive to new proposals and wish to continue working with IAPO until the foreseeable future.

#### *IAPO funding transparency*

The Governing Board members declare relevant conflicts of interests and conflicts of loyalty at each Board meeting and between meetings. A register of interests is maintained.

Reference to IAPO's code of conduct and policy regulating IAPO's relationship with, and independence from, sponsors can be found at [www.iapo.org.uk/consensus-framework-ethical-collaboration](http://www.iapo.org.uk/consensus-framework-ethical-collaboration) and [www.iapo.org.uk/healthcare-industry-partners](http://www.iapo.org.uk/healthcare-industry-partners).

The overall proportion of industry to non-industry income for the year was approximately 98%.

#### *Pension arrangements*

IAPO operates an occupational pension scheme, and also operates a policy of contributions directly into staff members' chosen personal pension schemes, with no obligation for staff to make personal contributions. The issue of pension deficit, which would apply to an occupational scheme, does not therefore arise.

## Trustees' Report for the Year Ended 31 December 2023

---

### Future Plans

IAPO's Strategy for 2022-2024 is listed at:

<https://www.iapo.org.uk/sites/default/files/files/IAPO%20Strategy%202023-2024%20Draft.pdf>

Our vision, mission and tactical plans are adapted to build back better a patient-centred, pandemic prepared universal health coverage by 2030.

#### *Vision 2022-2024*

To ensure through global solidarity and national action that every patient enjoys healthcare that is:

- ◆ Patient-centred (PC) (broader definition)
- ◆ Pandemic prepared (PP)
- ◆ A Universal Health Coverage (UHC)

#### *Mission 2022-2024*

- ◆ Empower our members with cutting edge knowledge and advocacy skills in bringing about PC & PP UHC 2030.
- ◆ Work with our membership, alliances, partners, and other stakeholders to drive research and policy development activity that establishes the evidence base needed in support of PC & PP UHC 2030 and strengthen patient involvement and co-creation in research.
- ◆ Motivate the empowered patient community into using the evidence base created to shape the institutional, law, policy, practice, and standards framework needed for PC & PP UHC 2030 at global, regional (APEC, AU and EU etc) and national levels.

#### *Tactical Plan 2022-2024*

To attain PC (Broader Definition) and PP UHC 2030 it is important that IAPO advocates the delivery of:

- ◆ Safe Healthcare
- ◆ Quality Healthcare
- ◆ Accessible Healthcare. Access is across four areas.
- ◆ Non-Discriminatory Healthcare
- ◆ Physically Accessible Healthcare
- ◆ Information Accessibility
- ◆ Affordable Healthcare
- ◆ Acceptable Healthcare: Culturally Competent and Patient-Centred (Broader Definition)

In addition to the above, IAPO is collaborating closely with the WHO Work Plan 13 and ensuring that the WHO flagship Global Patient Safety Action Plan 2022-2030 is translated and implemented into national patient safety institutional, legislative, policy, practice and standards through patient and family engagement and co-creation/coproduction.

## Trustees' Report for the Year Ended 31 December 2023

---

### Statement of Trustees' Responsibilities

The trustees (who are also the directors of the company for the purposes of company law) are responsible for preparing the trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial period which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including income and expenditure, of the charitable company for that period.

In preparing those financial statements, the trustees are required to:

- ◆ select suitable accounting policies and then apply them consistently;
- ◆ observe the methods and principles in the Charities SORP;
- ◆ make judgements and estimates that are reasonable and prudent;
- ◆ state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- ◆ prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable charity will continue in business.

The trustees are responsible for keeping proper accounting records, which disclose with reasonable accuracy at any time, the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

### Statement as to disclosure to our auditors

In so far as the trustees are aware at the date of approving this report:

- ◆ there is no relevant audit information, being information needed by the auditor in connection with preparing their report, of which the charity's auditor is unaware; and
- ◆ the trustees having made enquiries of fellow directors and the group's auditor that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a director in order to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

## Trustees' Report for the Year Ended 31 December 2023

---

### Reappointment of auditors

A proposal to reappoint Knox Cropper LLP as the charity's statutory auditors will be put to members at our forthcoming annual general meeting.

Approved and authorised for issue by the Governing Board on 24 September 2024 and signed on their behalf by:



**Ellos Elland Lodzeni,**  
Chair of the Board, IAPO



## **Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31<sup>st</sup> December 2023**

### **Opinion**

We have audited the financial statements of International Alliance of Patients' Organization for the year ended 31 December 2023 which comprise the Statement of Financial Activities (including the Income and Expenditure Account), the Balance Sheet and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- ◆ Give a true and fair view of the state of the charitable company's affairs as at 31 December 2023 and of its income and expenditure, for the period then ended;
- ◆ Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- ◆ Have been prepared in accordance with the requirements of the Companies Act 2006.

### **Conclusions relating to going concern**

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### **Other information**

The other information comprises the information included in the Trustees' Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If

## **Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31<sup>st</sup> December 2023**

we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

### **Opinion on other matters prescribed by the Companies Act 2006**

In our opinion, based on the work undertaken in the course of the audit:

- ◆ The information given in the Trustees' Report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- ◆ The directors' report, included within the Trustees' Report, has been prepared in accordance with applicable legal requirements.

### **Matters on which we are Required to Report by Exception**

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- ◆ Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- ◆ The financial statements are not in agreement with the accounting records and returns; or
- ◆ Certain disclosures of Trustees' remuneration specified by law are not made; or
- ◆ We have not received all the information and explanations we require for our audit; or
- ◆ The trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Trustees' Report.

### **Responsibilities of Trustees**

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

## Independent Auditor's Report to the Members of International Alliance of Patients' Organizations for the Year Ended 31<sup>st</sup> December 2023

### Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- ◆ The Charitable Company is required to comply with both company law and charity law and, based
- ◆ The Charitable Company is required to comply with both company law and charity law and, based on our knowledge of its activities, we identified that the legal requirement to accurately account for restricted funds was of key significance.
- ◆ We gained an understanding of how the charitable company complied with its legal and regulatory framework, including the requirement to properly account for restricted funds, through discussions with management and a review of the documented policies, procedures and controls.
- ◆ The audit team, which is experienced in the audit of charities, considered the charitable company's susceptibility to material misstatement and how fraud may occur. Our considerations included the risk of management override.
- ◆ Our approach was to check that all restricted income was properly identified and separately accounted for and to ensure that only valid and appropriate expenditure was charged to restricted funds. This included reviewing journal adjustments and unusual transactions.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

### Use of our report

This report is made solely to the charitable company's trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

*Knox Cropper LLP*

25 September 2024

Simon Goodridge (Senior Statutory Auditor)  
For and on behalf of Knox Cropper LLP (Statutory Auditor)  
65 Leadenhall Street  
London  
EC3A 2AD

**Statement of Financial Activities (incorporating an income and expenditure account) for the Year Ended 31 December 2023**

|                                                 |                                  |                          |                        |                   | <b>Total<br/>2023</b> | <b>Total<br/>2022</b> |
|-------------------------------------------------|----------------------------------|--------------------------|------------------------|-------------------|-----------------------|-----------------------|
|                                                 | <b>N<br/>o<br/>t<br/>e<br/>s</b> | <b>Unrestrict<br/>ed</b> | <b>Designat<br/>ed</b> | <b>Restricted</b> | <b>(year)</b>         | <b>(year)</b>         |
|                                                 |                                  | <b>£</b>                 | <b>£</b>               | <b>£</b>          | <b>£</b>              | <b>£</b>              |
| <b>Income from charitable activities:</b>       |                                  |                          |                        |                   |                       |                       |
| Membership                                      |                                  | 2,767                    | -                      | -                 | 2,767                 | 4,092                 |
| Healthcare Industry Partners                    |                                  | 83,938                   | -                      | -                 | 83,938                | 234,401               |
| APPC congress                                   |                                  | -                        | 32,309                 | -                 | 32,309                | 59,065                |
| GPC congress                                    |                                  | -                        | 82,145                 | -                 | 82,145                | -                     |
| Africa congress                                 |                                  | -                        | -                      | -                 | -                     | -                     |
| Latin congress                                  |                                  | -                        | -                      | -                 | -                     | 23,909                |
| Special Projects                                |                                  | -                        | -                      | 410,197           | 410,197               | 257,863               |
| Other charitable activities                     |                                  | 9,371                    | -                      | -                 | 9,371                 | 3,312                 |
| <b>Total</b>                                    | <b>2</b>                         | <b>96,076</b>            | <b>114,454</b>         | <b>410,197</b>    | <b>620,727</b>        | <b>582,642</b>        |
| <b>Expenditure on charitable Activities:</b>    |                                  |                          |                        |                   |                       |                       |
| <b>Charitable activities:-</b>                  |                                  |                          |                        |                   |                       |                       |
| · Capacity building, advocacy and collaboration |                                  | (152,278)                | -                      | -                 | (152,278)             | (187,933)             |
| · Asia Pacific Patients Congress                |                                  | -                        | (698)                  | -                 | (698)                 | (64,785)              |
| · Global Patients Congress                      |                                  | -                        | (96,995)               | -                 | (96,995)              | (1,355)               |
| · Africa Patients Congress                      |                                  | -                        | -                      | -                 | -                     | -                     |
| · LatAm Patients Congress                       |                                  | -                        | -                      | -                 | -                     | (47,379)              |
| · Special projects                              |                                  | -                        | -                      | (358,286)         | (358,286)             | (97,674)              |
| <b>Total</b>                                    | <b>4</b>                         | <b>(152,278)</b>         | <b>(97,693)</b>        | <b>(358,286)</b>  | <b>(608,257)</b>      | <b>(399,126)</b>      |
| <b>Net income / (expenditure)</b>               |                                  | <b>(56,202)</b>          | <b>16,761</b>          | <b>51,911</b>     | <b>12,470</b>         | <b>183,516</b>        |
| <b>Transfers</b>                                |                                  | <b>-</b>                 | <b>-</b>               | <b>-</b>          | <b>-</b>              | <b>-</b>              |
| <b>Net movement in funds</b>                    |                                  | <b>(56,202)</b>          | <b>16,791</b>          | <b>51,911</b>     | <b>12,470</b>         | <b>183,516</b>        |
| <b>Reconciliation of funds:</b>                 |                                  |                          |                        |                   |                       |                       |
| <b>Funds brought forward</b>                    |                                  | <b>287,351</b>           | <b>(38,112)</b>        | <b>283,533</b>    | <b>532,772</b>        | <b>349,257</b>        |
| <b>Total funds carried forward</b>              |                                  | <b>231,149</b>           | <b>(21,351)</b>        | <b>335,444</b>    | <b>545,242</b>        | <b>532,772</b>        |

All transactions are derived from continuing activities.

All recognised gains and losses are included in the Statement of Financial Activities.

## Balance Sheet as at 31 December 2023

|                                                       | Notes     | 2023<br>£        | 2022<br>£        |
|-------------------------------------------------------|-----------|------------------|------------------|
| <b>Fixed assets</b>                                   | <b>8</b>  | <b>-</b>         | <b>-</b>         |
| <b>Current assets</b>                                 |           |                  |                  |
| Debtors                                               | 9         | 6,868            | 8,115            |
| Cash in hand and in bank                              |           | 690,597          | 625,567          |
|                                                       |           | <u>697,465</u>   | <u>633,682</u>   |
| <b>Creditors: amounts falling due within one year</b> | <b>10</b> | <b>(152,223)</b> | <b>(100,910)</b> |
|                                                       |           | <u>545,242</u>   | <u>532,772</u>   |
| <b>Net current assets</b>                             |           |                  |                  |
|                                                       |           | <u>545,242</u>   | <u>532,772</u>   |
| <b>Net assets</b>                                     | <b>11</b> | <b>545,242</b>   | <b>532,772</b>   |
|                                                       |           | <u>545,242</u>   | <u>532,772</u>   |
| <b>Funds</b>                                          |           |                  |                  |
| Unrestricted Funds                                    |           | 231,149          | 287,351          |
| Designated Funds                                      |           | (21,351)         | (38,112)         |
| Restricted Funds                                      |           | 335,444          | 283,533          |
|                                                       |           | <u>335,444</u>   | <u>283,533</u>   |
| <b>Total Funds</b>                                    | <b>13</b> | <b>545,242</b>   | <b>532,772</b>   |
|                                                       |           | <u>545,242</u>   | <u>532,772</u>   |

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

These financial statements were approved and authorised for issue by the Governing Board on 24 September 2024 and signed on their behalf by:



**Ellos Ellard Lodzeni**  
Chair



**Dr Anthony John Holland**  
Treasurer

Registered company number: 08495711 (England and Wales)

The notes on pages 27 to 37 form part of these financial statements.

## Cash flow statement for the year ended 31 December 2023

|                                                        | 2023                    | 2022      |                           |
|--------------------------------------------------------|-------------------------|-----------|---------------------------|
| Cashflows from operating activities                    |                         |           |                           |
| Surplus/(deficit) for the financial year               | 12,470                  | 183,516   |                           |
| Adjustments for:                                       |                         |           |                           |
| Depreciation Charge                                    | -                       | 134       |                           |
| (Increase)/Decrease in debtors                         | 1,247                   | 1,157     |                           |
| Increase/(Decrease) in creditors                       | 51,313                  | 7,785     |                           |
|                                                        | 65,030                  | 190,277   |                           |
| Net increase / (decrease) in cash and cash equivalents | 65,030                  | 190,277   |                           |
| Cash at 1 January 2023                                 | 625,567                 | 435,290   |                           |
| Cash at 31 December 2023                               | A 690,597               | 625,567   |                           |
| A) Components of cash and cash equivalents             |                         |           |                           |
| Cash at bank and in hand                               | 690,597                 | 625,567   |                           |
| B) Analysis of changes in net debt                     |                         |           |                           |
|                                                        | At 1<br>January<br>2023 | Cashflows | At 31<br>December<br>2023 |
| Cash and cash equivalents                              | 625,567                 | 65,030    | 690,597                   |
|                                                        | 625,567                 | 65,030    | 690,597                   |

## Notes to the Financial Statements for the Year Ended 31 December 2023

---

### 1. Accounting Policies

#### 1.1 Accounting convention

The financial statements of the charitable company, which is a public benefit entity under FRS102, have been prepared in accordance with the 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (SORP) (FRS102 second edition - effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

The financial statements are presented in Sterling (£).

Results for the trading subsidiary, IAPO Trading Limited (Company Number 08863190) are not consolidated on the grounds that it was dormant and not material to the group.

#### Statement on going concern

After reviewing the charity's forecasts and projections, the directors have reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. The charity therefore continues to adopt the going concern basis in preparing its financial statements.

#### 1.2 Company status

The parent charity is a company limited by guarantee. The directors of the company are the trustees named on page 1. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

#### 1.3 Incoming resources

All incoming resources are included in the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable certainty.

#### 1.4 Expenditure

All expenditure is included on an accruals basis and is inclusive of all VAT, which cannot be reclaimed, and is reported as part of the expenditure to which it relates:

- ◆ Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.
- ◆ Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.
- ◆ All costs are allocated between expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, other costs are apportioned on the basis staff time incurred.

## Notes to the Financial Statements for the Year Ended 31 December 2023

---

The core elements of charitable expenditure are as follows:

**Capacity Building:** Realising active partnerships with patients' organisations, maximising their impact through capacity building.

**Advocacy:** Advocating internationally with a strong patients' voice on the relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies.

**Collaboration:** Building cross-sector alliance and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives.

### 1.5 Funds

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Designated funds are funds which are 'ring-fenced' to be used for the specific purpose of the congress.

Restricted funds are funds, which are to be used in accordance with specific restrictions imposed by the donor. The aim and use of the restricted fund is set out in the notes of the financial statements.

### 1.6 Tangible fixed assets and depreciation

Capital expenditure on items costing £1,000 or higher are recorded as tangible fixed assets. Tangible fixed assets are stated at historical cost less depreciation.

Depreciation is provided to reflect the useful estimated economic life of computer equipment assets at a rate of 33% per annum (reducing balance method).

## Notes to the Financial Statements for the Year Ended 31 December 2023

### 2. Incoming resources

|              | OTHER          | Healthcare<br>Industry<br>Partners | Projects       | Total          |
|--------------|----------------|------------------------------------|----------------|----------------|
|              | £              | £                                  | £              | £              |
| GSK          | -              | 39,584                             | -              | 39,584         |
| IFPMA        | -              | 44,354                             | -              | 44,354         |
| Projects     | -              | -                                  | 410,197        | 410,197        |
| Other income | 126,592        | -                                  | -              | 126,592        |
|              | <u>126,592</u> | <u>83,938</u>                      | <u>410,197</u> | <u>620,727</u> |

### Income Resources comparative

|                               | OTHER        | Healthcare<br>Industry<br>Partners | Projects       | Total          |
|-------------------------------|--------------|------------------------------------|----------------|----------------|
|                               | £            | £                                  | £              | £              |
| Merck                         | -            | 48,332                             | -              | 48,332         |
| MYLAN PHARMACEUTICALS PVT LTD | -            | 44,151                             | -              | 44,151         |
| IFPMA                         | -            | 40,245                             | -              | 40,245         |
| Pfizer Inc                    | -            | 25,946                             | -              | 25,946         |
| GSK IHC                       | -            | 42,815                             | -              | 42,815         |
| P4PS OBSERVATORY              | -            | 5,769                              | -              | 5,769          |
| MSD INTERNATIONAL             | -            | 27,155                             | -              | 27,155         |
| Congress Sponsorship          | -            | 82,973                             | -              | 82,973         |
| Projects                      | -            | -                                  | 257,863        | 257,863        |
| Other income                  | 7,404        | (11)                               | -              | 7,393          |
|                               | <u>7,404</u> | <u>317,375</u>                     | <u>257,863</u> | <u>582,642</u> |

## Notes to the Financial Statements for the Year Ended 31 December 2023

### 3. Congress Support Income 2023

|                         | APPC congress | GPC congress  | Total          |
|-------------------------|---------------|---------------|----------------|
|                         | £             | £             | £              |
| ROCHE PHARMA HOLDING    | 32,309        | 39,220        | 71,529         |
| NOVARTIS                | -             | 11,679        | 11,679         |
| BIOMARIN PHARMACEUTICAL | -             | 31,246        | 31,246         |
|                         | <u>32,309</u> | <u>82,145</u> | <u>114,454</u> |

### Congress Support income comparative 2022

|                  | Asia Pacific Congress | Latin America Patients Congress | Total 2022    |
|------------------|-----------------------|---------------------------------|---------------|
|                  | £                     | £                               | £             |
| BOEHRINGER INGEL | 59,065                | -                               | 59,065        |
| Merck            | -                     | 23,909                          | 23,909        |
|                  | <u>59,065</u>         | <u>23,909</u>                   | <u>82,973</u> |

## Notes to the Financial Statements for the Year Ended 31 December 2023

### 4. Expenditure on Charitable Activities

|                                               | Staff Costs    | Other Costs    | Support Costs | Total          |
|-----------------------------------------------|----------------|----------------|---------------|----------------|
| Capacity Building, advocacy and collaboration | 86,326         | -              | 65,952        | 152,278        |
| Congress                                      | 7,008          | 86,288         | 4,397         | 97,693         |
| Special Projects                              | 63,071         | 277,628        | 17,587        | 358,286        |
| <b>Total</b>                                  | <b>156,405</b> | <b>363,916</b> | <b>87,936</b> | <b>608,257</b> |

### *Expenditure on Charitable Activities comparative*

|                                               | Staff Costs    | Other Costs    | Support Costs | Total 2022     |
|-----------------------------------------------|----------------|----------------|---------------|----------------|
| Capacity Building, advocacy and collaboration | 88,131         | 32,668         | 67,134        | 187,933        |
| Congress                                      | -              | 112,661        | 858           | 113,519        |
| Special Projects                              | 53,597         | 40,558         | 3,519         | 97,674         |
| <b>Total</b>                                  | <b>141,728</b> | <b>185,887</b> | <b>71,511</b> | <b>399,126</b> |

### 5. Analysis of support costs

|                             | Capacity Building, advocacy and collaboration | Congress     | Special Projects | Total         |
|-----------------------------|-----------------------------------------------|--------------|------------------|---------------|
| Rent and Rates              | 5,321                                         | 355          | 1,419            | 7,095         |
| Other Office Costs          | 38,300                                        | 2,553        | 10,213           | 51,066        |
| Legal and Professional Fees | 17,750                                        | 1,184        | 4,733            | 23,667        |
| Audit Fees                  | 4,581                                         | 305          | 1,222            | 6,108         |
| <b>Total</b>                | <b>65,952</b>                                 | <b>4,397</b> | <b>17,587</b>    | <b>87,936</b> |

## Notes to the Financial Statements for the Year Ended 31 December 2023

### *Analysis of support costs comparative*

|                                | Capacity Building,<br>advocacy and<br>collaboration | Congress   | Special<br>Projects | Total 2022    |
|--------------------------------|-----------------------------------------------------|------------|---------------------|---------------|
| Rent and Rates                 | 5,710                                               | 72         | 300                 | 6,082         |
| Other Office Costs             | 40,446                                              | 517        | 2,120               | 43,083        |
| Legal and Professional<br>Fees | 15,768                                              | 202        | 826                 | 16,796        |
| Audit Fees                     | 5,210                                               | 67         | 273                 | 5,550         |
| <b>Total</b>                   | <b>67,134</b>                                       | <b>858</b> | <b>3,519</b>        | <b>71,511</b> |

### 6. Trustees and staff remuneration

The trustees received no remuneration, but 6 Trustee received reimbursements of £22,056 (2022: £3,455) for travel and subsistence expenses incurred on behalf of the charity.

### *Staff remuneration and numbers*

|                    | Total<br>2023<br>£ | Total<br>2022<br>£ |
|--------------------|--------------------|--------------------|
| Wages and salaries | 125,376            | 127,094            |
| Social Security    | 13,167             | 14,390             |
| Pension costs      | 660                | 244                |
|                    | <b>139,203</b>     | <b>141,728</b>     |

The average number of full and part-time employees during the year was 3. No individual employee received emoluments in excess of £60,000 (2022: 1 in the band £70,001 to £80,000). Key management personnel costs amounted to £74,315 (2022: £71,544).

## Notes to the Financial Statements for the Year Ended 31 December 2023

### 7. Operating Surplus

Operating surplus is stated after charging.

|                                         | Total<br>2023 | Total<br>2022 |
|-----------------------------------------|---------------|---------------|
|                                         | £             | £             |
| Auditors Remuneration                   | 5,550         | 5,550         |
| Depreciation of Assets                  | -             | 134           |
| Operating Lease Charges (office rental) | 7,095         | 5,633         |

### 8. Fixed Assets

|                     | Computer<br>equipment<br>£ |
|---------------------|----------------------------|
| Cost                |                            |
| Brought forward     | 4,169                      |
| Carried forward     | 4,169                      |
| Depreciation        |                            |
| Brought forward     | 4,169                      |
| Charge for the year | -                          |
| Carried forward     | 4,169                      |
| Net book value      |                            |
| At 31 December 2023 | -                          |
| At 31 December 2022 | -                          |

There are no charges or securities held over any fixed assets. All fixed assets are held in the charity and none in the trading subsidiary. Depreciation was nil was in the previous period.

## Notes to the Financial Statements for the Year Ended 31 December 2023

### 9. Debtors

|             | 2023<br>£    | 2022<br>£    |
|-------------|--------------|--------------|
| Debtors     | -            | 1,235        |
| Prepayments | 6,868        | 6,880        |
|             | <u>6,868</u> | <u>8,115</u> |

### 10. Creditors: amount falling due within one year

|                 | 2023<br>£      | 2022<br>£      |
|-----------------|----------------|----------------|
| Deferred income | 113,590        | 73,423         |
| Accruals        | 38,633         | 27,487         |
|                 | <u>152,223</u> | <u>100,910</u> |

### 11. Analysis of net assets between funds

|                        | Unrestricted<br>Fund<br>£ | Designated<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total Funds<br>£ |
|------------------------|---------------------------|--------------------------|--------------------------|------------------|
| Current assets         | 231,149                   | -                        | 466,316                  | 697,465          |
| Current liabilities    | -                         | (21,351)                 | (130,872)                | (152,223)        |
| As at 31 December 2023 | <u>231,149</u>            | <u>(21,351)</u>          | <u>335,444</u>           | <u>545,242</u>   |

## Notes to the Financial Statements for the Year Ended 31 December 2023

### 12. Analysis of net assets between funds comparative

|                        | Unrestricted Fund<br>£ | Designated Funds<br>£ | Restricted Funds<br>£ | Total Funds<br>£ |
|------------------------|------------------------|-----------------------|-----------------------|------------------|
| Current assets         | 287,351                | -                     | 346,331               | 633,682          |
| Current liabilities    | -                      | (38,112)              | (62,798)              | (100,910)        |
| As at 31 December 2022 | 287,351                | (38,112)              | 283,533               | 532,772          |

The deficit in the designated fund is due to timing difference between the time we held the event and the time we received the income.

### 13. Movement in funds 2023

|                            | At 31 December 2022<br>£ | Incoming Resources<br>£ | Resources Expended<br>£ | Transfers<br>£ | At 31 December 2023<br>£ |
|----------------------------|--------------------------|-------------------------|-------------------------|----------------|--------------------------|
| <b>Unrestricted fund</b>   | 287,351                  | 96,076                  | (152,278)               | -              | 231,149                  |
| <b>Designated Funds: -</b> |                          |                         |                         |                |                          |
| APPC congress              | 2,367                    | 32,309                  | (698)                   | -              | 33,978                   |
| GPC congress               | 5,233                    | 82,145                  | (96,995)                | -              | (9,617)                  |
| Africa congress            | (22,241)                 | -                       | -                       | -              | (22,241)                 |
| Latin Congress             | (23,471)                 | -                       | -                       | -              | (23,471)                 |
| <b>Restricted funds: -</b> |                          |                         |                         |                |                          |
| PREFER                     | 29,296                   | -                       | -                       | (29,296)       | -                        |
| Special projects *         | 254,237                  | 410,197                 | (358,286)               | 29,296         | 335,444                  |
|                            | 532,772                  | 620,727                 | (608,257)               | -              | 545,242                  |

## Notes to the Financial Statements for the Year Ended 31 December 2023

### 14. Movements in funds comparative

|                            | At 31<br>December<br>2021 | Incoming<br>Resources | Resources<br>Expended | Transfers       | At 31<br>December<br>2022 |
|----------------------------|---------------------------|-----------------------|-----------------------|-----------------|---------------------------|
|                            | £                         | £                     | £                     | £               | £                         |
| <b>Unrestricted fund</b>   | <b>264,025</b>            | <b>241,805</b>        | <b>(187,933)</b>      | <b>(30,546)</b> | <b>287,351</b>            |
| <b>Designated Funds: -</b> |                           |                       |                       |                 |                           |
| APPC congress              | (22,459)                  | 59,065                | (64,785)              | 30,546          | 2,367                     |
| GPC congress               | 6,589                     |                       | (1,355)               |                 | 5,233                     |
| Africa congress            | (22,241)                  |                       |                       |                 | (22,241)                  |
| Latin Congress             |                           | 23,909                | (47,379)              |                 | (23,471)                  |
| <b>Restricted funds: -</b> |                           |                       |                       |                 |                           |
| PREFER                     | 38,352                    |                       | (9,056)               | -               | 29,296                    |
| Special projects*          | 65,761                    | 257,863               | (69,387)              | -               | 254,237                   |
| Other projects - Get Real  | 19,231                    |                       | (19,231)              | -               | -                         |
|                            | <b>349,257</b>            | <b>582,642</b>        | <b>(418,432)</b>      | <b>-</b>        | <b>532,772</b>            |

## Notes to the Financial Statements for the Year Ended 31 December 2023

## 15. SOFA Comparative

|                                                 |                       |                 |                 |                | Total<br>2022  |
|-------------------------------------------------|-----------------------|-----------------|-----------------|----------------|----------------|
|                                                 | N<br>o<br>t<br>e<br>s | Unrestricted    | Designated      | Restricted     | (year)         |
|                                                 |                       | £               | £               | £              | £              |
| <b>Income from charitable activities:</b>       |                       |                 |                 |                |                |
| Membership                                      |                       | 4,092           | -               | -              | 4,092          |
| Healthcare Industry Partners                    |                       | 234,401         | -               | -              | 234,401        |
| APPC congress                                   |                       | -               | 59,065          | -              | 59,065         |
| GPC congress                                    |                       | -               | -               | -              | -              |
| Africa congress                                 |                       | -               | -               | -              | -              |
| Latin congress                                  |                       | -               | 23,909          | -              | 23,909         |
| Special Projects                                |                       | -               | -               | 257,863        | 257,863        |
| Other charitable activities                     |                       | 3,312           | -               | -              | 3,312          |
| <b>Total</b>                                    | <b>2</b>              | <b>241,805</b>  | <b>82,973</b>   | <b>257,863</b> | <b>582,642</b> |
| <b>Expenditure on charitable Activities:</b>    |                       |                 |                 |                |                |
| Charitable activities:-                         |                       |                 |                 |                |                |
| · Capacity building, advocacy and collaboration |                       | 187,933         | -               | -              | 187,933        |
| · Asia Pacific Patients Congress                |                       | -               | 64,785          | -              | 64,785         |
| · Global Patients Congress                      |                       | -               | 1,355           | -              | 1,355          |
| · Africa Patients Congress                      |                       | -               | -               | -              | -              |
| · LatAm Patients Congress                       |                       | -               | 47,379          | -              | 47,379         |
| · Special projects                              |                       | -               | -               | 97,674         | 97,674         |
| <b>Total</b>                                    | <b>4</b>              | <b>187,933</b>  | <b>113,519</b>  | <b>97,674</b>  | <b>399,126</b> |
| <b>Net income / (expenditure)</b>               |                       | <b>53,872</b>   | <b>(30,546)</b> | <b>160,189</b> | <b>183,516</b> |
| <b>Transfers</b>                                |                       | <b>(30,546)</b> | <b>30,546</b>   | <b>-</b>       | <b>-</b>       |
| <b>Net movement in funds</b>                    |                       | <b>23,326</b>   | <b>-</b>        | <b>160,189</b> | <b>183,516</b> |
| <b>Reconciliation of funds:</b>                 |                       |                 |                 |                |                |
| Funds brought forward                           |                       | 264,025         | (38,112)        | 123,344        | 349,257        |
| <b>Total funds carried forward</b>              |                       | <b>287,351</b>  | <b>(38,112)</b> | <b>283,533</b> | <b>532,772</b> |

# Thank You

---

The International Alliance of Patients' Organizations is registered in England and Wales as charity n° 1155577 and company limited by guarantee n° 08495711.



## Address

Registered office: Hounslow House, 7 Bath Road, Hounslow TW3 3EB, UK.



## Website

[www.iapo.org.uk](http://www.iapo.org.uk)



**INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

England & Wales - Charity number 1155577

---

# Accounts

---

**Company registration number (England and Wales): 08495711**  
**Charity registration number (England and Wales): 1155577**

**INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

**(Incorporated as a Company Limited by Guarantee  
and not having a Share Capital)**

**ANNUAL REPORT AND FINANCIAL STATEMENTS**

**FOR THE YEAR ENDED 31 DECEMBER 2022**



# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **CONTENTS**

---

|                                                                                       | <b>Page</b>  |
|---------------------------------------------------------------------------------------|--------------|
| <b>Reference and Administrative Details of the Charity, its Trustees and Advisers</b> | <b>1</b>     |
| <b>Trustees Report</b>                                                                | <b>2-28</b>  |
| <b>Independent Auditor's Report</b>                                                   | <b>29-31</b> |
| <b>Statement of Financial Activities</b>                                              | <b>32</b>    |
| <b>Balance Sheet</b>                                                                  | <b>33</b>    |
| <b>Notes to the Financial Statements</b>                                              | <b>34-43</b> |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS

---

|                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|--------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Company number</b>                                  | 08495711 (England and Wales)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Charity number</b>                                  | 1155577 (England and Wales)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Registered office</b>                               | International Alliance of Patients' Organizations<br>49-51 East Road<br>LONDON<br>N1 6AH                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Governing Board members<br/>(Board of Trustees)</b> | Ellos Ellard Lodzeni (Vice-chair, appointed 22 Feb 2022)<br>Karen Alparce-Villanueva (Resigned 22 Feb 2022)<br>Neda Milevska-Kostova (Chair, appointed 22 Feb 2022)<br>Sita Ratna Devi Duddi (Resigned 22 Feb 2022)<br>Rosalia Liliana Tieri (Appointed 16 Dec 2020)<br>Orajitt Bumrungkulswat (Appointed 16 Dec 2020)<br>Adebisi Omolola Bright (Appointed 16 Dec 2020)<br>Professor Lara Claire Bloom (Appointed 22 Feb 2022)<br>Anthony John Holland (Appointed 22 Feb 2022)<br>Paul Albert Mendoza (Appointed 22 Feb 2022) |
| <b>Chief Executive</b>                                 | Kawaldip Sehmi – To 1st August 2023                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Interim Chief Executive</b>                         | Dani Mothci – from 4th August 2023                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Bankers</b>                                         | NatWest Bank Plc<br>PO Box 12258<br>1 Prices Street<br>LONDON<br>EC2R 8BP                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Lawyers</b>                                         | Bates Wells<br>10 Queen Street Place<br>LONDON<br>EC4R 1BE                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Independent auditor</b>                             | Knox Cropper LLP<br>65 Leadenhall Street<br>London<br>EC3A 2AD                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Website</b>                                         | <a href="http://www.iapo.org.uk">www.iapo.org.uk</a>                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

The directors, who are also the trustees of the charity, are pleased to present their report together with the financial statements of the charity for the year ended 31 December 2022 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

Results for the trading subsidiary, IAPO Trading Limited (Company Number 08863190) are not consolidated on the grounds that it was dormant and not material to the group.

The trustees have complied with the duty to have due regard to guidance issued by the Charity Commission and have adopted the Statement of Recommended Practice for charities (SORP) (FRS 102 second edition effective 1 January 2019).

### **Aims and objectives of the organisation**

The objects of the International Alliance of Patients' Organizations (IAPO), as set out in the Memorandum and Articles of Association, are the promotion of the relief of sickness and preservation and protection of health for the public benefit through fostering patient-centred healthcare worldwide and in particular by developing the capacity of patients' organizations.

IAPO is a unique global alliance representing patients of all nationalities, across all disease areas, and promoting patient-centred healthcare around the world. IAPO brings a global patient voice to healthcare decision-making based on the belief that patients' voices are amplified and heard effectively when patients' organizations are linked, can share best practices and practical strategies, and are connected with resources. Our members are patients' organizations working at the international, regional, national and local levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability.

IAPO was first established in 1999 in the Netherlands as a Dutch Stichting and then de-registered in 2014 to be registered in England and Wales as a UK Charity and Company Limited by Guarantee on 30<sup>th</sup> January 2014. IAPO has a membership of nearly 300 organizations across 71 countries covering 51 diseases groups. IAPO is a non-State Actor in official relations with the World Health Organization (WHO) and has a memorandum of understanding with the International Council of Nurses (ICN), International Hospital Federation (IHF), International Pharmaceutical Federation (FIP), World Medical Association (WMA), International Society for Quality in Health Care (ISQua), The Professional Society for Health Economics and Outcomes Research (ISPOR) and The Union for International Cancer Control (UICC). and with many other non-State Actors.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

### **IAPO's vision and mission**

**IAPO's vision is that patients throughout the world are at the centre of healthcare.**

**IAPO's mission is to help build patient-centred healthcare worldwide by:**

- **Realizing active partnerships with patients' organizations, maximizing their impact through capacity building**
- **Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies**
- **Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives**

**IAPO's activities include:**

- **Advocacy at global level on relevant aspects of healthcare policy to influence international health agendas and policies**
- **Providing membership services, including capacity building and shared learning, to its members, who are patient-led organizations across the world**
- **Empowering its members to undertake their own advocacy at regional and national meetings**
- **Providing opportunities for stakeholders from across the health sector to meet and work together to advance patient involvement in health services and decision-making**
- **Research on emerging areas of interest to patients' organizations and to underpin the evidence base for showing the importance of patient involvement to public health.**

### **Structure**

**The organisation is a charitable company limited by guarantee, incorporated on 19 April 2013 and registered as a charity on 1 February 2014. The company was established under a Memorandum of Association which defined the objects and powers of the company. It is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £1.**

**All assets and liabilities from the International Alliance of Patients Organizations and its predecessor not-for-profit structure registered in the Netherlands, were transferred to the new UK incorporated charity on 1 February 2014. IAPO Netherlands was (voluntarily) dissolved from the Netherlands Trade Register with effect from 31 May 2015, executed on 21 Oct 2015.**

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

### **Appointment and Induction of Governing Board**

Every member of the IAPO Governing Board is elected by IAPO's members, through a process defined in the [Memorandum and Articles of Association](#), [By Laws](#) and [Election Code of Conduct](#). Every year, in advance of the Annual General Meeting (AGM), the number of vacancies on the Board is notified to all members, who may then nominate someone from their organisations (a Board member or senior staff member) to IAPO's Governing Board. The full list of nominees is sent to all members in advance of the AGM; members may vote by post or proxy or in person at the AGM.

Governing Board members serve for a maximum of two terms of three years subject to the retirement by rotation clause; once their term of service is complete, they or anyone from their organization cannot be re-elected to the Board for at least a year. All new members of the Board receive induction including core information about the work and history of the organization, and conversations with the Chief Executive Officer and the Chair.

All Governing Board members sign a Code of Conduct when they are appointed to the Board. All staff and Governing Board members are required to complete a conflict-of-interest form at every Board meeting. The Governing Board have no beneficial interest in the charitable company or its trading subsidiary. No Governing Board member receives any remuneration for services as a trustee.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Chair's Report Financial Year 1st January to 31st December 2022

The year 2022 has been a time of continued great challenges for many patient organisations. We all learnt how to operate in difficult circumstance and keep serving our patient members and stakeholders virtually instead of face-to-face. IAPO, as many other organisations, learnt how to reach out to our members and partners digitally as our staff and suppliers learnt new digital skills and developed innovative communication and connectivity channels.

During 2022, IAPO has started to slowly open to in-person events and collaboration, however maintaining virtual and hybrid options for ensuring patients safely engage in many opportunities worldwide.

Our members have been busy participating in various pandemic preparedness initiatives nationally and regionally. IAPO is part of the WHO's global initiatives to negotiate new international public health instruments to ensure that our health systems are no longer vulnerable to global threats. We once again reiterate that we must continue to work together in national unity and global solidarity to ensure that we strengthen our global health governance and healthcare delivery systems.

We must continue to address health system strengthening to bridge over the many fault lines that appeared along the entire spectrum of our national healthcare services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course. But, at the same time, we must not forget that emergency preparedness is only one aspect of ensuring sustainable, affordable and accessible healthcare through universal health coverage for everyone everywhere.

The pandemic has been a blessing in disguise, too. It spurred new urgency for patient engagement in medicines and health devices research and regulation. When on March 11, 2020, WHO Director General declared the novel coronavirus (COVID-19) outbreak as a global pandemic, the global biopharmaceutical industry and regulators began a golden phase in international cooperation with patients as they started forging new multi-sectoral innovative partnerships in medicines and health device research, development, and regulation.

IAPO is also aware that this golden phase in international cooperation has raised new issues of equity and access to innovative health technologies. We must reflect upon universal health coverage 2030 once again and see how we can ensure equitable access to innovative, safe, quality, acceptable and patient centred medicines, health devices and other medical products that patients need without suffering financial hardship.

I particularly want to thank all our stakeholders who rallied around us and the global patient movements in 2021 and joined us in guiding our member organisations and the world through the complex healthcare ecosystem created by the pandemic. Our stakeholders participated generously and ensured that we achieved all our objectives set for 2021 and kept in phase with our Strategy. Please see our [IAPO Achievements 2022](#) and our [Strategy 2022-2024](#)

We must first thank the World Health Organization and its Director General Dr Tedros Adhanom Ghebreyesus for continuing providing leadership during the pandemic and in the aftermath when leadership was even more needed. Under Dr Ghebreyesus' leadership, we all witnessed that the world can do more and build back better, using the power of togetherness in good preparedness and healthcare research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing the pandemic threat and trends as they rose. The WHO's fight against the misinformation and infodemic has helped our patient organisations a lot.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

Year 2022 was a congress year for IAPO, but due to the still unstable peripandemic period, for the safety of our membership and participants, we have decided to postpone one anniversary 10<sup>th</sup> Global Patient Congress to 2023, and to organize it in Geneva, side by side with the 76<sup>th</sup> World Health Assembly, together with the member states celebrating the end of the pandemic and setting an accelerated post-pandemic agenda. But, we did not miss the opportunity to use 2022 for diverse online and virtual networking and exchange events to talk to our constituency and other stakeholders and better prepare for the times ahead of us, in representing patient voice at the global and regional health fora. This included also development of different toolkits, infographics, educational materials and courses, to help build resilient and engaged patient and family community.

In 2022, we continued to stay in close touch and inform our members and wider patient community on the new developments in the academic research and innovation, as well as in proposed and adopted global and regional policies, that would help them understand and better advocate for patient-centred, safe, affordable and accessible healthcare for everyone worldwide, starting from their own country and health system.

We then thank the medicine and health device regulators, and health technology assessment bodies that worked seamlessly in global solidarity to give us innovative medicines and health devices to address the needs of the patients during and after the pandemic.

The regulators have included us within their decision-making processes and have established good patient engagement framework for co-creation.

Lastly, I want to thank our healthcare industry partners who have supported us and our member organisations in this difficult challenging time through sponsorship, educational grants, and research projects. Without their support, we could not have reached the audience we have and made the impact we have in 2022.

Our 2022-2024 Strategy was conceived during the pandemic in 2020 through collaboration with all our stakeholders and addresses the key need that we collaborate globally along the entire healthcare value chain to attain a Patient Centred (PC) and Pandemic Prepared (PP) Universal Health Coverage (UHC 2030).

The achievements of 2022 have been further shared and evidenced on our website [www.iapo.org.uk](http://www.iapo.org.uk) and our social media:

- <https://twitter.com/iapovoice?lang=en>
- <https://www.facebook.com/IAPOvoice/>



Prim Dr Neda Milevska-Kostova

Chair of the Board IAPO

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

### Governance

The International Alliance of Patients' Organizations has a Board of Trustees and Directors overseeing its governance and direction, supported by a secretariat headed by the Chief Executive Officer.

| BOARD OF TRUSTEES AND DIRECTORS |              |                 |
|---------------------------------|--------------|-----------------|
| Name                            | Position     | Country         |
| Dr. Neda Milevska-Kostova       | Chair        | North Macedonia |
| Mr. Ellos Ellard Lodzeni        | Vice Chair   | Malawi          |
| Mrs. Rosalia Liliana Tieri      | Board Member | Argentina       |
| Mrs. Orajitt Bumrungkulswat     | Secretary    | Thailand        |
| Mrs. Adebisi Omolola Bright     | Board Member | Nigeria         |
| Professor Lara Claire Bloom     | Treasurer    | United Kingdom  |
| Anthony John Holland            | Board Member | United Kingdom  |
| Paul Albert Mendoza             | Board Member | Philippines     |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

The international Alliance of Patients Organizations adapted its 2023 strategic plan to match the rapid and chaotic post-pandemic healthcare ecosystem changes that our members were experiencing.

Our Strategic Plan had to be modified to not only meet the demands of the rapidly changing current external healthcare ecosystem, but also to ensure that we build back a better universal health coverage 2030 by ensuring that patient centred healthcare is not undermined in the recovery phases going on globally.

We aimed to keep our health systems safe, accessible, acceptable, affordable, and non- discriminatory, delivering quality healthcare throughout the build back better phases.

In 2022 IAPO advocated that the whole of government-society and- industry increase investment in building back better and FAIRER health systems. This required that we must:

- Empower patients.
- Drive patient led research into patient preferences and global health systems.
- Shape law, regulation, policy, practice, and standards.

We requested our membership, alliances, and industry partners to support us in 2022 in the following areas:

### IAPO activities in innovation and access

IAPO established new alliances and networks and held webinars empowering patients, driving research, and shaping law, policy, practice, and standards framework to improve patient centred healthcare and open access in the following innovative health technologies:

- Personalised healthcare and precision medicine (genomic medicines).
- Digital health
- Virtual clinics and telehealth care
- Self-care
- AI and machine Learning
- Patient engagement in research and development
- Humanising healthcare

### Governance

Good governance in healthcare enables patient engagement and co-production, and enhances patient safety, quality, and access. IAPO is engaging in:

- WHO Global Patient Safety Action Plan 2021-2030
- Patient centred decision-making in Regulatory and HTA ecosystems
- Data Governance- privacy, confidentiality, ownership and sharing
- Transparency International

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Equity

The central pillar of UN's Universal Health Coverage 2030 Sustainable Development Goal is Health Equity: The absence of unfair, avoidable or remediable differences among groups of people, whether those groups are.

defined socially, economically, demographically, or geographically or by other dimensions of inequality (e.g. sex, gender, ethnicity, disability, or sexual orientation). Health is a fundamental human right. Health equity is achieved when everyone can attain their full potential for health and well-being.

- UHC 2030, Healthcare Financing and Patient/Public/Private Partnerships
- Rare Diseases: The UN Resolution on Persons Living with a Rare Disease December 2021
- Paediatrics UN Convention on the Rights of the Child
- Women's Health: With IAPO's Metrodora Awards
- Mental Health

### IAPO OUTPUT, AND IMPACT 2022

In 2022, the first year of our 2022-2024 Strategic Plan, our vision was to attain a Patient Centred (PC) and Pandemic Prepared (PP) Universal Health Coverage (UHC 2030) in all countries.

Our main objective was to ensure that there is a sufficient availability of patient-centric, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each WHO Member State, along with essential and innovative medicines and health devices, which are accessible, acceptable and affordable, and delivered without the patients suffering financial hardship or discrimination.

Our 2022 strategy was to:

1. Empower patient communities globally to advocate effectively for patient-centred and pandemic prepared universal health coverage for all.
2. Drive research processes and the co-creation of evidence base in support of patient-centred and pandemic prepared universal health coverage and strengthen patient involvement in clinical research and global health institutes.
3. Shape law, policy and practice by applying the empowered patient community and evidence base created to shape the institutional, law, policy, practice, and standards framework to bring about patient-centred and pandemic prepared universal health coverage at global, regional and national levels

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Empowerment in 2022

IAPO has been collaborating with several organisations in 2022 in developing resources for patient groups on specific areas of:

- Health Literacy
- Patient Safety
- Antimicrobial Resistance
- Personalised Medicine
- Universal Health Coverage

### Empowering patients through Congresses

In 2022 IAPO used two Regional Congresses as capacity building events to empower our patient groups in Latin America and Asia-Pacific. The Congresses are our flagship event where we bring together our membership with a variety of high-level health care stakeholders to discuss important issues for patients worldwide.

### Output and impact

Please see the output and impact in reports and videos here:

- [1st Virtual Latin American Patients Congress General Information](#)
- [1st Virtual Latin American Patients Congress Full Programme and Speaker Session Details](#) and [Recordings](#)

The 4<sup>th</sup> Asia Pacific Patients Congress programme and videos can be found here:

- [4th Asia-Pacific Patients Congress General Information](#)
- [4th Asia-Pacific Patients Congress videos](#)

### Empowering patients through health literacy

IAPO in collaboration with Viartis created the Virtual Patient Academy as a Resource for low and middle income countries whose vision is to create communities of empowered patients that take ownership in the management of their medical condition through customized health information. The site currently features different modules based on specific medical conditions. It provides patients access to disease awareness videos, posters, patient stories, frequently asked questions, additional resources and contact details for support centres.

### Output and Impact

Please see the site: <https://thepatientacademy.com/>

IAPO engaged with Pfizer to develop informative infographics about risks of COVID-19 for patients with multimorbidities and chronic conditions, such as CVD, obesity, diabetes, and COPD. Infographics were translated into seven languages and distributed across social media and throughout patient networks.

IAPO engaged with the IAPO Patients for Patient Safety Observatory in development of self-paced patient courses on patient safety, specifically oriented at patient understanding of the Global Patient Safety Action Plan 2021-2030 and how can patients and families engage in improving patient safety. IAPO and IAPO P4PS Observatory also co-developed an Antimicrobial Resistance course in English, Italian and Spanish, for ensuring patients understand the importance of appropriate use of antibiotics and how they can contribute in the fight against AMR.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2021**

---

### Empowering patients on quality primary healthcare in the UHC 2030

IAPO believes that primary healthcare (PHC) is essential for access - it is closest to patients and caregivers and can provide the most comprehensive, holistic and continued care. In line with this, we collaborated with IAPO Patients for Patient Safety (P4PS) Observatory and the Primary Health Care Performance Initiative (PHCPI) to drive greater action, investment, accountability, and improvement for strong primary health care globally.

#### Output and impact

To mark UHC Day, on 12 December 2022, in collaboration with IAPO Patients for Patient Safety Observatory we organised a webinar titled: "How important is safe and quality primary healthcare in the UHC 2030 equation?" to discuss the importance of a safe and quality primary healthcare (PHC) as part of UHC. See the recording here: <https://youtu.be/al596Ac8UeI>

Lastly, we stood with 150+ organizations to urge action on PHC through launching of the Allies Improving PHC's Open Letter during UNGA 77, urging leaders to prioritize primary health care as a 3-for-1 investment in universal health coverage, health security and better health and well-being.

### Empowering patients on WHO Global Patient Safety Action Plan

IAPO is fully committed to reducing avoidable patient harm to zero in all our healthcare services from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course.

#### Output and impact

- At the 4<sup>th</sup> Asia Pacific Patients Congress, IAPO held a session titled 'Translating the WHO Global Patient Safety Action Plan - Patient and Family Engagement Section into National Patient Safety Networks and Alliances in Asia-Pacific' which raised awareness and developed common strategies to advance WHO's Global Patient Safety Action Plan's fourth strategy to Engage and empower patients and families to help and support the journey to safer health care.
- IAPO raised interventions at World Health Assembly and WHO Regional Committees in Africa, Eastern Mediterranean, Europe, South Asia, Western Pacific

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

---

### Patient Solidarity Day 2022

Patient Solidarity Day takes place each December with thousands of people from around the world rallying around one key issue facing patients and raise awareness by hosting events and showing support for the Day.

### Output and impact

On Friday 9th December 2022, health stakeholders from all over the world stood together, united in celebration of Patient Solidarity Day (PSD). This was the tenth year running that we joined hands to mark the Day. PSD 2022, saw IAPO members, patients, various healthcare organizations, policymakers, academia, institutions, industry and other stakeholders come together to call for medication safety in recognition of the prevalence of medication-related harm.

PSD 2022 theme, 'Patients for Medication Safety', allowed us to rally around a key tenet of IAPO's Patient-centred Healthcare Declaration that patients must be able to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. PSD 2022 was used as an opportunity to urge the whole of government and whole of society to work with the whole of the patient community in national unity and global solidarity to ensure that patients and families are engaged and empowered to help and support the journey to safer healthcare (Strategic Objective 4 of GPSAP 2021-2030).

### Shape law, policy, and practice in patient centred-universal health coverage at global, regional, and national levels in 2022

IAPO collaboration with the World Health Organization in shaping global health policy in 2022 as follows:

#### WHO Executive Board 150th session, January 2022

The 150th session of the World Health Organization's Executive Board (EB) took place virtually on 24th - 29th January 2022. Thanks to IAPO's official relations status with the World Health Organization, we leveraged this meeting by delivering three statements in line with our call for global patient-centred healthcare.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

---

### Output and impact

IAPO made 3 interventions, addressing the WHO Member States on:

- Agenda Item 7: Political declaration of the third high-level meeting of the General Assembly on the prevention and control of non-communicable diseases
- Agenda item 7b: Draft recommendations to strengthen and monitor diabetes responses within national non-communicable disease programmes, including potential targets
- Agenda Item 14: Standardization of medical devices nomenclature

SEE FULL STATEMENTS: <https://www.iapo.org.uk/news/2022/feb/22/iapo-statements-who-executive-board-150th-session-january-2022>

### *75th World Health Assembly*

IAPO values its special status as a non-State Actor in Official Relationship with WHO and uses this privilege to advocate on important global health matters affecting our patient organisations by addressing the Member States at each World Health Assembly.

IAPO participated in the 75th session of the World Health Assembly on 22 May 2022 - 28 May 2022.

### Output and impact

IAPO made 4 interventions, addressing the WHO Member States on:

- Agenda Item 13.1 Global action on patient safety
- Agenda item 13.2 Political declaration on NCDs and Agenda item 13.3 Expanding access to effective treatments for cancer and rare and orphan diseases.
- Agenda Item 13.7 Standardization of medical devices nomenclature
- Constituency Statement on Agenda item 17 and Agenda item 18

### *WHO Regional Committees*

IAPO repeated the same messages that we advocated on at the World Health Assembly at the Regional Health Assemblies:

We participated virtually in the WHO Regional Committees:

- Regional Committee for the Western Pacific
- Regional Committee for Europe
- Regional Committee for Africa
- Regional Committee for South-East Asia
- Regional Committee for the Americas
- Regional Committee for the Eastern Mediterranean Region

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### [Side event at WHO Regional Committee for Africa:](#)

#### Output and impact

With the WHO's Regional Committee for Africa adopting, for the first time, a procedure for accreditation for regional non-State actors not in official relations with the WHO to participate in the sessions of the WHO Regional Committee for Africa, our event was an opportunity to come together to review the requirements for the accreditation process and how we can work together to ensure more patient organizations in Africa achieve this status.

- On 24 August 2022, IAPO held a virtual side event to the World Health Organisation (WHO) Regional Committee for Africa on how African Patient Organizations can influence change in Africa by becoming non-State actors in official relations or an accredited organisation in WHO Africa.

### [Side events WHO Regional committee Southeast Asia in Bhutan](#)

#### Output and impact

- **Side-Event 1- Marking world patient safety day in WHO SEA on 17 September 2022?**  
IAPO convened a meeting in Paro at the Tashi Namgay Conference Hall that was easily accessible to the main Regional Committee Le Meridian Conference Centre to discuss ideas with WHO Member States on making the World Patient Safety Day a great event. We shared our ideas and directed people to the Official Campaign site.  
We wanted to make sure that on 17th September 2022, the whole of government, whole of society and the whole of patient movement marks World Patient Safety Day. 20 NSAs and 7 High Level Member States and Bhutan Minister of Health dropped in to wish us good luck. 150 People attend the event.
- **Side-Event 2 A compassionate and humanised health system will always deliver safe healthcare to all everywhere**

Our local partner, Bhutan Visit, provided free guides and transport to help our 60 delegate participants to get to TaktSang Conference Centre at the base of the TaktSang Monastery (AKA Tiger's Nest).

We had a small walk with 60 participants along an exciting trek historic and gathered at a local Monastery on the foothill. Due to the inclement weather, this walk could not be carried out to the top and the Tiger's Nest and we ended up holding a small assembly (Sangha) at the TaktSang Conference Centre and followed by a local cultural programme and country cooking meal. We had a high Lama come and discuss with us the nature of compassionate and humanised healthcare Southeast Asian culture.

This event was a follow-on side-event from our initial side-event at the 75th World Health Assembly in Geneva in May 2022. The Bhutan Ministry of health sent the Director of Public Health to speak on behalf of Health Minister of Bhutan Her Excellency Dasho Dechen Wangmo, we also shared this session with WHO Patient Safety and Quality Units, International Council of Nurses (ICN), World Medical Association (WMA), International Experience Exchange with Patient Organizations (IEEPO) and IAPO about compassion in healthcare and Bhutan's Service with Care and Compassion Initiative (SCCI).

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Output and impact

IAPO highlighted WHO's commitment to compassion in healthcare as promoted in their:

- Policy recommendation: Policy Levers to Enhance Health Workforce Performance for Compassionate and Respectful Care (2021) <https://bit.ly/3RIUPIE>
- Learning Briefs: The role of compassion in maintaining EHS during the COVID-19 pandemic (2022) <https://bit.ly/3pZcASr>
- IAPO also highlighted IEEPO Position Paper Humanising healthcare: a call for transformational change. <https://bit.ly/3COWpDM>

### WHO World Patient Safety Day 2022

IAPO has now established the marking of the WHO World Patients Safety Day on 17 September as an annual event with our members. IAPO and its Members marked the day by promoting Medication Safety and calling for Medication Without Harm.

### Output and impact

IAPO in collaboration with the International Council of Nurses (ICN), International Federation of Pharmaceutical Manufacturers & Associations (IFPMA), International Pharmaceutical Federation (FIP) and World Medical Association (WMA) had a special webinar conference to demonstrate commitment to the WHO Global Patient Safety Action Plan 2021 and advocate for all governments, key stakeholders, and partners to deploy patient safety as a priority in all health sector policies and programs. The event achieved the following:

- Triggered a collective discussion amongst relevant health stakeholders and sealed their commitment towards patient safety in their respective areas of action.
- Showed that all the actors of the health system are aligned and working in partnership.
- Demonstrated our efforts to provide the highest quality health care and products to patients.
- Reminded colleagues of the importance of investing in reliable and resilient health systems and health workforces.
- Showcased practical ways in which each health actor can further patient safety.

With IAPO Patients for Patient Safety Observatory we also co-developed a World Patient Safety Day map – an interactive crowdsourcing tool to showcase the power of patient voice on patient safety worldwide. See the map here: <http://wpsdmap.amrpatientalliance.org>

### Personalised Cancer Care Alliance

In 2022, IAPO set up the [Personalised Cancer Care Alliance \(PCCA\)](#), an alliance of cancer patients, carers and representatives of patient organizations from within the WHO Eastern Mediterranean and selected countries from WHO Africa and Europe to advance health literacy in cancer, advocacy skills and education on personalised cancer care.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Output and Impact

In 2023, the Alliance launched [a position paper on personalised cancer care \(PCC\) in the Eastern Mediterranean](#), the first of its kind in the region to put PCC in the spotlight of high level policy makers while providing a comprehensive road map for patients' organizations and civil society to advocate and lobby for PCC. The paper sets the baseline for further discussion and development of personalised cancer care within our health systems and regions to ensure we have a predictive, preventative, participatory, personalised and pre-emptive (5 Ps) cancer care.

### [African Medicines Agency Treaty Alliance AMATA](#)

The African Medicines Agency Treaty Alliance (AMATA) is a multi-stakeholder alliance set up to advocate for the ratification and implementation of the African Medicines Agency (AMA) Treaty and for meaningful engagement with patients and other relevant parties, in all aspects of the Agency framework. The idea of the alliance was born in view of the urgency unveiled by COVID-19 where IAPO saw the need to support African patient organisations access to safe and quality vaccines, medicines, personal protection equipment, health devices and diagnostic kits to face present and future pandemics.

### Output and Impact

On Wednesday, 14 December 2022 the African Medicines Agency Treaty Alliance (AMATA) held an official side event at the Conference on Public Health in Africa (CPHIA 2022) on the African Medicines Agency. General consensus was that it was a successful session and that CPHIA was a great opportunity to advocate for AMA and the need for regulatory strengthening in Africa and make the link with pandemic preparedness.

There is a "before Kigali and after Kigali" for AMATA, as having most AMATA founders united, advocating on the ground and meeting in person, made the Alliance stronger. The side-event concluded with Kigali Declaration: The Time is Now: AMATA Calls for the rapid operationalisation of the African Medicines Agency and for regulatory system strengthening to be recognized as a key element of preparedness for future pandemics and post-pandemic recovery.

On Wednesday, 27 April 2022, we launched the AMATA webinar series – AMATA in conversation with key opinion leaders on the shaping of the African Medicines Agency (AMA). The webinars were fashioned as a unique opportunity to hear from leading figures from the continent's health policy landscape on the future of AMA and how non-state actors can get involved from the get-go. Bring your questions. Our first guest speaker was Dr. Margaret Agama-Antyetei, who shared the next steps in the operationalization of AMA, who are the actors involved and how patients, industry and civil society can contribute to the development of the Agency.

On Wednesday, 28 September 2022 we held the second webinar of the AMATA webinar series – AMATA in conversation with guest speaker Hon. Michel Sidibé, Africa Union Special Envoy for the African Medicines Agency (AMA). He shared the next steps in the development of AMA, both at political and operational level, how we can ensure AMA includes a framework of meaningful engagement with patients, industry, academia and civil society, how we can further align to make meaningful contribution, as a coalition of non-state actors, to the implementation of AMA, as well as how AMATA can help complete the ratification process and shape the future of the Agency and so much more.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### AMR Patient Alliance building awareness and capacity

IAPO in collaboration with IAPO Patients for Patient Safety Observatory has gone strength to strength with our partner patient organizations from different regions and countries in advancing our [Global Patient Consensus Statement and a Call to Action](#). The newly formed [AMR Patient Alliance](#) has convened civil society groups representing patients, carers and advocates in a global alliance to address the AMR pandemic.

### Output and Impact

The AMR Patient Alliance is a place where patients can exchange views, be educated, and acquire knowledge and resources that we need to raise awareness about the importance of sustaining the efficacy of antibiotics - for as long as possible, for as many patients as possible. Learn more about the Alliance here: <https://www.amrpatientalliance.org>.

### IAPO in the Fight the Fakes Alliance in 2022

IAPO as a founding member of the new Fight the Fakes (FTF) Alliance, a new multi-stakeholder non-profit association registered in Geneva (Switzerland), continues to fight against fake falsified medicines. IAPO has been a partner in this alliance for over seven years since it was first set up as a grassroots advocacy campaign. IAPO is on the governance structure and the FTF Alliance is taking the fight against substandard and falsified medicines to the next level. We now have over 20 large alliances as members.

### Output and Impact

We have joined health care professionals, manufacturers, wholesalers, researchers and patients. The Alliance is uniquely positioned to scale up action to prevent falsified medicines from endangering people's health and well-being. More information on this: <https://fightthefakes.org/events/>

### **Driving research processes and development of evidence base for patient centred-universal health coverage in 2022**

IAPO is driving research and development by encouraging patient engagement at a national level. In 2022, we undertook many activities and created new partnerships.

### Output and Impact

#### IAPO Scientific Advisory Board

IAPO Scientific Advisory Board continues to support the organization in its scientific programme in ensuring that patients have access to quality safe and evidence-based healthcare. The inaugural ScientificBoard and its membership can be found here: <https://bit.ly/38scZ6L>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Metrodora Award – recognising outstanding women achievers in science and health

IAPO in partnership with Viartis held the second edition of the international Metrodora Awards, following the success of the inaugural event in 2020. The international Metrodora Awards 2022 continued the legacy of recognising women leaders and innovators who have made significant contributions across all disciplines of scientific research, clinical practice, health education, health policy, and mental health as well as patient advocacy.

The 2022 Metrodora Awards showcased the outstanding achievements and dedication of eminent women in science and medicine around the world. We believe female innovators will continue to play a leading role in encouraging more women and girls to pursue their dream of making more positive contributions in driving scientific and medical breakthroughs.

Watch the event highlight video to get a recap of the Awards and the inspiring speeches from key speakers and winners: <https://www.iapo.org.uk/news/2022/aug/10/2022-metrodora-awards-winners>

### ISPOR - The Professional Society for Health Economics and Outcomes Research

IAPO continues to collaborate with and contribute towards ISPOR conferences and research programmes.

### ISQua - The International Society for Quality in Health Care

IAPO continues to work with ISQUA to improve research and development of good practice globally to improve access to quality universal health coverage 2030.

### IAPO Patients for Patient Safety Observatory

IAPO has established a partnership with IAPO Patient for Patient Safety Observatory (IAPO P4PS Observatory) Geneva to have a single-point global research development platform for gathering and analysing patients' expertise and experience that would feed into the national, regional and global policies aimed at improving safety and quality of care for patients and by the patients.

The rationale behind the establishment of IAPO P4PS Observatory is that patient harm has become a great public health problem, and it now requires expert patient oversight and co-creation. To do this, the P4PS Observatory has put patient led research into practice, and patient experience back into research. Patient harm not only causes great suffering, injury and death, it also erodes public trust in healthcare systems and costs billions of USD to address compensation and fines. The WHO Director General in his report and Resolution WHA 72.6 May 2019 Global Action on Patient Safety has asked every WHO Member State to produce plans to implement this resolution in the global consultation WHO Flagship "A Decade of Patient Safety 2020-2030": <https://bit.ly/2KFN1Vg>.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Research Collaboration

#### CIOMS

The Council for International Organizations of Medical Sciences (CIOMS) is an international, non-governmental, non-profit organization established jointly by WHO and UNESCO in 1949. CIOMS represents a substantial proportion of the biomedical scientific community through its member organizations, which include many of the biomedical disciplines, national academies of sciences and medical research councils. CIOMS mission is to advance public health through guidance on health research including ethics, medical product development and safety.

IAPO has been collaborating with CIOMS in 2022 and this collaboration led to the co-production of the influential CIOMS Patient involvement in the development, regulation and safe use of medicines Working Group X Report. <https://cioms.ch/publications/product/patient-involvement/>

#### GetReal Institute

IAPO continues its collaboration with the Get Real Institute. We are building on our collaboration success of two IMI projects: GetReal and The GetReal Initiative (learn more), and have brought together a wide variety of stakeholders to drive the sustainable development and adoption of tools, methods and best practices in the

generation and use of RWE (real world evidence) for better health care decision-making.

#### The GetReal Institute is:

- A Platform to reach common understanding and prioritisation of critical opportunities and challenges in the generation and use of RWE
- An Incubator and “design lab” for strategies and tools to clarify scientific and operational uncertainties in RWE approaches and methods
- A Source of trusted, high quality RWE education and training resources
- A Hub for connecting RWE-related initiatives within Europe and beyond

### IMI Prefer-Patient Preferences

PREFER was set up to research and develop instruments, policies and guidelines to elicit patient preferred outcomes. The recommendations were to support development of guidelines for industry, Regulatory Authorities and HTA bodies on how and when to include patient perspectives on benefits and risks of medicinal products.

Over the last five years, collaborated on running patient preference studies in both academic and industry settings. The Prefer Partners and their experience provided a better understanding of what effective, efficient and equitable recommended best-practice approach to patient-preference studies. IAPO with Prefer demonstrated how patient preference studies can give valuable information to support decision making for regulators and HTA bodies.

See Recommendations: <https://zenodo.org/record/6470918#.YmgoMO1ByUk>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Membership

#### IAPO's Annual General Meeting

IAPO held its Annual General Meeting on Saturday 26 February 2022 at 12.00pm GMT. At the AGM, we announced the results of the Governing Board Elections which saw the following Board Members elected to IAPO's Governing Board:

- Lara Bloom, The Ehlers-Danlos Society (UK Resident)
- Tony Holland, International Prader-Willi Syndrome Organisation - IPWSO (UK Resident)
- Ellos Lodzeni, Patient and Community Welfare Foundation of Malawi - PAWEM (African Region)
- Paul Albert S. Mendoza, Psoriasis Philippines (Western Pacific Region)

#### Launched the Network Membership Category

We launched a new opportunity to join our global alliance of patient organizations and help us promote patient-centred healthcare across the world. In addition to the existing Full, Associate, and Affiliated membership categories, we now offer the Network Membership: a free membership category available to those organizations who want to be part of our network but have no means to pay for fees. The Network Membership is available to those patient organizations or healthcare-related organizations, networks or alliances committed to improving healthcare and to the principle of patient-centred healthcare.

#### Pandemic Rebate and Hardship Discounts

The pandemic saw many patients' organisations fold. Those that remain are all working to very thin budgets and have boards, staff and volunteers who are exhausted. IAPO agreed to give a rebate on the membership fee and wrote off their fee debt. Going into 2023 and 2024 we have to review how we can include more patient organisations from low- and middle-income countries to join us and participate with us without paying fees as Membership Fee forms a small part of our overall income.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Communications

**Newsletter:** We doubled our newsletter subscription number from 5900 to 12070 subscribers who receive our monthly newsletter which covers our congresses, member activities, Patient centred advocacy news and information. In 2023 we are encouraging more patient organizations to submit articles for publication.

**Twitter:** [@IAPOvoice](#) , [@PatientSolidarityDay](#), [@AfricanAmata](#), [@PCCAlliance](#)

**Facebook:** We operate [IAPOvoice](#), [International Alliance of Patients' Organizations](#), [African page](#), [PatientSolidarity Day](#), [Personalised Cancer Care Alliance](#)

**LinkedIn:** [International Alliance of Patients' Organizations](#), [Metrodora Awards](#), [Personalised Cancer Care Alliance](#).

**Website:** Continues to be the main focal point for IAPO's dissemination and communications activities. We have seen an increase in number of page views: with over 105,000 page views in 2022 compared to 82,100 in 2021. [www.iapo.org.uk](http://www.iapo.org.uk)

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2022

---

### IAPO Membership in 2022

IAPO consolidated its membership in 2022 and sought new members covering rare diseases and non-communicable diseases. IAPO had 278 members at 31<sup>st</sup> December 2022. IAPO is now also actively seeking more members from WHO Eastern Mediterranean Region, South East Asia and the Western Pacific that are under-represented.

| Region                        |            |
|-------------------------------|------------|
| African members               | 43         |
| Eastern Mediterranean members | 10         |
| European members              | 96         |
| Latin American members        | 67         |
| North American members        | 24         |
| South East Asian member       | 14         |
| Western Pacific members       | 24         |
| <b>TOTAL</b>                  | <b>278</b> |

| Membership Type |            |
|-----------------|------------|
| Full            | 99         |
| Associate       | 37         |
| Network         | 142        |
| Affiliate       | 0          |
| <b>TOTAL</b>    | <b>278</b> |

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

### **IAPO funding transparency**

The Governing Board members declare interests and sign conflict of interest register at the start of each Board meeting. The register is maintained with any changes between meetings.

Reference to IAPO's Code of conduct and policy regulating IAPO's relationship with, and independence from, sponsors can be found at: [www.iapo.org.uk/consensus-framework-ethical-collaboration](http://www.iapo.org.uk/consensus-framework-ethical-collaboration) and [www.iapo.org.uk/healthcare-industry-partners](http://www.iapo.org.uk/healthcare-industry-partners).

The overall proportion of industry to non-industry income for the year was approximately 93%.

### **Public benefit**

In setting our objectives and planning our activities trustees have given consideration to the Charity Commission's general guidance on public benefit (PB1, PB2 and PB3) and have taken these into account in making all decisions. We have not departed from the guidance in 2022.

IAPO objects are the promotion of the relief of sickness and the preservation and protection of health for the public benefit. IAPO pursues this through fostering patient-centred healthcare worldwide and, in particular, by developing the capacity of patients' organisations.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

IAPO's services are open to all people and our membership reflects a diverse group of patients' organisations representing patients with communicable and non-communicable diseases, including patients with diseases that are stigmatised in many societies.

IAPO had 278 members comprising umbrella groups and single organisations in 2020 who directly represented views of over 1 million patients in 71 countries across 52 disease areas. The services the charity provides are designed to build the capacity of patients' organisations, allowing them to better assist the needs of patients and carers (and their own member patient organisations in some cases) from across the world.

Access to IAPO's website is freely available to the public. Currently it is in English, with some sections in Spanish. The website contains a wide range of information on IAPO's activities and on patient-centred healthcare, which is of benefit to the public, particularly those who wish to set up local patients' organisations.

By improving access to information, training and other capacity building programmes for patients and their representative organizations, IAPO improves access to healthcare itself. By raising awareness and through capacity building and education of health care providers, we increase access to acceptable services that respect patients' preferences, values, rights and needs.

IAPO has a wealth of evidence, gained from patients' organizations worldwide, which demonstrates that patient involvement in patients' care leads to better health outcomes and lower costs for the whole of society. The charity works with patients' organizations that are not for profit and non-government organisations who demonstrate commitment to improving patient-centred healthcare which is reflected in the charity's membership criteria.

### **Risk Management**

A risk register is prepared by the CEO and presented annually to the Board to discuss ensuring that there are effective and adequate risk management and internal control systems in place to manage the major risks to which the Charity is exposed. IAPO prepares the risk register by understanding the risk environment of IAPO and its operations and then identifies the key risks. The CEO and the Treasurer then undertake a thorough analysis and evaluation of the risks identified before coming up with a treatment for the risks.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2022**

---

Risks are identified under headings of Financial, Funding, Governance, Operational and Personnel. These are then quantified using a Likelihood/Impact matrix, and mitigation actions detailed. Discussions are underway with the Audit Committee to ensure that the risks are appraised regularly before each board meeting to assess IAPO's risk profile.

IAPO is undertaking a new fundraising strategy to reduce reliance upon the pharmaceutical companies. IAPO will diversify its funding by approaching international trust funds, international development agencies and large programmes to raise non-industry partner funding.

### **Financial review**

Incoming resources for the year amounted to £582,642 (2021: £380,706), which was higher than the previous year due to a strategic increase in research and special projects funded by our partners.

Expenditure in 2022 was £399,126 (2021: £270,656). Expenditure is also higher than the previous year, in line with the fact that we increased our output in research and Special Projects.

### **Reserves Policy**

The IAPO Board approved a Reserves Policy in September 2014, with a target level of free reserves of 6-12 months' running costs for 6 months. 6 months running cost is c.£199,563. This policy was set with due regard to guidance from Charity Commission (CC19 – Charity Reserves) and is reviewed annually.

The level of unrestricted reserves, as at 31<sup>st</sup> December 2022 is £287,351. This is within the target in the reserves policy, and will be monitored by the Board of Trustees.

### **Going Concern**

The trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. As they have considered the impact of the COVID-19 pandemic on both its income and expenditure for at least a period of twelve months from the date of approval of these financial statements and are expecting to make a surplus in 2022. Despite the unfortunate change in management after the passing of IAPO's Chief Executive, the board took time to contact all funders and commit to fulfilling and meeting current projects, events and current collaborative works. Our current partners and funders have been very receptive to new proposals and wish to continue working with IAPO until the foreseeable future.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### Pension arrangements

With auto-enrolment legislation coming into force in Autumn 2017, we set up an Occupational Pension Scheme.

IAPO also operates a policy of contributions directly into staff members' chosen personal pension schemes, with no obligation for staff to make personal contributions. The issue of pension deficit, which would apply to an occupational scheme, does not therefore arise.

### Pay and remuneration of senior management

IAPO has a team of research officers and volunteers led by a Chief Executive.

### Future Activities

IAPO's plan of activities for 2021 are listed at:

[https://www.iapo.org.uk/sites/default/files/files/IAPO\\_Planned%20Activities%20in%202021.pdf](https://www.iapo.org.uk/sites/default/files/files/IAPO_Planned%20Activities%20in%202021.pdf)

IAPO's Strategy for 2022-2024 is listed at:

<https://www.iapo.org.uk/sites/default/files/files/IAPO%20Strategy%202022-2024%20Draft.pdf>

Our vision, mission and tactical plans are adapted to build back better a patient centred, pandemic prepared universal health coverage 2030.

- **VISION 2022-24**

- To ensure through global solidarity and national action that every patient enjoys healthcare that is:
  - Patient centred (PC) (broader definition)
  - Pandemic prepared (PP)
  - A Universal Health Coverage (UHC)

- **MISSION 2022-24**

- Empower our members with cutting edge knowledge and advocacy skills in bringing about PC & PP UHC 2030.
- Work with our membership, alliances, partners, and other stakeholders to drive research and policy development activity that establishes the evidence base needed in support of PC & PP UHC 2030 and strengthen patient involvement and co-creation in research.
- Motivate the empowered patient community into using the evidence base created to shape the institutional, law, policy, practice, and standards framework needed for PC & PP UHC 2030 at global, regional (APEC, AU and EU etc) and national levels.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

***FOR THE YEAR ENDED 31 DECEMBER 2022***

---

### **· TACTICAL PLAN 2022-24**

- To attain PC (Broader Definition) and PP UHC 2030 it is important that IAPO advocates the delivery of:
- Safe Healthcare
- Quality Healthcare
- Accessible Healthcare. Access is across four areas.
- Non-Discriminatory Healthcare
- Physically Accessible Healthcare
- Information Accessibility
- Affordable Healthcare
- Acceptable Healthcare: Culturally Competent and Patient Centred (Broader Definition)

In addition to the above, IAPO is collaborating closely in the WHO Work Plan 13 and ensuring that the WHO flagship Global Patient Safety Action Plan 2021-2030 is translated and implemented into national patient safety institutional, legislative, policy, practice and standards through patient and family engagement and cocreation/coproduction.

### **Statement of Trustees' responsibilities**

The Trustees are responsible for preparing the financial statements for each financial period which give a true and fair view of the state of affairs of the company and of the deficit or surplus of the company for that period. In preparing those financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping proper accounting records, which disclose with reasonable accuracy at any time, the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2022**

---

### **Statement as to disclosure to our auditors**

**In so far as the trustees are aware at the date of approving this report:-**

- there is no relevant audit information, being information needed by the auditor in connection with preparing their report, of which the charity's auditor is unaware; and
- the trustees having made enquiries of fellow directors and the group's auditor that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a director in order to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

### **Reappointment of auditors**

**A proposal to reappoint Knox Cropper as the charity's statutory auditors will be put to members at our forthcoming Annual General Meeting.**

**Approved and authorised for issue by the Board of Trustees on 28 September 2023 and signed on their behalf by:-**



**Prim Dr Neda Milevska-Kostova  
Chair of the Board IAPO**

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2022**

---

### **Opinion**

We have audited the financial statements of International Alliance of Patients' Organization for the year ended 31 December 2022 which comprise the Statement of Financial Activities (including the Income and Expenditure Account), the Balance Sheet and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2021 and of its income and expenditure, for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### **Conclusions relating to going concern**

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### **Other information**

The other information comprises the information included in the Trustees' Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2022

---

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report, included within the Trustees' Report, has been prepared in accordance with applicable legal requirements.

### Matters on which we are Required to Report by Exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or
- Certain disclosures of Trustees' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit; or
- The trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Trustees' Report.

### Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

### Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- The Charitable Company is required to comply with both company law and charity law and, based on our knowledge of its activities, we identified that the legal requirement to accurately account for restricted funds was of key significance.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2022

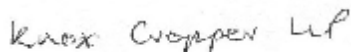
---

- We gained an understanding of how the charitable company complied with its legal and regulatory framework, including the requirement to properly account for restricted funds, through discussions with management and a review of the documented policies, procedures and controls.
- The audit team, which is experienced in the audit of charities, considered the charitable company's susceptibility to material misstatement and how fraud may occur. Our considerations included the risk of management override.
- Our approach was to check that all restricted income was properly identified and separately accounted for and to ensure that only valid and appropriate expenditure was charged to restricted funds. This included reviewing journal adjustments and unusual transactions.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

### Use of our report

This report is made solely to the charitable company's trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



28 September 2023

Simon Goodridge (Senior Statutory Auditor)  
For and on behalf of Knox Cropper LLP (Statutory Auditor)  
65 Leadenhall Street  
London  
EC3A 2AD

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 DECEMBER 2022

|                                                 |                       |              |            |            | Total<br>2022 | Total<br>2021 |
|-------------------------------------------------|-----------------------|--------------|------------|------------|---------------|---------------|
|                                                 | N<br>o<br>t<br>e<br>s | Unrestricted | Designated | Restricted | (year)        | (year)        |
|                                                 |                       | £            | £          | £          | £             | £             |
| Income from charitable activities:              |                       |              |            |            |               |               |
| Membership                                      |                       | 4,092        | -          | -          | 4,092         | 1,974         |
| Healthcare Industry Partners                    |                       | 234,401      | -          | -          | 234,401       | 224,540       |
| APPC congress                                   |                       |              | 59,065     |            | 59,065        | 43,314        |
| GPC congress                                    |                       |              | -          |            | -             | -             |
| Africa congress                                 |                       |              | -          |            | -             | 38,887        |
| Latin congress                                  |                       |              | 23,909     |            | 23,909        |               |
| Special Projects                                |                       |              |            | 257,863    | 257,863       | 57,269        |
| Other charitable activities                     |                       | 3,313        |            |            | 3,313         | 14,721        |
| Total                                           | 2                     | 241,805      | 82,973     | 257,863    | 582,642       | 380,706       |
| Expenditure on charitable Activities:           |                       |              |            |            |               |               |
| Charitable activities:-                         |                       |              |            |            |               |               |
| · Capacity building, advocacy and collaboration |                       | 187,933      | -          | -          | 187,933       | 114,859       |
| · Asia Pacific Patients Congress                |                       | -            | 64,785     | -          | 64,785        | 71,094        |
| · Global Patients Congress                      |                       | -            | 1,355      | -          | 1,355         | 2,608         |
| · Africa Patients Congress                      |                       | -            | -          | -          | -             | 61,129        |
| · LatAm Patients Congress                       |                       | -            | 47,379     | -          | 47,379        |               |
| · Special projects                              |                       | -            | -          | 97,674     | 97,674        | 20966.75      |
| Total                                           | 3                     | 187,933      | 113,519    | 97,674     | 399,126       | 270,656       |
| Net income / (expenditure)                      |                       | 53,872       | -30,546    | 160,189    | 183,516       | 110,050       |
| Transfers                                       |                       | -30,546      | 30,546     |            |               |               |
| Net movement in funds                           |                       | 23,326       | -          | 160,189    | 183,516       | 110,050       |
| Reconciliation of funds:                        |                       |              |            |            |               |               |
| Funds brought forward                           |                       | 264,025      | -38,112    | 123,344    | 349,257       | 239,208       |
| Total funds carried forward                     |                       | 287,351      | -38,112    | 283,533    | 532,772       | 349,257       |

All transactions are derived from continuing activities.

All recognised gains and losses are included in the Statement of Financial Activities.

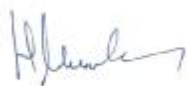
# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## BALANCE SHEET AS AT 31 DECEMBER 2022

|                                                       | Notes    | 2022<br>£        | 2021<br>£       |
|-------------------------------------------------------|----------|------------------|-----------------|
| <b>Fixed assets</b>                                   | <b>6</b> | <b>-</b>         | <b>134</b>      |
| <b>Current assets</b>                                 |          |                  |                 |
| Debtors                                               | 7        | 8,115            | 6,958           |
| Cash in hand and in bank                              |          | 625,567          | 435,290         |
|                                                       |          | <u>633,682</u>   | <u>442,248</u>  |
| <b>Creditors: amounts falling due within one year</b> | <b>8</b> | <b>(100,910)</b> | <b>(93,125)</b> |
|                                                       |          | <u>532,772</u>   | <u>349,123</u>  |
| <b>Net current assets</b>                             |          | <b>532,772</b>   | <b>349,123</b>  |
|                                                       |          | <u>532,772</u>   | <u>349,257</u>  |
| <b>Net assets</b>                                     |          | <b>532,772</b>   | <b>349,257</b>  |
| <b>Funds</b>                                          |          |                  |                 |
| Unrestricted Funds                                    |          | 287,351          | 264,025         |
| Designated Funds                                      |          | (38,112)         | (38,112)        |
| Restricted Funds                                      |          | 283,533          | 123,344         |
|                                                       |          | <u>532,772</u>   | <u>349,257</u>  |
| <b>Total Funds</b>                                    | <b>9</b> | <b>532,772</b>   | <b>349,257</b>  |

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

These financial statements were approved and authorised for issue by the Board of Trustees on 28 September 2023 and signed on their behalf by:-



Dr. Neda Milevska-Kostova  
Chair



Professor Lara Claire Bloom  
Treasurer

Registered company number: 08495711 (England and Wales)

The notes on pages 34 to 43 form part of these financial statements

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

---

### 1 Accounting Policies

#### 1.1 Accounting convention

The financial statements of the charitable company, which is a public benefit entity under FRS102, have been prepared in accordance with the 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (SORP) (FRS102 second edition - effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

The financial statements are presented in Sterling (£).

Results for the trading subsidiary, IAPO Trading Limited (Company Number 08863190) are not consolidated on the grounds that it was dormant and not material to the group.

#### Statement on going concern

After reviewing the charity's forecasts and projections, the directors have reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. The charity therefore continues to adopt the going concern basis in preparing its financial statements.

#### 1.2 Company status

The parent charity is a company limited by guarantee. The directors of the company are the trustees named on page 1. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

#### 1.3 Incoming resources

All incoming resources are included in the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable certainty.

**Healthcare Industry Partners:** IAPO's Industry Partners are companies, foundations and associations who commit to providing various levels of unrestricted financial support each year, contributing to IAPO's core costs. IAPO's Partners Framework provides a framework for IAPO and industry stakeholders to interact and collaborate in a transparent and accountable way.

**Restricted Project:** Pfizer UpJohn Metrodora Awards to honour women scientists Pfizer Upjohn Stroke Twinning Project and Study

**Designated Events and Congresses** in 2022 were the 1<sup>st</sup> Latin American Patients Congress 16<sup>th</sup> June 2022 and the 4<sup>th</sup> Asia Pacific Patients on the 23-24<sup>th</sup> November 2022.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

---

**GetReal:** IAPO is a partner in GetReal, a three-year collaborative European Project exploring how real world research data can be used in the development of drugs, to increase effectiveness and enrich decision-making by regulatory authorities and health technology assessment (HTA) agencies.

**IMI Prefer:** IAPO is a partner in researching, developing and advocating that patient preferences should be included in decision-making

**Other Income:** Other income includes "In Kind" support and briefing paper sales, which includes financial support and reimbursement provided to IAPO to attend conferences and meetings around the world.

### 1.4 Expenditure

All expenditure is included on an accruals basis and is inclusive of all VAT, which cannot be reclaimed, and is reported as part of the expenditure to which it relates:

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.
- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.
- All costs are allocated between expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, other costs are apportioned on the basis staff time incurred.

The core elements of charitable expenditure are as follows:-

**Capacity Building:** Realising active partnerships with patients' organizations, maximising their impact through capacity building.

**Advocacy:** Advocating internationally with a strong patients' voice on the relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies.

**Collaboration:** Building cross-sector alliance and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives.

### 1.5 Funds

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Designated funds are funds which are 'ring-fenced' to be used for the specific purpose of the congress.

Restricted funds are funds, which are to be used in accordance with specific restrictions imposed by the donor. The aim and use of the restricted fund is set out in the notes of the financial statements.

### 1.6 Tangible fixed assets and depreciation

Capital expenditure on items costing £1,000 or higher are recorded as tangible fixed assets. Tangible fixed assets are stated at historical cost less depreciation.

Depreciation is provided to reflect the useful estimated economic life of computer equipment assets at a rate of 33% per annum (reducing balance method).

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

### 2 Incoming resources

|                               | OTHER | Healthcare<br>Industry<br>Partners<br>£ | Projects<br>£ | Total<br>£ |
|-------------------------------|-------|-----------------------------------------|---------------|------------|
| Merck                         |       | 48,332                                  |               | 48,332     |
| MYLAN PHARMACEUTICALS PVT LTD |       | 44,151                                  |               | 44,151     |
| IFPMA                         |       | 40,245                                  |               | 40,245     |
| PFizer Inc                    |       | 25,946                                  |               | 25,946     |
| GSK IHC                       |       | 42,815                                  |               | 42,815     |
| P4PS OBSERVATORY              |       | 5,769                                   |               | 5,769      |
| MSD INTERNATIONAL             |       | 27,155                                  |               | 27,155     |
| <b>Congress Sponsorship</b>   |       | 82,973                                  |               | 82,973     |
| <b>Projects</b>               |       | 257,863                                 |               | 257,863    |
| <b>Other income</b>           | 7,404 | (11)                                    |               | 7,393      |
|                               | 7,404 | 575,238                                 | -             | 582,642    |

### Income Resources comparative

|                                        | Charitable<br>Activities &<br>Others<br>£ | Healthcare<br>Industry Partners<br>£ | Projects<br>£ | Total<br>£ |
|----------------------------------------|-------------------------------------------|--------------------------------------|---------------|------------|
| GSK IHC                                | -                                         | 36,181                               | -             | 36,181     |
| EMD Serano                             | -                                         | 16,791                               | -             | 16,791     |
| Leo Pharma                             | -                                         | 17,763                               | -             | 17,763     |
| PhARMA                                 | -                                         | 35,626                               | -             | 35,626     |
| MSD MERCK                              | -                                         | 21,449                               | -             | 21,449     |
| Roche Pharma Holding                   | -                                         | 41,412                               | -             | 41,412     |
| IFPMA                                  | -                                         | 55,319                               | -             | 55,319     |
| Congress Sponsorship                   | -                                         | -                                    | 82,202        | 82,202     |
| Projects                               | -                                         | -                                    | 57,269        | 57,269     |
| <b>Other Activities and membership</b> | 16,694                                    | -                                    | -             | 16,694     |
|                                        | 16,694                                    | 224,541                              | 139,471       | 380,706    |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

### Congress Sponsorship 2022

|                  | Asia Pacific Congress | Latin America<br>Patients Congress | Total  |
|------------------|-----------------------|------------------------------------|--------|
|                  | £                     | £                                  | £      |
| BOEHRINGER INGEL | 59,065                |                                    | 59,065 |
| Merck            |                       | 23,909                             | 23,909 |
|                  | <hr/>                 | <hr/>                              | <hr/>  |
|                  | 59,065                | 23,909                             | 82,973 |
|                  | <hr/>                 | <hr/>                              | <hr/>  |

### Congress Sponsorship 2021

|                      | Asia Pacific<br>Congress | Africa Patient Congress | Total  |
|----------------------|--------------------------|-------------------------|--------|
|                      | £                        | £                       | £      |
| Roche Pharma Holding | 21,866                   | -                       | 21,866 |
| Leo Pharma           | -                        | 17,763                  | 17,763 |
| Merck                | 21,449                   | -                       | 21,449 |
| Johnson Johnson      | -                        | 21,124                  | 21,124 |
|                      | <hr/>                    | <hr/>                   | <hr/>  |
|                      | 43,314                   | 38,887                  | 82,202 |
|                      | <hr/>                    | <hr/>                   | <hr/>  |

### 3 Analysis of support costs

All support costs are allocated directly to charitable activities and as such there are no support costs.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

---

### 4 Trustees and staff remuneration

The trustees received no remuneration, but 1 Trustee received reimbursements of £3,455 (2021: £1,442) for travel and subsistence expenses incurred on behalf of the charity.

#### Staff remuneration and numbers

|                    | Total<br>2021<br>£ | Total<br>2021<br>£ |
|--------------------|--------------------|--------------------|
| Wages and salaries | 127,094            | 124,338            |
| Social Security    | 14,390             | 13,754             |
| Pension costs      | 244                | 1,362              |
|                    | <hr/>              | <hr/>              |
|                    | 141,728            | 139,454            |
|                    | <hr/>              | <hr/>              |

The average number of full and part-time employees during the year was 3. One individual employee received emoluments in excess of £60,000 in the band £70,001 to £80,000 (2021: 1). Key management personnel costs amounted to £ 71,703 (2021: £71,544).

### 5 Operating Surplus

Operating surplus is stated after charging

|                                         | Total<br>2021<br>£ | Total<br>2021<br>£ |
|-----------------------------------------|--------------------|--------------------|
| Auditors Remuneration                   | 5,550              | 5,040              |
| Depreciation of Assets                  | 134                | 66                 |
| Operating Lease Charges (office rental) | -                  | 12,213             |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

### 6 Fixed Assets

|                     | Computer<br>equipment<br>£ |
|---------------------|----------------------------|
| Cost                |                            |
| Brought forward     | 4,169                      |
| Carried forward     | 4,169                      |
| Depreciation        |                            |
| Brought forward     | 4,035                      |
| Charge for the year | 134                        |
| Carried forward     | 4,169                      |
| Net book value      |                            |
| At 31 December 2022 | -                          |
| At 31 December 2021 | 134                        |

There are no charges or securities held over any fixed assets. All fixed assets are held in the charity and none in the trading subsidiary. Depreciation of £99 was charged in the accounts for the previous period.

### 7. Debtors

|                | 2021<br>£ | 2021<br>£ |
|----------------|-----------|-----------|
| Debtors        | 1,235     | 78        |
| Prepayments    | 6,880     | 6,880     |
| Accrued income | -         | -         |
|                | 8,115     | 6,958     |

### 8. Creditors: amount falling due within one year

|                 | 2021<br>£ | 2021<br>£ |
|-----------------|-----------|-----------|
| Creditors       | -         | -         |
| Deferred income | 73,423    | 72,741    |
| Accruals        | 27,487    | 20,385    |
|                 | 100,910   | 93,125    |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

### 9. Analysis of net assets between funds

|                                | Unrestricted<br>Fund<br>£ | Designated<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total Funds<br>£ |
|--------------------------------|---------------------------|--------------------------|--------------------------|------------------|
| Tangible fixed assets          | 0                         |                          |                          | -                |
| Current assets                 | 267,735                   | 89,086                   | 276,861                  | 633,682          |
| Current liabilities            | (20,745)                  | (6,742)                  | (73,423)                 | (100,910)        |
| Net assets at 31 December 2022 | 246,990                   | 82,344                   | 203,438                  | 532,772          |

### 10. Analysis of net assets between funds comparative

|                                | Unrestricted<br>Fund<br>£ | Designated<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total<br>Funds<br>£ |
|--------------------------------|---------------------------|--------------------------|--------------------------|---------------------|
| Tangible fixed assets          | 134                       | -                        | -                        | 134                 |
| Current assets                 | 284,276                   | (38,112)                 | 196,084                  | 442,248             |
| Current liabilities            | (20,385)                  | -                        | (72,740)                 | (93,125)            |
| Net assets at 31 December 2021 | 264,025                   | (38,112)                 | 123,344                  | 349,257             |

The deficit in the designated fund is due to timing difference between the time we held the event and the time we received the income.

### 11. Movements in funds

|                                                | At 31<br>December<br>2021<br>£ | Incoming<br>Resources<br>£ | Resources<br>Expended<br>£ | Transfers<br>£ | At 31<br>December<br>2022<br>£ |
|------------------------------------------------|--------------------------------|----------------------------|----------------------------|----------------|--------------------------------|
| Unrestricted fund                              | 264,025                        | 241,805                    | (187,933)                  | (30,546)       | 287,351                        |
| <b>Designated Funds: -</b>                     |                                |                            |                            |                |                                |
| APPC congress                                  | (22,459)                       | 59,065                     | (64,785)                   | 30,546         | 2,367                          |
| GPC congress                                   | 6,589                          |                            | (1,355)                    |                | 5,234                          |
| Africa congress                                | (22,241)                       |                            |                            |                | (22,241)                       |
| Latin Congress                                 |                                | 23,909                     | (47,379)                   |                | (23,471)                       |
| <b>Restricted funds: -</b>                     |                                |                            |                            |                |                                |
| PREFER                                         | 38,352                         |                            | (9,056)                    | -              | 29,296                         |
| Special projects - Up john and Metrodora, PCCA | 65,761                         | 257,863                    | (69,387)                   | -              | 254,237                        |
| Other projects - Get Real                      | 19,231                         |                            | (19,231)                   | -              | -                              |
|                                                | 349,257                        | 582,642                    | -418,432                   | -              | 532,772                        |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

### Movements in funds Comparative

|                                          | At 31<br>December<br>2020 | Incoming<br>Resources | Resources<br>Expended | Transfers | At 31<br>December<br>2021 |
|------------------------------------------|---------------------------|-----------------------|-----------------------|-----------|---------------------------|
|                                          | £                         | £                     | £                     | £         | £                         |
| Unrestricted fund                        | 137,647                   | 241,235               | (114,857)             | -         | 264,025                   |
| <b>Designated Funds: -</b>               |                           |                       |                       |           |                           |
| APPC congress                            | 5,320                     | 43,314                | (71,094)              | -         | (22,460)                  |
| GPC congress                             | 9,198                     | -                     | (2,608)               | -         | 6,590                     |
| Africa congress                          | -                         | 38,888                | (61,130)              |           | (22,242)                  |
| <b>Restricted funds: -</b>               |                           |                       |                       |           |                           |
| PREFER                                   | 32,512                    | 5,840                 | -                     | -         | 38,352                    |
| Special projects - Up john and Metrodora | 14,332                    | 51,429                | -                     | -         | 65,761                    |
| Other projects - Get Real                | 40,198                    | -                     | (20,967)              | -         | 19,231                    |
|                                          | <u>239,207</u>            | <u>380,706</u>        | <u>(270,656)</u>      | <u>-</u>  | <u>349,257</u>            |

### Projects Overhead recharge

the overhead cost, primarily consisting of staff cost, for 2022 accounts.

### Metrodora Awards

The first ever international Metrodora Awards – a celebration of women leaders in science and health improving NCD care and management was established by IAPO and Pfizer Upjohn. Over the past few years, the number of women leaders in science and health has grown significantly. However, while there has been progress towards gender equality, women science and health leaders are still under-represented globally. Women constitute only 30% of the world's researchers with too few of them occupying decision-making roles in academic and research institutions, which further hinders their ability to shape the research agenda <https://www.iapo.org.uk/news/2020/oct/27/metrodora-awards>

### Prefer

Prefer will run over the next one year and establish recommendations to support development of guidelines for industry, Regulatory Authorities and HTA bodies on how and when to include patient perspectives on benefits and risks of medicinal products.

We have given all our input to patient preference studies run in both academic and industry setting by others. Our perspective has provided a better understanding of what the recommended best-practice approach to patient-preference studies should be in the future. The Recommendations are in consultation and we will disseminate results later to show how patient preference studies can give valuable information to support decision making for regulators and HTA bodies.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

---

### GetReal

Get-Real IMI Project which concluded in 2021, and has now been set-up as a separate entity with IAPO being a main partner in the new Get Real Institute. Get REal explored how real-world research data could be used in the development of drugs, to increase effectiveness and enrich decision-making by regulatory authorities and health technology assessment (HTA) agencies. IAPO's role was to bring the perspective of patients and patients' organizations to this work and facilitate the input of member organizations into the study. As a patient partner in this project, IAPO contributed to improving medicine development process, so patients have access to the drugs that they need. Surplus funds were ring fenced to be spent specifically on this project. As most of our activity was over the Zoom Virtually, none of the estimated travel and accommodation and other costs were incurred. Also, as the pandemic had locked out most of the hospitals and patient movement, patient organisations did not travel to the European Union and its DG Sante as intended. This resulted in an underspent and this saving is passed back to the European Union's IMI Consortia at the Dutch University.

### UpJohn

This financial award was made at the tail end of the dissolution of UpJohn and its sale into Mylan. <https://www.pfizer.com/news/press-release/press-release-detail/pfizer-completes-transaction-combine-its-upjohn-business>

UpJohn had some money left over for patient advocacy and events and expected IAPO to spread the income across three events. APPC, Metrodora Awards and Stroke Support Project. The Stroke Support was a global capacity building work amongst patient organisations representing the Stroke survivors, caregivers and community that has been lacking. Though there are patient representative groups from the developed G20 countries in the region, voices from the Low- and Middle- Income Countries (LMICs) in the region are underrepresented and sometimes non-existent. These are also the countries with poor health infrastructure and fragmented systems, high out of pocket and no follow up programs. There is an urgent need to create patient support groups and credible voices in countries like India, Mexico, Philippines, Egypt and many other such countries.

## 12. Related parties

There were no related party transactions during the year or prior year.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

|                                                 | Notes    | Unrestricted<br>£ | Designated<br>£ | Restricted<br>£ | Total<br>2021<br>(year)<br>£ |
|-------------------------------------------------|----------|-------------------|-----------------|-----------------|------------------------------|
| <b>Income from charitable activities:</b>       |          |                   |                 |                 |                              |
| Membership                                      |          | 1,974             | -               | -               | 1,974                        |
| Healthcare Industry Partners                    |          | 224,540           | -               | -               | 224,540                      |
| APPC congress                                   |          | -                 | 43,314          | -               | 43,314                       |
| GPC congress                                    |          | -                 | -               | -               | -                            |
| Africa congress                                 |          | -                 | 38,888          | -               | 38,888                       |
| Special Projects                                |          | -                 | -               | 57,269          | 57,269                       |
| Other charitable activities                     |          | 14,721            | -               | -               | 14,721                       |
| <b>Total</b>                                    | <b>2</b> | <b>241,235</b>    | <b>82,202</b>   | <b>57,269</b>   | <b>380,706</b>               |
| <b>Expenditure on charitable Activities:</b>    |          |                   |                 |                 |                              |
| <b>Charitable activities:-</b>                  |          |                   |                 |                 |                              |
| · Capacity building, advocacy and collaboration |          | 114,857           | -               | -               | 114,857                      |
| · Asia Pacific Patients Congress                |          | -                 | 71,094          | -               | 71,094                       |
| · Global Pacific Patients Congress              |          | -                 | 2,608           | -               | 2,608                        |
| · Africa Patients Congress                      |          | -                 | 61,130          | -               | 61,130                       |
| · Special projects                              |          | -                 | -               | 20,967          | 20,967                       |
| <b>Total</b>                                    | <b>3</b> | <b>114,857</b>    | <b>134,832</b>  | <b>20,967</b>   | <b>270,656</b>               |
| <b>Net income / (expenditure)</b>               |          | <b>126,378</b>    | <b>(52,630)</b> | <b>36,302</b>   | <b>110,050</b>               |
| <b>Transfers</b>                                |          | <b>-</b>          | <b>-</b>        | <b>-</b>        | <b>-</b>                     |
| <b>Net movement in funds</b>                    |          | <b>126,378</b>    | <b>(52,630)</b> | <b>36,302</b>   | <b>110,050</b>               |
| <b>Reconciliation of funds:</b>                 |          |                   |                 |                 |                              |
| Funds brought forward                           |          | 137,647           | 14,518          | 87,042          | 239,207                      |
| <b>Total funds carried forward</b>              |          | <b>264,025</b>    | <b>(38,112)</b> | <b>123,344</b>  | <b>349,257</b>               |

**INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

England & Wales - Charity number 1155577

---

# Accounts

---

Company registration number (England and Wales): 08495711  
Charity registration number (England and Wales): 1155577

**INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

(Incorporated as a Company Limited by Guarantee  
and not having a Share Capital)

**ANNUAL REPORT AND FINANCIAL STATEMENTS**

**FOR THE YEAR ENDED 31 DECEMBER 2021**



# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## CONTENTS

---

|                                                                                |                   |
|--------------------------------------------------------------------------------|-------------------|
| Reference and Administrative Details of the Charity, its Trustees and Advisers | <b>Page<br/>1</b> |
| Trustees Report                                                                | <b>2-22</b>       |
| Independent Auditor's Report                                                   | <b>23-25</b>      |
| Statement of Financial Activities                                              | <b>26</b>         |
| Balance Sheet                                                                  | <b>27</b>         |
| Notes to the Financial Statements                                              | <b>28-38</b>      |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS

---

|                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                     |
|--------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Company number</b>                                  | 08495711 (England and Wales)                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Charity number</b>                                  | 1155577 (England and Wales)                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Registered office</b>                               | International Alliance of Patients' Organizations<br>49-51 East Road<br>LONDON<br>N1 6AH                                                                                                                                                                                                                                                                                                                            |
| <b>Governing Board members<br/>(Board of Trustees)</b> | Ellos Ellard Lodzeni<br>Karen Alparce-Villanueva (Resigned 22 Feb 2022)<br>Neda Milevska-Kostova (Chair)<br>Sita Ratna Devi Duddi (Resigned 22 Feb 2022)<br>Rosalia Liliana Tieri (Appointed 16 Dec 2020)<br>Orajitt Bumrungkulswat<br>Adebisi Omolola Bright<br>Professor Lara Claire Bloom (Appointed 22 Feb 2022)<br>Anthony John Holland (Appointed 22 Feb 2022)<br>Paul Albert Mendoza (Appointed 22 Feb 2022) |
| <b>Chief Executive</b>                                 | Kawaldip Sehmi                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Bankers</b>                                         | NatWest Bank Plc<br>PO Box 12258<br>1 Prices Street<br>LONDON<br>EC2R 8BP                                                                                                                                                                                                                                                                                                                                           |
| <b>Lawyers</b>                                         | Bates Wells<br>10 Queen Street Place<br>LONDON<br>EC4R 1BE                                                                                                                                                                                                                                                                                                                                                          |
| <b>Independent auditor</b>                             | Knox Cropper LLP<br>65 Leadenhall Street<br>London<br>EC3A 2AD                                                                                                                                                                                                                                                                                                                                                      |
| <b>Website</b>                                         | <a href="http://www.iapo.org.uk">www.iapo.org.uk</a>                                                                                                                                                                                                                                                                                                                                                                |

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

### ***FOR THE YEAR ENDED 31 DECEMBER 2021***

---

The directors, who are also the trustees of the charity, are pleased to present their report together with the financial statements of the charity for the year ended 31 December 2021 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

Results for the trading subsidiary, IAPO Trading Limited (Company Number 08863190) are not consolidated on the grounds that it was dormant and not material to the group.

The trustees have complied with the duty to have due regard to guidance issued by the Charity Commission and have adopted the Statement of Recommended Practice for charities (SORP) (FRS 102 second edition effective 1 January 2019).

#### **Aims and objectives of the organisation**

The objects of the International Alliance of Patients' Organizations (IAPO), as set out in the Memorandum and Articles of Association, are the promotion of the relief of sickness and preservation and protection of health for the public benefit through fostering patient-centred healthcare worldwide and in particular by developing the capacity of patients' organizations.

IAPO is a unique global alliance representing patients of all nationalities, across all disease areas, and promoting patient-centred healthcare around the world. IAPO brings a global patient voice to healthcare decision-making based on the belief that patients' voices are amplified and heard effectively when patients' organizations are linked, can share best practices and practical strategies, and are connected with resources. Our members are patients' organizations working at the international, regional, national and local levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability.

IAPO was first established in 1999 in the Netherlands as a Dutch Stichting and then de-registered in 2014 to be registered in England and Wales as a UK Charity and Company Limited by Guarantee on 30<sup>th</sup> January 2014. IAPO has a membership of nearly 300 organizations across 71 countries covering 51 diseases groups. IAPO is a non-State Actor in official relations with the World Health Organization (WHO) and has a memorandum of understanding with the International Council of Nurses (ICN), International Hospital Federation (IHF), International Pharmaceutical Federation (FIP), World Medical Association (WMA), International Society for Quality in Health Care (ISQua), The Professional Society for Health Economics and Outcomes Research (ISPOR) and The Union for International Cancer Control (UICC). and with many other non-State Actors.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2021**

---

### **IAPO's vision and mission**

IAPO's **vision** is that patients throughout the world are at the centre of healthcare.

IAPO's **mission** is to help build patient-centred healthcare worldwide by:

- Realizing active partnerships with patients' organizations, maximizing their impact through capacity building
- Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
- Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives

### **IAPO's activities include:**

- Advocacy at global level on relevant aspects of healthcare policy to influence international health agendas and policies
- Providing membership services, including capacity building and shared learning, to its members, who are patient-led organizations across the world
- Empowering its members to undertake their own advocacy at regional and national meetings
- Providing opportunities for stakeholders from across the health sector to meet and work together to advance patient involvement in health services and decision-making
- Research on emerging areas of interest to patients' organizations and to underpin the evidence base for showing the importance of patient involvement to public health.

### **Structure**

The organisation is a charitable company limited by guarantee, incorporated on 19 April 2013 and registered as a charity on 1 February 2014. The company was established under a Memorandum of Association which defined the objects and powers of the company. It is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

All assets and liabilities from the International Alliance of Patients Organizations and its predecessor not-for-profit structure registered in the Netherlands, were transferred to the new UK incorporated charity on 1 February 2014. IAPO Netherlands was (voluntarily) dissolved from the Netherlands Trade Register with effect from 31 May 2015, executed on 21 Oct 2015.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

***FOR THE YEAR ENDED 31 DECEMBER 2021***

---

### **Appointment and Induction of Governing Board**

Every member of the IAPO Governing Board is elected by IAPO's members, through a process defined in the [Memorandum and Articles of Association](#), [By Laws](#) and [Election Code of Conduct](#) . Every year, in advance of the Annual General Meeting, the number of vacancies on the Board is notified to all members, who may then nominate someone from their organisations (a Board member or senior staff member) to IAPO's Governing Board. The full list of nominees is sent to all members in advance of the AGM; members may vote by post or proxy or in person at the AGM.

Governing Board members serve for a maximum of two terms of three years subject to the retirement by rotation clause; once their term of service is complete, they or anyone from their organization cannot be re-elected to the Board for at least a year. All new members of the Board receive induction including core information about the work and history of the organization, and conversations with the Chief Executive Officer and the Chair.

All Governing Board members sign a Code of Conduct when they are appointed to the Board. All staff and Governing Board members are required to complete a conflict-of-interest form at every Board meeting. The Governing Board have no beneficial interest in the charitable company or its trading subsidiary. No Governing Board member receives any remuneration for services as a trustee.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

### FOR THE YEAR ENDED 31 DECEMBER 2021

---

#### Chair's Report Financial Year 1st January to 31st December 2021

The year 2021 has been a time of great challenges for many patient organisations. We all learnt how to operate in difficult circumstance and keep serving our patient members and stakeholders virtually instead of face-to-face. IAPO, as many other organisations, learnt how to reach out to our members and partners digitally as our staff and suppliers learnt new digital skills and developed innovative communication and connectivity channels.

IAPO is now slowly opening to in-person events and collaboration while still aware that we are not free from the pandemic yet. We are hearing consistently about COVID-19 related healthcare service disruption and of collapsing healthcare systems.

Our members have been busy participating in various pandemic preparedness initiatives nationally and regionally. IAPO is part of the WHO's global initiatives to negotiate new international public health instruments to ensure that our health systems are no longer vulnerable to global threats. We once again reiterate that we must continue to work together in national unity and global solidarity to ensure that we strengthen our global health governance and healthcare delivery systems.

We must address health system strengthening to bridge over the many fault lines that appeared along the entire spectrum of our national healthcare services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course.

The pandemic has been a blessing in disguise too. It spurred new urgency for patient engagement in medicines and health devices research and regulation. When on March 11, 2020, WHO Director General declared the novel coronavirus (COVID-19) outbreak as a global pandemic, the global biopharmaceutical industry and regulators began a golden phase in international cooperation with patients as they started forging new multi-sectoral innovative partnerships in medicines and health device research, development, and regulation.

IAPO is also aware that this golden phase in international cooperation has raised new issues of equity and access to innovative health technologies. We must reflect upon universal health coverage 2030 once again and see how we can ensure equitable access to innovative, safe, quality, acceptable and patient centred medicines, health devices and other medical products that patients need without suffering financial hardship.

I particularly want to thank all our stakeholders who rallied around us and the global patient movements in 2021 and joined us in guiding our member organisations and the world through the complex healthcare ecosystem created by the pandemic. Our stakeholders participated generously and ensured that we achieved all our objectives set for 2021 and kept in phase with our Strategy 2019-2021. Please see our [IAPO Achievements 2021](#) and our [Strategy 2019-2021](#)

We must first thank the World Health Organization and its Director General Dr Tedros Adhanom Ghebreyesus for continuing providing leadership as the world began to take control of the pandemic in 2021. Dr Ghebreyesus has set a good pandemic preparedness and healthcare research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing the pandemic threat and trends as they rose. The WHO's fight against the misinformation and infodemic has helped our patient organisations a lot.

We then thank the pharmaceutical industry, medicine and health device regulators, and health technology assessment bodies that worked seamlessly in global solidarity to give us innovative medicines and health devices to address the needs of the patients during the pandemic.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

### **FOR THE YEAR ENDED 31 DECEMBER 2021**

---

At our Virtual Global Patients Congress 2020, Thomas Cueni Director General of the International Federation of Pharmaceutical Manufacturers Association (IFPMA) and some of his members gave us great insight into vaccines development and the WHO Solidarity Trials that looked at repurposing of existing drugs to treat COVID-19, especially if they are already approved (for other indications) and have well established safety profiles. IAPO continues to enjoy close relationship with the

International Drug Regulators Authority Conference and the European Medicines Agency and the FDA. The regulators have included us within their decision-making processes and have established good patient engagement framework for co-creation.

Lastly, I want to thank our healthcare industry partners who have supported us and our member organisations in this difficult challenging time through sponsorship, educational grants, and research projects. Without their support, we could not have reached the audience we have and made the impact we have in 2021.

Our 2022-2024 Strategy was conceived during the pandemic in 2020 through collaboration with all our stakeholders and addresses the key need that we collaborate globally along the entire healthcare value chain to attain a Patient Centred (PC) and Pandemic Prepared (PP) Universal Health Coverage (UHC 2030).

The achievements of 2021 have been further shared and evidenced on our website [www.iapo.org.uk](http://www.iapo.org.uk) and our social media:

- <https://twitter.com/iapovoice?lang=en>
- <https://www.facebook.com/IAPOvoice/>



Dr. Neda Milevska-Kostova

Chair of the Board IAPO

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2021**

---

### Governance

The International Alliance of Patients' Organizations has a Board of Trustees and Directors overseeing its governance and direction, supported by a secretariat headed by the Chief Executive Officer.

| <b>BOARD OF TRUSTEES AND DIRECTORS</b> |                 |                 |
|----------------------------------------|-----------------|-----------------|
| <b>Name</b>                            | <b>Position</b> | <b>Country</b>  |
| Dr. Neda Milevska-Kostova              | Chair           | North Macedonia |
| Mr. Ellos Ellard Lodzeni               | Board Member    | Malawi          |
| Mrs. Rosalia Liliana Tieri             | Board Member    | Argentina       |
| Mrs. Orajitt Bumrungskulswat           | Board Member    | Thailand        |
| Mrs. Adebisi Omolola Bright            | Board Member    | Nigeria         |
| Professor Lara Claire Bloom            | Treasurer       | United Kingdom  |
| Anthony John Holland                   | Board Member    | United Kingdom  |
| Paul Albert Mendoza                    | Board Member    | Philippines     |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

***FOR THE YEAR ENDED 31 DECEMBER 2021***

---

### IAPO Strategy in 2021

In 2021, the last year of our 2019-2021 Strategic Plan, our vision remained to see patient-centred universal health coverage (PC -UHC) established in all countries.

Our main objective was to ensure that there is a sufficient availability of patient-centric, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each WHO Member State, along with essential and innovative medicines and health devices, which are accessible, acceptable and affordable, and delivered without the patients suffering financial hardship or discrimination.

Our 2021 strategy was to:

1. Empower patient communities globally to advocate effectively for patient-centred universal health coverage for all.
2. Drive research processes and the development of evidence base for patient-centred universal health coverage.
3. Shape law, policy and practice in patient-centred universal health coverage at global, regional and national levels.

### Empowerment in 2021

IAPO has been collaborating with several organisations in 2021 in developing resources for patient groups on specific areas of:

- Patient Safety
- Antimicrobial Resistance
- Gene and Cell Therapies

In addition, IAPO supported the development of a Beta Moodle Platform to test out a new platform to make our reports, toolkits, resources, and videos more accessible and in a structured manner.

In 2021 IAPO collaborated with the International Federation of Medical Associations to develop new guidelines on [Patient Involvement in Medical Education](#). These guidelines empower patients by giving them a road map of how to engage and co-produce medical education curricula that is patient centred and improves medical practice on the frontline.

In 2021 IAPO used two Regional Congresses as capacity building events to empower our patient groups in Africa and Asia-Pacific.

The full Africa congress programme and videos can be accessed here:

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

- [African Patients Congress 2021 General Information](#)
- [African Patients Congress 2021 Full Programme and Speaker Session Details and Recordings](#)

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2021

---

The full 3<sup>rd</sup> Asia Pacific Patients Congress programme and videos can be found here:

- <https://www.iapo.org.uk/events/3rd-asia-pacific-patients-congress>  
<https://www.youtube.com/user/IAOPatientVoice>

## Empowering patients on WHO Global Patient Safety Action Plan

IAPO is fully committed to reducing avoidable patient harm to zero in all our healthcare services from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course. At the 74th World Health Assembly, IAPO endorsed the resolution proposed by the WHO Executive Board to adopt the WHO Global Patient Safety Action Plan 2021-2030.

<https://apps.who.int/iris/rest/bitstreams/1360307/retrieve>

At our 3<sup>rd</sup> Asia Pacific Patients Congress, November 2021, IAPO started a training and education programme on the Plan by hosting a workshop to determine what action is needed by patients and families and how their engagement can be enhanced having understood their knowledge and skills needs. The full course will be available on line.

## Patient Solidarity Day 2021

Patient Solidarity Day takes place each December. Thousands of people from around the world rally around one key issue facing patients and raise awareness by hosting events and showing support for the Day.

On Friday 3<sup>rd</sup> December 2021, health stakeholders from all over the world stood together, united in celebration of Patient Solidarity Day (PSD). This was the ninth year running that we have joined hands to mark the Day.

PSD 2021, saw IAPO members, patients, various healthcare organizations, policy-makers, academia, institutions, industry and other stakeholders come together to call for patient cocreation in the implementation of the Global Patient Safety Action Plan 2021-2030 (GPSAP 21-30) to ensure zero patient harm globally.

PSD 2021 theme, 'Patients Co-creating Safe Healthcare', allowed us to rally around a key tenet of IAPO's Patient-centred Healthcare Declaration that patients must be able to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives.

PSD 2021 was used as an opportunity to urge the whole of government and whole of society to work with the whole of the patient community in national unity and global solidarity to ensure that patients and families are engaged and empowered to help and support the journey to safer healthcare (Strategic Objective 4 of GPSAP 21-30).

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

### FOR THE YEAR ENDED 31 DECEMBER 2021

---

## Shape law, policy, and practice in patient centred-universal health coverage at global, regional, and national levels in 2021

[IAPO collaboration with the World Health Organization in shaping global health policy in 2021](#)

### *74<sup>th</sup> World Health Assembly*

IAPO values its special status as a non-State Actor in Official Relationship with WHO and uses this privilege to advocate on important global health matters affecting our patient organisations by addressing the Member States at each World Health Assembly.

IAPO participated in the Special session of World Health Assembly 29 November 2021 - 1 December 2021. Due to the ongoing COVID19 restrictions, this special virtual session replaced the in-person World Health Assembly we were all used to.

IAPO made 4 interventions, addressing the WHO Member States on:

- Agenda Item 13.1 Global action on patient safety
- Agenda item 13.2 Political declaration on NCDs and Agenda item 13.3 Expanding access to effective treatments for cancer and rare and orphan diseases
- Agenda Item 13.7 Standardization of medical devices nomenclature
- Constituency Statement on Agenda item 17 and Agenda item 18

IAPO felt that while COVID19 raged, it distracted health systems from address our needs as many health services were suspended or curtailed. Patient safety become a serious issue as hospital acquired infections (COVID19) increased and patient harm due to medication and treatment errors increased in stressed health systems.

IAPO also saw the 'Moon Shot' that was the race to find an answer to our immunity to the virus unveil new health technologies and platforms (mRNA and AdeneoVirus platforms) that could help us increase access innovative cancer and rare diseases treatment. IAPO wanted personalised healthcare, precision oncology and gene and cell therapies to become institutionalised in healthcare and UHC.

SEE FULL STATEMENTS: <https://www.iapo.org.uk/news/2021/jun/2/iapo-statements-74th-world-health-assembly-may-2021>

### *WHO Regional Committees*

IAPO repeated the same messages that we advocated on at the World Health Assembly at the Regional Health Assemblies:

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2021

---

### *WHO Regional Committees*

IAPO repeated the same messages that we advocated on at the World Health Assembly at the Regional Health Assemblies

We participated virtually in the WHO Regional Committees:

- Regional Committee for the Western Pacific
- Regional Committee for Europe
- Regional Committee for Africa
- Regional Committee for South-East Asia
- Regional Committee for the Americas
- Regional Committee for the Eastern Mediterranean Region

## WHO World Patient Safety Day 2021

IAPO has now established the marking of the WHO World Patients Safety Day on 17 September as an annual event with our members. IAPO and its Members marked the day by promoting the theme Safe maternal and new-born care.

IAPO had a special webinar conference on safe and respectful maternal and new-born healthcare in prisons and refugee camps. IAPO's campaign attracted over 900 delegates to hear from Hon. Penilla Gunther MP, Member of Swedish Parliament, who has led maternal and new-born care reform in prisons and other social settings.

The delegates also heard from Lars Klingsbo, founder EEZER AB, the motor bike ambulance services in Africa, on how maternal and new-born mortality has been reduced through early and safe travel to antenatal clinics using motor bike ambulance. <https://eezer.org/?lang=en>

The delegates then heard from a number of organisations on child birth within refugee communities and the unacceptable conditions endured by the mother and new-borns resulting in high mortality and morbidity.

<https://www.iapo.org.uk/news/2021/aug/23/announcing-world-patient-safety-day-2021>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

### **FOR THE YEAR ENDED 31 DECEMBER 2021**

---

#### African Medicines Agency Treaty Alliance AMATA

The African Medicines Agency Treaty Alliance (AMATA) is a multi-stakeholder alliance set up to advocate for the ratification and implementation of the African Medicines Agency (AMA) Treaty and for meaningful engagement with patients and other relevant parties, in all aspects of the Agency framework.

The idea of the alliance was born in view of the urgency unveiled by COVID-19 where IAPO saw the need to support African patient organisations access to safe and quality vaccines, medicines, personal protection equipment, health devices and diagnostic kits to face present and future pandemics.

Together with a group of 46 organisations (now 55), IAPO issued in February 2021 a Multi-stakeholder Call for AU Heads of State to Ratify the AMA Treaty. The Call highlighted the importance of including in the governance of the future Agency, a mechanism to engage with a range of stakeholders who would benefit from regulatory harmonisation and could bring their expertise to the discussion.

The Multi-stakeholder Call was inspired by the Entebbe Statement, an earlier declaration made by patient organisations at IAPO's Patient Regional Congress in Uganda in 2017, calling for early drafting, adoption and ratification of the AMA Treaty and advocating for patient engagement in all aspects of the Agency framework.

#### AMR Patient Alliance building awareness and capacity

IAPO has gone strength to strength with our partner patient organizations from different regions and countries in advancing our Global Patient Consensus Statement and a Call to Action. The newly formed AMR Patient Alliance has convened civil society groups representing patients, carers and advocates in a global alliance to address the AMR pandemic. The AMR Patient Alliance is a place where patients can exchange views, be educated, and acquire knowledge and resources that we need to raise awareness about the importance of sustaining the efficacy of antibiotics - for as long as possible, for as many patients as possible. Learn more about the Alliance here: <https://bit.ly/3nE4GLF>

#### IAPO in the Fight the Fakes Alliance in 2021

IAPO as a founding member of the new Fight the Fakes (FTF) Alliance, a new multi-stakeholder non-profit association registered in Geneva (Switzerland), continues to fight against fake falsified medicines. IAPO has been a partner in this alliance for over seven years since it was first set up as a grassroots advocacy campaign. IAPO is on the governance structure and the FTF Alliance is taking the fight against substandard and falsified medicines to the next level. We now have over 20 large alliances as members. We have joined health care professionals, manufacturers, wholesalers, researchers and patients. The Alliance is uniquely positioned to scale up action to prevent falsified

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

medicines from endangering people's health and well-being. More information on this: See our Activity <https://fightthefakes.org/events/>

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2021

---

### Driving research processes and development of evidence base for patient centred universal health coverage in 2021

#### IAPO Scientific Advisory Board

IAPO Scientific Advisory Board continues to support the organization in its scientific programme in ensuring that patients have access to quality safe and evidence based healthcare. The inaugural Scientific Board and its membership can be found here: <https://bit.ly/38scZ6L>

#### Metrodora Award – recognising outstanding women achievers in science and health

IAPO in partnership with Viatriis introduced the first international Metrodora Awards, named was a Greek physician who lived between 200 to 400 CE and wrote the first known medical text to be authored by a woman, to empower and recognize women leaders who are delivering positive changes in healthcare and research.

The 2021 Metrodora awards have been postponed to March 2022 because of COVID19 restrictions. <https://metroдораawards.org/>

#### ISPOR - The Professional Society for Health Economics and Outcomes Research

IAPO continues to collaborate with and contribute towards ISPOR conferences and research programmes.

#### ISQua - The International Society for Quality in Health Care

IAPO continues to work with ISQUA to improve research and development of good practice globally to improve access to quality universal health coverage 2030.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2021

---

### Patients for Patient Safety Observatory

IAPO has established a partnership with Patient for Patient Safety Observatory (P4PS Observatory) Geneva too have a single-point global research and development platform for gathering and analysing patients' expertise and experience that would feed into the national, regional and global policies aimed at improving safety and quality of care for patients and by the patients.

The reason why P4PS Observatory was formed was because patient harm has become a great public health problem, and it now requires expert patient oversight and co-creation. To do this, the P4PS Observatory has put patient led research into practice, and patient experience back into research. Patient harm not only causes great suffering, injury and death, it also erodes public trust in healthcare systems and costs billions of USD to address compensation and fines. The WHO Director General in his report and Resolution WHA 72.6 May 2019 Global Action on Patient Safety has asked every WHO Member State to produce plans to implement this resolution in the global consultation WHO Flagship "A Decade of Patient Safety 2020-2030": <https://bit.ly/2KFN1Vg>

### Duke NUS Singapore and IAPO HTA Research in Asia Pacific and LMIC

IAPO has initiated research in Health technology Assessment and patient engagement in Asia Pacific and Low- and Middle-Income Countries with Duke NUS Singapore. Results will be published in June 2022 Published research papers Person Centred Value based Healthcare (Sprink, IAPO et al)

[https://sprink.co.uk/files/2021\\_09\\_01\\_PCVBHC\\_Report.pdf](https://sprink.co.uk/files/2021_09_01_PCVBHC_Report.pdf)

Self-Care Readiness Indicator (World Self Care Federation <https://bit.ly/3BrAafJ> ) The impact of COVID-19 on the care of patients with noncommunicable diseases in low-and middle-income countries: an online survey of patient perspectives (R devi et al <https://bit.ly/36kXBvN> )

A Methodology for Mapping the Patient Journey for Noncommunicable Diseases in Low- and Middle-Income Countries (R. Devi et al <https://bit.ly/3Bn8hW8>)

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2021

---

### IAPO Members survey

IAPO conducted a survey to help identify ways of strengthening collaboration among IAPO members' network and ensure we prioritise our resources and continue to respond to our member organizations' priorities and needs throughout and beyond the pandemic. Results to be launched in 2021.

### Communications

**Newsletter:** Our monthly newsletter reaches out to over 5900 subscribers and has covered our congresses, member activities, the COVID-19 pandemic news and information. In 2022 we are encouraging more patient organizations to submit articles for publication.

**Twitter:** @IAPOvoice and @PatientSolidarityDay

**Facebook:** We operate IAPOvoice, International Alliance of Patients' Organizations, African page and Patient Solidarity Day

**Website:** Continues to be the main focal point for IAPO's dissemination and communications activities. We have seen an increase in number of page views: with over 100,000 page views in 2021 compared to 92,154 in 2020. [www.iapo.org.uk](http://www.iapo.org.uk)

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2021

---

### IAPO Membership in 2021

IAPO consolidated its membership in 2021 and sought new members covering rare diseases and non-communicable diseases. IAPO had 289 members at 31<sup>st</sup> December 2021. IAPO is now also actively seeking more members from WHO Eastern Mediterranean Region, South East Asia and the Western Pacific that are under-represented.

| Region                        | %           |
|-------------------------------|-------------|
| African members               | 15%         |
| Eastern Mediterranean members | 4%          |
| European members              | 35%         |
| Latin American members        | 25%         |
| North American members        | 8%          |
| South East Asian member       | 4%          |
| Western Pacific members       | 9%          |
| <b>TOTAL</b>                  | <b>100%</b> |

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

***FOR THE YEAR ENDED 31 DECEMBER 2021***

---

### **IAPO funding transparency**

The Governing Board members declare interests and sign conflict of interest register at the start of each Board meeting. The register is maintained with any changes between meetings.

Reference to IAPO's Code of conduct and policy regulating IAPO's relationship with, and independence from, sponsors can be found at: [www.iapo.org.uk/consensus-framework-ethical-collaboration](http://www.iapo.org.uk/consensus-framework-ethical-collaboration) and [www.iapo.org.uk/healthcare-industry-partners](http://www.iapo.org.uk/healthcare-industry-partners).

The overall proportion of industry to non-industry income for the year was approximately 93%.

### **Public benefit**

In setting our objectives and planning our activities trustees have given consideration to the Charity Commission's general guidance on public benefit (PB1, PB2 and PB3) and have taken these into account in making all decisions. We have not departed from the guidance in 2021.

IAPO objects are the promotion of the relief of sickness and the preservation and protection of health for the public benefit. IAPO pursues this through fostering patient-centred healthcare worldwide and, in particular, by developing the capacity of patients' organisations.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

### ***FOR THE YEAR ENDED 31 DECEMBER 2021***

---

IAPO's services are open to all people and our membership reflects a diverse group of patients' organisations representing patients with communicable and non-communicable diseases, including patients with diseases that are stigmatised in many societies.

IAPO had 289 members comprising umbrella groups and single organisations in 2020 who directly represented views of over 1 million patients in 71 countries across 52 disease areas. The services the charity provides are designed to build the capacity of patients' organisations, allowing them to better assist the needs of patients and carers (and their own member patient organisations in some cases) from across the world.

Access to IAPO's website is freely available to the public. Currently it is in English, with some sections in Spanish. The website contains a wide range of information on IAPO's activities and on patient-centred healthcare, which is of benefit to the public, particularly those who wish to set up local patients' organisations.

By improving access to information, training and other capacity building programmes for patients and their representative organizations, IAPO improves access to healthcare itself. By raising awareness and through capacity building and education of health care providers, we increase access to acceptable services that respect patients' preferences, values, rights and needs.

IAPO has a wealth of evidence, gained from patients' organizations worldwide, which demonstrates that patient involvement in patients' care leads to better health outcomes and lower costs for the whole of society. The charity works with patients' organizations that are not for profit and non-government organisations who demonstrate commitment to improving patient-centred healthcare which is reflected in the charity's membership criteria.

#### **Risk Management**

A risk register is prepared by the CEO and presented annually to the Board to discuss ensuring that there are effective and adequate risk management and internal control systems in place to manage the major risks to which the Charity is exposed. IAPO prepares the risk register by understanding the risk environment of IAPO and its operations and then identifies the key risks. The CEO and the Treasurer then undertake a thorough analysis and evaluation of the risks identified before coming up with a treatment for the risks.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

### ***FOR THE YEAR ENDED 31 DECEMBER 2021***

---

Risks are identified under headings of Financial, Funding, Governance, Operational and Personnel. These are then quantified using a Likelihood/Impact matrix, and mitigation actions detailed. Discussions are underway with the Audit Committee to ensure that the risks are appraised regularly before each board meeting to assess IAPO's risk profile.

IAPO is undertaking a new fundraising strategy to reduce reliance upon the pharmaceutical companies. IAPO will diversify its funding by approaching international trust funds, international development agencies and large programmes to raise non-industry partner funding.

#### **Financial review**

Incoming resources for the year amounted to £380,706 (2020: £509,091), which was lower than the previous year as we did not hold a GPC congress.

Expenditure in 2021 was £270,656 (2020: £436,449). Expenditure is also lower than the previous year, in line with the fact that we did not hold a GPC congress.

#### **Reserves Policy**

The IAPO Board approved a Reserves Policy in September 2014, with a target level of free reserves of 6-12 months' running costs for 6 months. This policy was set with due regard to guidance from Charity Commission (CC19 – Charity Reserves) and is reviewed annually.

The level of unrestricted reserves, as at 31<sup>st</sup> December 2021 is £264,025. This is below the target in the reserves policy, and will be reviewed by the Board of Trustees.

#### **Going Concern**

The trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. As they have considered the impact of the COVID-19 pandemic on both its income and expenditure for at least a period of twelve months from the date of approval of these financial statements and are expecting to make a surplus in 2021.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

### FOR THE YEAR ENDED 31 DECEMBER 2021

---

#### **Pension arrangements**

With auto-enrolment legislation coming into force in Autumn 2017, we set up an Occupational Pension Scheme.

IAPO also operates a policy of contributions directly into staff members' chosen personal pension schemes, with no obligation for staff to make personal contributions. The issue of pension deficit, which would apply to an occupational scheme, does not therefore arise.

#### **Pay and remuneration of senior management**

IAPO has a team of research officers and volunteers led by a Chief Executive.

#### **Future Activities**

IAPO's plan of activities for 2021 are listed at:

[https://www.iapo.org.uk/sites/default/files/files/IAPO\\_Planned%20Activities%20in%202021.pdf](https://www.iapo.org.uk/sites/default/files/files/IAPO_Planned%20Activities%20in%202021.pdf)

IAPO's Strategy for 2022-2024 is listed at:

<https://www.iapo.org.uk/sites/default/files/files/IAPO%20Strategy%202022-2024%20Draft.pdf>

Our vision, mission and tactical plans are adapted to build back better a patient centred, pandemic prepared universal health coverage 2030.

- **VISION 2022-24**
  - To ensure through global solidarity and national action that every patient enjoys healthcare that is:
    - Patient centred (PC) (broader definition)
    - Pandemic prepared (PP)
    - A Universal Health Coverage (UHC)
- **MISSION 2022-24**
  - Empower our members with cutting edge knowledge and advocacy skills in bringing about PC & PP UHC 2030.
  - Work with our membership, alliances, partners, and other stakeholders to drive research and policy development activity that establishes the evidence base needed in support of PC & PP UHC 2030 and strengthen patient involvement and co-creation in research.
  - Motivate the empowered patient community into using the evidence base created to shape the institutional, law, policy, practice, and standards framework needed for PC & PP UHC 2030 at global, regional (APEC, AU and EU etc) and national levels.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2021**

---

- **TACTICAL PLAN 2022-24**

- To attain PC (Broader Definition) and PP UHC 2030 it is important that IAPO advocates the delivery of:
  - Safe Healthcare
  - Quality Healthcare
  - Accessible Healthcare. Access is across four areas.
  - Non-Discriminatory Healthcare
  - Physically Accessible Healthcare
  - Information Accessibility
  - Affordable Healthcare
  - Acceptable Healthcare: Culturally Competent and Patient Centred (Broader Definition)

In addition to the above, IAPO is collaborating closely in the WHO Work Plan 13 and ensuring that the WHO flagship Global Patient Safety Action Plan 2021-2030 is translated and implemented into national patient safety institutional, legislative, policy, practice and standards through patient and family engagement and cocreation/coproduction.

### **Statement of Trustees' responsibilities**

The Trustees are responsible for preparing the financial statements for each financial period which give a true and fair view of the state of affairs of the company and of the deficit or surplus of the company for that period. In preparing those financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping proper accounting records, which disclose with reasonable accuracy at any time, the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2021**

---

### **Statement as to disclosure to our auditors**

In so far as the trustees are aware at the date of approving this report:-

- there is no relevant audit information, being information needed by the auditor in connection with preparing their report, of which the charity's auditor is unaware; and
- the trustees having made enquiries of fellow directors and the group's auditor that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a director in order to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

### **Reappointment of auditors**

A proposal to reappoint Knox Cropper as the charity's statutory auditors will be put to members at our forthcoming Annual General Meeting.

Approved and authorised for issue by the Board of Trustees on 13<sup>th</sup> December 2022 and signed on their behalf by:-



Dr. Neda Milevska-Kostova  
Chair of the Board

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2021**

---

### **Opinion**

We have audited the financial statements of International Alliance of Patients' Organization for the year ended 31 December 2021 which comprise the Statement of Financial Activities (including the Income and Expenditure Account), the Balance Sheet and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2021 and of its income and expenditure, for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### **Conclusions relating to going concern**

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### **Other information**

The other information comprises the information included in the Trustees' Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2021

---

### Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report, included within the Trustees' Report, has been prepared in accordance with applicable legal requirements.

### Matters on which we are Required to Report by Exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or
- Certain disclosures of Trustees' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit; or
- The trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Trustees' Report.

### Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

### Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- The Charitable Company is required to comply with both company law and charity law and, based on our knowledge of its activities, we identified that the legal requirement to accurately account for restricted funds was of key significance.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2021

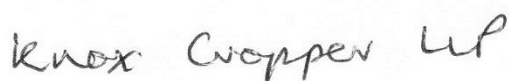
---

- We gained an understanding of how the charitable company complied with its legal and regulatory framework, including the requirement to properly account for restricted funds, through discussions with management and a review of the documented policies, procedures and controls.
- The audit team, which is experienced in the audit of charities, considered the charitable company's susceptibility to material misstatement and how fraud may occur. Our considerations included the risk of management override.
- Our approach was to check that all restricted income was properly identified and separately accounted for and to ensure that only valid and appropriate expenditure was charged to restricted funds. This included reviewing journal adjustments and unusual transactions.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

### Use of our report

This report is made solely to the charitable company's trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



22 December 2022

Simon Goodridge (Senior Statutory Auditor)  
For and on behalf of Knox Cropper LLP (Statutory Auditor)  
65 Leadenhall Street  
London  
EC3A 2AD

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 DECEMBER 2021

|                                                 | Notes | Unrestricted<br>£ | Designated<br>£ | Restricted<br>£ | Total<br>2021<br>(year)<br>£ | Total<br>2020<br>(year)<br>£ |
|-------------------------------------------------|-------|-------------------|-----------------|-----------------|------------------------------|------------------------------|
| <b>Income from charitable activities:</b>       |       |                   |                 |                 |                              |                              |
| Membership                                      |       | 1,974             | -               | -               | 1,974                        | 127                          |
| Healthcare Industry Partners                    |       | 224,540           | -               | -               | 224,540                      | 118,808                      |
| APPC congress                                   |       | -                 | 43,314          | -               | 43,314                       | 44,209                       |
| GPC congress                                    |       | -                 | -               | -               | -                            | 270,421                      |
| Africa congress                                 |       | -                 | 38,888          | -               | 38,888                       | -                            |
| Special Projects                                |       | -                 | -               | 57,269          | 57,269                       | 68,556                       |
| Other charitable activities                     |       | 14,721            | -               | -               | 14,721                       | 6,970                        |
| <b>Total</b>                                    | 2     | <b>241,235</b>    | <b>82,202</b>   | <b>57,269</b>   | <b>380,706</b>               | <b>509,091</b>               |
| <b>Expenditure on charitable Activities:</b>    |       |                   |                 |                 |                              |                              |
| Charitable activities:-                         |       |                   |                 |                 |                              |                              |
| • Capacity building, advocacy and collaboration |       | 114,857           | -               | -               | 114,857                      | 181,572                      |
| • Asia Pacific Patients Congress                |       | -                 | 71,094          | -               | 71,094                       | 38,889                       |
| • Global Pacific Patients Congress              |       | -                 | 2,608           | -               | 2,608                        | 154,369                      |
| • Africa Patients Congress                      |       | -                 | 61,130          | -               | 61,130                       | -                            |
| • Special projects                              |       | -                 | -               | 20,967          | 20,967                       | 61,619                       |
| <b>Total</b>                                    | 3     | <b>114,857</b>    | <b>134,832</b>  | <b>20,967</b>   | <b>270,656</b>               | <b>436,449</b>               |
| <b>Net income/(expenditure)</b>                 |       | <b>126,378</b>    | <b>(52,630)</b> | <b>36,302</b>   | <b>110,050</b>               | <b>72,643</b>                |
| Transfers                                       |       | -                 | -               | -               | -                            | -                            |
| <b>Net movement in funds</b>                    |       | <b>126,378</b>    | <b>(52,630)</b> | <b>36,302</b>   | <b>110,050</b>               | <b>72,643</b>                |
| <b>Reconciliation of funds:</b>                 |       |                   |                 |                 |                              |                              |
| Funds brought forward                           |       | <b>137,647</b>    | <b>14,518</b>   | <b>87,042</b>   | <b>239,207</b>               | <b>166,565</b>               |
| <b>Total funds carried forward</b>              |       | <b>264,025</b>    | <b>(38,112)</b> | <b>123,344</b>  | <b>349,257</b>               | <b>239,207</b>               |

All transactions are derived from continuing activities.  
All recognised gains and losses are included in the Statement of Financial Activities.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## BALANCE SHEET AS AT 31 DECEMBER 2021

|                                                       | Notes | 2021<br>£      | 2020<br>£      |
|-------------------------------------------------------|-------|----------------|----------------|
| <b>Fixed assets</b>                                   | 6     | 134            | 200            |
| <b>Current assets</b>                                 |       |                |                |
| Debtors                                               | 7     | 6,958          | 127,992        |
| Cash in hand and in bank                              |       | 435,290        | 227,316        |
|                                                       |       | <u>442,248</u> | <u>355,308</u> |
| <b>Creditors: amounts falling due within one year</b> | 8     | (93,125)       | (116,301)      |
|                                                       |       | <u>349,123</u> | <u>239,007</u> |
| <b>Net current assets</b>                             |       |                |                |
|                                                       |       | <u>349,123</u> | <u>239,007</u> |
| <b>Net assets</b>                                     |       | <b>349,257</b> | <b>239,207</b> |
| <b>Funds</b>                                          |       |                |                |
| Unrestricted Funds                                    |       | 264,025        | 137,647        |
| Designated Funds                                      |       | (38,112)       | 14,518         |
| Restricted Funds                                      |       | 123,344        | 87,042         |
|                                                       |       | <u>249,257</u> | <u>239,207</u> |
| <b>Total Funds</b>                                    | 9     | <b>349,257</b> | <b>239,207</b> |

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

These financial statements were approved and authorised for issue by the Board of Trustees on 13<sup>th</sup> December 2022 and signed on their behalf by:-



Dr. Neda Milevska-Kostova  
Chair

Registered company number: 08495711 (England and Wales)

The notes on pages 28 to 38 form part of these financial statements

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

---

### 1 Accounting Policies

#### 1.1 Accounting convention

The financial statements of the charitable company, which is a public benefit entity under FRS102, have been prepared in accordance with the 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (SORP) (FRS102 second edition - effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

The financial statements are presented in Sterling (£).

Results for the trading subsidiary, IAPO Trading Limited (Company Number 08863190) are not consolidated on the grounds that it was dormant and not material to the group.

#### Statement on going concern

After reviewing the charity's forecasts and projections, the directors have reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. The charity therefore continues to adopt the going concern basis in preparing its financial statements.

#### 1.2 Company status

The parent charity is a company limited by guarantee. The directors of the company are the trustees named on page 1. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

#### 1.3 Incoming resources

All incoming resources are included in the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable certainty.

Healthcare Industry Partners: IAPO's Industry Partners are companies, foundations and associations who commit to providing various levels of unrestricted financial support each year, contributing to IAPO's core costs. IAPO's Partners Framework provides a framework for IAPO and industry stakeholders to interact and collaborate in a transparent and accountable way.

Restricted Project: Pfizer UpJohn Metrodora Awards to honour women scientists (\$58,000), Pfizer Upjohn Stroke Twinning Project and Study (\$30,000)

Designated Events and Congresses in 2021 were the African Patients Congress 20<sup>th</sup> -21<sup>st</sup> July 2021 and the 3<sup>rd</sup> Asia Pacific Patients on the 16-17<sup>th</sup> November 2021. The African Patients Congress had four partners. The Asia Pacific Congress had five partners.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

---

GetReal: IAPO is a partner in GetReal, a three-year collaborative European Project exploring how real world research data can be used in the development of drugs, to increase effectiveness and enrich decision-making by regulatory authorities and health technology assessment (HTA) agencies.

IMI Prefer: IAPO is a partner in researching, developing and advocating that patient preferences should be included in decision-making

Other Income: Other income includes "In Kind" support and briefing paper sales, which includes financial support and reimbursement provided to IAPO to attend conferences and meetings around the world.

### 1.4 Expenditure

All expenditure is included on an accruals basis and is inclusive of all VAT, which cannot be reclaimed, and is reported as part of the expenditure to which it relates:

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.
- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.
- All costs are allocated between expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, other costs are apportioned on the basis staff time incurred.

The core elements of charitable expenditure are as follows:-

Capacity Building: Realising active partnerships with patients' organizations, maximising their impact through capacity building.

Advocacy: Advocating internationally with a strong patients' voice on the relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies.

Collaboration: Building cross-sector alliance and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives.

### 1.5 Funds

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Designated funds are funds which are 'ring-fenced' to be used for the specific purpose of the congress.

Restricted funds are funds, which are to be used in accordance with specific restrictions imposed by the donor. The aim and use of the restricted fund is set out in the notes of the financial statements.

### 1.6 Tangible fixed assets and depreciation

Capital expenditure on items costing £1,000 or higher are recorded as tangible fixed assets. Tangible fixed assets are stated at historical cost less depreciation.

Depreciation is provided to reflect the useful estimated economic life of computer equipment assets at a rate of 33% per annum (reducing balance method).

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

### 2 Incoming resources

|                                 | Charitable<br>Activities &<br>Others | Healthcare<br>Industry Partners | Projects       | Total                 |
|---------------------------------|--------------------------------------|---------------------------------|----------------|-----------------------|
|                                 | £                                    | £                               | £              | £                     |
| GSK IHC                         | -                                    | 36,181                          | -              | <b>36,181</b>         |
| EMD Serano                      | -                                    | 16,791                          | -              | <b>16,791</b>         |
| Leo Pharma                      | -                                    | 17,763                          | -              | <b>17,763</b>         |
| PhARMA                          | -                                    | 35,626                          | -              | <b>35,626</b>         |
| MSD MERCK                       | -                                    | 21,449                          | -              | <b>21,449</b>         |
| Roche Pharma Holding            | -                                    | 41,412                          | -              | <b>41,412</b>         |
| IFPMA                           | -                                    | 55,319                          | -              | <b>55,319</b>         |
| Congress Sponsorship            | -                                    | -                               | 82,202         | <b>82,202</b>         |
| Projects                        | -                                    | -                               | 57,269         | <b>57,269</b>         |
| Other Activities and membership | 16,694                               | -                               | -              | <b>16,694</b>         |
|                                 | <u>16,694</u>                        | <u>224,541</u>                  | <u>139,471</u> | <u><b>380,706</b></u> |

### Income Resources comparative

|                                 | Charitable<br>Activities &<br>Others | Healthcare<br>Industry<br>Partners | Projects       | Total<br>2020         |
|---------------------------------|--------------------------------------|------------------------------------|----------------|-----------------------|
|                                 | £                                    | £                                  | £              | £                     |
| GSK IHC                         | -                                    | 39,430                             | -              | <b>39,430</b>         |
| EMD Serano                      | -                                    | 30,795                             | -              | <b>30,795</b>         |
| E.R SquiBB                      | -                                    | 11,297                             | -              | <b>11,297</b>         |
| MSD Merck                       | -                                    | 37,286                             | -              | <b>37,286</b>         |
| Congress Sponsorship            | -                                    | -                                  | 314,630        | <b>314,630</b>        |
| Novo Nordisk India Private Ltd  | -                                    | -                                  | 1,519          | <b>1,519</b>          |
| Pfizer                          | -                                    | -                                  | 67,037         | <b>67,037</b>         |
| Other Activities and membership | 7,097                                | -                                  | -              | <b>7,097</b>          |
|                                 | <u>7,097</u>                         | <u>118,808</u>                     | <u>383,186</u> | <u><b>509,091</b></u> |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

---

### Congress Sponsorship 2021

|                      | Asia Pacific<br>Congress<br>£ | Africa Patient Congress<br>£ | <b>Total<br/>£</b>        |
|----------------------|-------------------------------|------------------------------|---------------------------|
| Roche Pharma Holding | 21,866                        | -                            | <b>21,866</b>             |
| Leo Pharma           | -                             | 17,763                       | <b>17,763</b>             |
| Merck                | 21,449                        | -                            | <b>21,449</b>             |
| Johnson Johnson      | -                             | 21,124                       | <b>21,124</b>             |
|                      | <hr/> 43,314 <hr/>            | <hr/> 38,887 <hr/>           | <hr/> <b>82,202</b> <hr/> |

### 3 Analysis of support costs

All support costs are allocated directly to charitable activities and as such there are no support costs.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

---

### 4 Trustees and staff remuneration

The trustees received no remuneration, but 1 Trustee received reimbursements of £1,442 (2020: £1,519) for travel and subsistence expenses incurred on behalf of the charity.

#### Staff remuneration and numbers

|                    | <b>Total<br/>2021<br/>£</b> | <b>Total<br/>2020<br/>£</b> |
|--------------------|-----------------------------|-----------------------------|
| Wages and salaries | <b>124,338</b>              | 103,754                     |
| Social Security    | <b>13,754</b>               | 14,789                      |
| Pension costs      | <b>1,362</b>                | 1,026                       |
|                    | <hr/>                       | <hr/>                       |
|                    | <b>139,454</b>              | 119,569                     |
|                    | <hr/>                       | <hr/>                       |

The average number of full and part-time employees during the year was 3. One individual employee received emoluments in excess of £60,000 (2020: one). Key management personnel costs amounted to £71,247(2020: £71,544).

### 5 Operating Surplus

Operating surplus is stated after charging

|                                         | <b>Total<br/>2021<br/>£</b> | <b>Total<br/>2020<br/>£</b> |
|-----------------------------------------|-----------------------------|-----------------------------|
| Auditors Remuneration                   | <b>5,040</b>                | 4,920                       |
| Depreciation of Assets                  | <b>66</b>                   | 99                          |
| Operating Lease Charges (office rental) | <b>12,213</b>               | 31,277                      |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

### 6 Fixed Assets

|                       | Computer<br>equipment<br>£ |
|-----------------------|----------------------------|
| <b>Cost</b>           |                            |
| Brought forward       | 4,169                      |
| Carried forward       | <u>4,169</u>               |
| <b>Depreciation</b>   |                            |
| Brought forward       | 3,969                      |
| Charge for the year   | 66                         |
| Carried forward       | <u>4,035</u>               |
| <b>Net book value</b> |                            |
| At 31 December 2021   | <u>134</u>                 |
| At 31 December 2020   | <u>200</u>                 |

There are no charges or securities held over any fixed assets. All fixed assets are held in the charity and none in the trading subsidiary. Depreciation of £99 was charged in the accounts for the previous period.

### 7. Debtors

|                | 2021<br>£    | 2020<br>£      |
|----------------|--------------|----------------|
| Debtors        | 78           | 97,356         |
| Prepayments    | 6,880        | 6,880          |
| Accrued income | -            | 23,756         |
|                | <u>6,958</u> | <u>127,992</u> |

### 8. Creditors: amount falling due within one year

|                 | 2021<br>£     | 2020<br>£      |
|-----------------|---------------|----------------|
| Creditors       | -             | -              |
| Deferred income | 72,741        | 41,722         |
| Accruals        | 20,385        | 74,579         |
|                 | <u>93,125</u> | <u>116,301</u> |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

### 9. Analysis of net assets between funds

|                                | Unrestricted<br>Fund<br>£ | Designated<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total<br>Funds<br>£   |
|--------------------------------|---------------------------|--------------------------|--------------------------|-----------------------|
| Tangible fixed assets          | 134                       | -                        | -                        | <b>134</b>            |
| Current assets                 | 284,276                   | (38,112)                 | 196,084                  | <b>442,248</b>        |
| Current liabilities            | (20,385)                  | -                        | (72,740)                 | <b>(93,125)</b>       |
|                                |                           |                          |                          |                       |
| Net assets at 31 December 2021 | <u>264,025</u>            | <u>(38,112)</u>          | <u>123,344</u>           | <u><b>349,257</b></u> |

### 10. Analysis of net assets between funds comparative

|                                | Unrestricted<br>Fund<br>£ | Designated<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total Funds<br>£      |
|--------------------------------|---------------------------|--------------------------|--------------------------|-----------------------|
| Tangible fixed assets          | 200                       | -                        | -                        | <b>200</b>            |
| Current assets                 | 159,647                   | 14,518                   | 181,143                  | <b>355,308</b>        |
| Current liabilities            | (22,200)                  | -                        | (94,101)                 | <b>(116,301)</b>      |
|                                |                           |                          |                          |                       |
| Net assets at 31 December 2020 | <u>137,647</u>            | <u>14,518</u>            | <u>87,042</u>            | <u><b>239,207</b></u> |

### 11. Movements in funds

|                                          | At 31<br>December<br>2020<br>£ | Incoming<br>Resources<br>£ | Resources<br>Expended<br>£ | Transfers<br>£ | At 31<br>December<br>2021<br>£ |
|------------------------------------------|--------------------------------|----------------------------|----------------------------|----------------|--------------------------------|
| Unrestricted fund                        | <b>137,647</b>                 | 241,235                    | (114,857)                  | -              | <b>264,025</b>                 |
| <u>Designated Funds: -</u>               |                                |                            |                            |                |                                |
| APPC congress                            | <b>5,320</b>                   | 43,314                     | (71,094)                   | -              | <b>(22,460)</b>                |
| GPC congress                             | <b>9,198</b>                   | -                          | (2,608)                    | -              | <b>6,590</b>                   |
| Africa congress                          | -                              | 38,888                     | (61,130)                   | -              | <b>(22,242)</b>                |
| <u>Restricted funds: -</u>               |                                |                            |                            |                |                                |
| PREFER                                   | <b>32,512</b>                  | 5,840                      | -                          | -              | <b>38,352</b>                  |
| Special projects - Up john and Metrodora | <b>14,332</b>                  | 51,429                     | -                          | -              | <b>65,761</b>                  |
| Other projects - Get Real                | <b>40,198</b>                  | -                          | (20,967)                   | -              | <b>19,231</b>                  |
|                                          | <u><b>239,207</b></u>          | <u><b>380,706</b></u>      | <u><b>(270,656)</b></u>    | <u>-</u>       | <u><b>349,257</b></u>          |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

### Movements in funds Comparative

|                                             | At 31<br>December<br>2019<br>£ | Incoming<br>Resources<br>£ | Resources<br>Expended<br>£ | Transfers<br>£ | At 31<br>December<br>2020<br>£ |
|---------------------------------------------|--------------------------------|----------------------------|----------------------------|----------------|--------------------------------|
| Unrestricted fund                           | (3,311)                        | 125,905                    | (181,572)                  | 196,625        | <b>137,647</b>                 |
| <u>Designated Funds: -</u>                  |                                |                            |                            |                |                                |
| APPC Congress                               | -                              | 44,209                     | (38,889)                   |                | <b>5,320</b>                   |
| GPC Congress                                | 89,771                         | 270,421                    | (154,369)                  | (196,625)      | <b>9,198</b>                   |
| <u>Restricted funds: -</u>                  |                                |                            |                            |                |                                |
| PREFER                                      | 32,512                         | -                          | -                          | -              | <b>32,512</b>                  |
| Special projects - Up john<br>and Metrodora | -                              | 68,556                     | (54,224)                   | -              | <b>14,332</b>                  |
| Other projects                              | 47,593                         | -                          | (7,395)                    | -              | <b>40,198</b>                  |
|                                             | <hr/>                          | <hr/>                      | <hr/>                      | <hr/>          | <hr/>                          |
|                                             | 166,565                        | 513,287                    | (448,040)                  | -              | <b>239,207</b>                 |

### Congress Overhead recharge

the overhead cost, primarily consisting of staff cost, and possibly overhead recharge were allocated for 2021. Costs were much higher than income received in the year, however this trend is likely to reverse in 2022.

### 3rd APPC2021 Virtual

On 16 - 17 November 2021, over 3800 patient advocates, government and policy makers, industry representatives, healthcare professionals, academia representatives, researchers and media came together for the virtual 3rd Asia-Pacific Patients Congress (APPC 2021). The theme was: "Recovering together through compassion, insight and co-creation".

Discussions held at the APPC 2021 all highlighted that patient, family, and community engagement in healthcare decision-making is critical in improving the effectiveness, efficiency, quality, safety and equity of health systems and health technologies development ecosystem. The congress concluded with a pledge for patient-centred healthcare where the patient is not only the user, but a contributor and a co-creator to its development.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

---

### African Patients Congress

The 1st Virtual African Patients Congress: 'Co-creating Better Healthcare Systems' (APC 2021) held on 20 -21 July 2021, was a patient led regional convening bringing together IAPO's African membership with a variety of high-level healthcare stakeholders to share their vision and experience on how we can build back better African health systems after the pandemic. Through a range of interactive capacity building and knowledge-sharing sessions, delegates developed the tools to ensure that the patient movement across the region is made up of strong patient advocates. The goal was to prepare ourselves, as patient advocates, to take on the challenges and opportunities that have arisen as a result of the COVID-19 pandemic, as well as from increasing regulatory harmonisation across Africa with the set-up of the African Medicines Agency.

APC 2021 brought together 2229 delegates in total representing 84 countries from regions of the world. 342 delegates were representatives of patient organizations, and 68 were IAPO member organizations. We also had 567 delegates representing Non-Governmental Organizations, 582 representing Governments, and 278 from Academia. Almost 120 delegates came from the Pharmaceutical Industry.

### Metrodora Awards

The first ever international Metrodora Awards – a celebration of women leaders in science and health improving NCD care and management was established by IAPO and Pfizer Upjohn. Over the past few years, the number of women leaders in science and health has grown significantly. However, while there has been progress towards gender equality, women science and health leaders are still under-represented globally. Women constitute only 30% of the world's researchers with too few of them occupying decision-making roles in academic and research institutions, which further hinders their ability to shape the research agenda <https://www.iapo.org.uk/news/2020/oct/27/metrodora-awards>

### Prefer

Prefer will run over the next one year and establish recommendations to support development of guidelines for industry, Regulatory Authorities and HTA bodies on how and when to include patient perspectives on benefits and risks of medicinal products.

We have given all our input to patient preference studies run in both academic and industry setting by others. Our perspective has provided a better understanding of what the recommended best-practice approach to patient-preference studies should be in the future. The Recommendations are in consultation and we will disseminate results later to show how patient preference studies can give valuable information to support decision making for regulators and HTA bodies.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

---

### GetReal

Get-Real IMI Project which concluded in 2021, and has now been set-up as a separate entity with IAPO being a main partner in the new Get Real Institute. Get REal explored how real-world research data could be used in the development of drugs, to increase effectiveness and enrich decision-making by regulatory authorities and health technology assessment (HTA) agencies. IAPO's role was to bring the perspective of patients and patients' organizations to this work and facilitate the input of member organizations into the study. As a patient partner in this project, IAPO contributed to improving medicine development process, so patients have access to the drugs that they need. Surplus funds were ring fenced to be spent specifically on this project. As most of our activity was over the Zoom Virtually, none of the estimated travel and accommodation and other costs were incurred. Also, as the pandemic had locked out most of the hospitals and patient movement, patient organisations did not travel to the European Union and its DG Sante as intended. This resulted in an underspent and this saving is passed back to the European Union's IMI Consortia at the Dutch University.

### UpJohn

This financial award was made at the tail end of the dissolution of UpJohn and its sale into Mylan. <https://www.pfizer.com/news/press-release/press-release-detail/pfizer-completes-transaction-combine-its-upjohn-business>

UpJohn had some money left over for patient advocacy and events and expected IAPO to spread the income across three events. APPC, Metrodora Awards and Stroke Support Project. The Stroke Support was a global capacity building work amongst patient organisations representing the Stroke survivors, caregivers and community that has been lacking. Though there are patient representative groups from the developed G20 countries in the region, voices from the Low- and Middle- Income Countries (LMICs) in the region are underrepresented and sometimes non-existent. These are also the countries with poor health infrastructure and fragmented systems, high out of pocket and no follow up programs. There is an urgent need to create patient support groups and credible voices in countries like India, Mexico, Philippines, Egypt and many other such countries.

## **12. Related parties**

There were no related party transactions during the year or prior year.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

### 13. SOFA 2020 Comparative

|                                                 | Unrestricted<br>£ | Designated<br>£ | Restricted<br>£ | Total<br>2020<br>£ |
|-------------------------------------------------|-------------------|-----------------|-----------------|--------------------|
| <b>Income from charitable activities:</b>       |                   |                 |                 |                    |
| Membership                                      | 127               | -               | -               | 127                |
| Healthcare Industry Partners                    | 118,808           | -               | -               | 118,808            |
| APPC congress                                   | -                 | 44,209          | -               | 44,209             |
| GPC congress                                    | -                 | 270,421         | -               | 270,421            |
| Special Projects                                | -                 | -               | 68,556          | 68,556             |
| Other charitable activities                     | 6,970             | -               | -               | 6,970              |
| <b>Total</b>                                    | <b>125,905</b>    | <b>314,630</b>  | <b>68,556</b>   | <b>509,091</b>     |
| <b>Expenditure on charitable Activities:</b>    |                   |                 |                 |                    |
| Charitable activities:-                         |                   |                 |                 |                    |
| • Capacity building, advocacy and collaboration | 181,572           | -               | -               | 181,572            |
| • Asia Pacific Patients Congress                | -                 | 38,889          | -               | 38,889             |
| • Global Pacific Patients Congress              | -                 | 154,369         | -               | 154,369            |
| • Special projects                              | -                 | -               | 61,619          | 61,619             |
| <b>Total</b>                                    | <b>181,572</b>    | <b>193,258</b>  | <b>61,619</b>   | <b>436,449</b>     |
| <b>Net income/(expenditure)</b>                 | <b>(55,667)</b>   | <b>121,372</b>  | <b>6,937</b>    | <b>72,642</b>      |
| Transfers                                       | 196,625           | (196,625)       | -               | -                  |
| <b>Net movement in funds</b>                    | <b>140,958</b>    | <b>(75,253)</b> | <b>6,937</b>    | <b>72,642</b>      |
| <b>Reconciliation of funds:</b>                 |                   |                 |                 |                    |
| Funds brought forward                           | (3,31)            | 89,771          | 80,105          | 166,565            |
| <b>Total funds carried forward</b>              | <b>137,647</b>    | <b>14,518</b>   | <b>87,042</b>   | <b>239,207</b>     |

**INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

England & Wales - Charity number 1155577

---

# Accounts

---

Company registration number (England and Wales): 08495711  
Charity registration number (England and Wales): 1155577

**INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

(Incorporated as a Company Limited by Guarantee  
and not having a Share Capital)

**FINANCIAL STATEMENTS AND ANNUAL REPORT  
FOR THE YEAR ENDED 31 DECEMBER 2020**



# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **CONTENTS**

---

|                                                                                |                   |
|--------------------------------------------------------------------------------|-------------------|
| Reference and Administrative Details of the Charity, its Trustees and Advisers | <b>Page<br/>1</b> |
| Trustees Report                                                                | <b>2-25</b>       |
| Independent Auditor's Report                                                   | <b>26-28</b>      |
| Statement of Financial Activities                                              | <b>29</b>         |
| Balance Sheet                                                                  | <b>30</b>         |
| Cash Flow Statement                                                            | <b>31</b>         |
| Notes to the Financial Statements                                              | <b>32-41</b>      |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS

---

|                                                        |                                                                                                                                                                                                                                                                                                                                                       |
|--------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Company number</b>                                  | 08495711 (England and Wales)                                                                                                                                                                                                                                                                                                                          |
| <b>Charity number</b>                                  | 1155577 (England and Wales)                                                                                                                                                                                                                                                                                                                           |
| <b>Registered office</b>                               | International Alliance of Patients' Organizations<br>49-51 East Road<br>LONDON<br>N1 6AH                                                                                                                                                                                                                                                              |
| <b>Governing Board members<br/>(Board of Trustees)</b> | Ellos Ellard Lodzeni<br>Karen Alparce-Villanueva<br>Neda Milevska-Kostova<br>Sita Ratna Devi Duddi (Chair)<br>Ya Hsin Wang (Resigned 15 Dec 2020)<br>Carol Chinwe Nwosu (Resigned 10 April 2020)<br>Rosalia Liliana Tieri (Appointed 16 Dec 2020)<br>Orajitt Bumrungkulswat (Appointed 16 Dec 2020)<br>Adebisi Omolola Bright (Appointed 16 Dec 2020) |
| <b>Chief Executive</b>                                 | Kawaldip Sehmi                                                                                                                                                                                                                                                                                                                                        |
| <b>Bankers</b>                                         | NatWest Bank Plc<br>PO Box 12258<br>1 Prices Street<br>LONDON<br>EC2R 8BP                                                                                                                                                                                                                                                                             |
| <b>Lawyers</b>                                         | Bates Wells<br>10 Queen Street Place<br>LONDON<br>EC4R 1BE                                                                                                                                                                                                                                                                                            |
| <b>Independent auditor</b>                             | Knox Cropper LLP<br>65 Leadenhall Street<br>London<br>EC3A 2AD                                                                                                                                                                                                                                                                                        |
| <b>Website</b>                                         | <a href="http://www.iapo.org.uk">www.iapo.org.uk</a>                                                                                                                                                                                                                                                                                                  |

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

### ***FOR THE YEAR ENDED 31 DECEMBER 2020***

---

The directors, who are also the trustees of the charity, are pleased to present their report together with the financial statements of the charity for the year ended 31 December 2020 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

Results for the trading subsidiary, IAPO Trading Limited (Company Number 08863190) are not consolidated on the grounds that it was dormant and not material to the group.

The trustees have complied with the duty to have due regard to guidance issued by the Charity Commission and have adopted the Statement of Recommended Practice for charities (SORP) (FRS 102 second edition effective 1 January 2019).

#### **Aims and objectives of the organisation**

The objects of the International Alliance of Patients' Organizations (IAPO), as set out in the Memorandum and Articles of Association, are the promotion of the relief of sickness and preservation and protection of health for the public benefit through fostering patient-centred healthcare worldwide and in particular by developing the capacity of patients' organizations.

IAPO is a unique global alliance representing patients of all nationalities, across all disease areas, and promoting patient-centred healthcare around the world. IAPO brings a global patient voice to healthcare decision-making based on the belief that patients' voices are amplified and heard effectively when patients' organizations are linked, can share best practices and practical strategies, and are connected with resources. Our members are patients' organizations working at the international, regional, national and local levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability.

IAPO was first established in 1999 in the Netherlands as a Dutch Stichting and then de-registered in 2014 to be registered in England and Wales as a UK Charity and Company Limited by Guarantee on 30<sup>th</sup> January 2014. IAPO has a membership of nearly 300 organizations across 71 countries covering 51 diseases groups. IAPO is a non-State Actor in official relations with the World Health Organization (WHO) and has a memorandum of understanding with the International Council of Nurses (ICN), International Hospital Federation (IHF), International Pharmaceutical Federation (FIP), World Medical Association (WMA), International Society for Quality in Health Care (ISQua), The Professional Society for Health Economics and Outcomes Research (ISPOR) and The Union for International Cancer Control (UICC). and with many other non-State Actors.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2020**

---

### **IAPO's vision and mission**

IAPO's **vision** is that patients throughout the world are at the centre of healthcare.

IAPO's **mission** is to help build patient-centred healthcare worldwide by:

- Realizing active partnerships with patients' organizations, maximizing their impact through capacity building
- Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
- Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives

### **IAPO's activities include:**

- Advocacy at global level on relevant aspects of healthcare policy to influence international health agendas and policies
- Providing membership services, including capacity building and shared learning, to its members, who are patient-led organizations across the world
- Empowering its members to undertake their own advocacy at regional and national meetings
- Providing opportunities for stakeholders from across the health sector to meet and work together to advance patient involvement in health services and decision-making
- Research on emerging areas of interest to patients' organizations and to underpin the evidence base for showing the importance of patient involvement to public health.

### **Structure**

The organisation is a charitable company limited by guarantee, incorporated on 19 April 2013 and registered as a charity on 1 February 2014. The company was established under a Memorandum of Association which defined the objects and powers of the company. It is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

All assets and liabilities from the International Alliance of Patients Organizations and its predecessor not-for-profit structure registered in the Netherlands, were transferred to the new UK incorporated charity on 1 February 2014. IAPO Netherlands was (voluntarily) dissolved from the Netherlands Trade Register with effect from 31 May 2015, executed on 21 Oct 2015.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2020**

---

### **Appointment and Induction of Governing Board**

Every member of the IAPO Governing Board is elected by IAPO's members, through a process defined in the [Memorandum and Articles of Association](#), [By Laws](#) and [Election Code of Conduct](#) . Every year, in advance of the Annual General Meeting, the number of vacancies on the Board is notified to all members, who may then nominate someone from their organisations (a Board member or senior staff member) to IAPO's Governing Board. The full list of nominees is sent to all members in advance of the AGM; members may vote by post or proxy or in person at the AGM.

Governing Board members serve for a maximum of two terms of three years subject to the retirement by rotation clause; once their term of service is complete, they or anyone from their organization cannot be re-elected to the Board for at least a year. All new members of the Board receive induction including core information about the work and history of the organization, and conversations with the Chief Executive Officer and the Chair.

All Governing Board members sign a Code of Conduct when they are appointed to the Board. All staff and Governing Board members are required to complete a conflict-of-interest form at every Board meeting. The Governing Board have no beneficial interest in the charitable company or its trading subsidiary. No Governing Board member receives any remuneration for services as a trustee.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

### **FOR THE YEAR ENDED 31 DECEMBER 2020**

---

#### **Chair's Report Financial Year 1st January to 31 St December 2020**

The year 2020 has been like no other year in living memory. It clearly was like no other year in the entire 21-year history of the International Alliance of Patients Organizations. I would now like to pass on my condolences to all our members, stakeholders and their families who have lost loved ones to the COVID-19 pandemic. We are still not free from the pandemic as we are facing long-COVID and other sequelae of the disease today, not forgetting the disrupted healthcare services and collapsing healthcare systems.

2020 was a year that gave a wakeup call to the global patients' movement that our health systems are all vulnerable to not only national issues, but also global influences. We need to work together in national unity and global solidarity to ensure that we strengthen our global health governance and healthcare delivery systems and address the fault lines that appeared along the entire spectrum of our national healthcare services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course.

Some say that the pandemic was a mixed blessing as it really spurred the WHO Member States, regulators and the global pharmaceutical and biotechnology industry to look at global cooperation in innovative medicines and health device research and development. The raising of the issue of vaccine equity has made it important that all countries have an equitable access to innovative, safe, quality, acceptable and patient centred medicines, health devices and other medical products that they need without suffering financial hardship.

I particularly want to thank all our stakeholders who rallied around the global patient movements and IAPO, and joined us in guiding our member organisations and the world through the complex healthcare ecosystem created by the pandemic.

We firstly thank the World Health Organization and its Director General Dr Tedros Adhanom Ghebreyesus for stepping up in the best traditions of the WHO and providing leadership on this global and grave health matter. Dr Ghebreyesus began very early on in shaping the pandemic healthcare research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing the pandemic threat and trends as they rose. The WHO's fight against the misinformation and infodemic has helped our patient organisations a lot.

We also want to thank two other WHO scientists who supported IAPO in 2020. We firstly thank WHO's Chief Scientist Dr Soumya Swaminathan for having graciously accepted our invitation and addressed and reassured over 1500 patient delegates on the progress of the pandemic at our Global Patients Congress 2020. Dr. Swaminathan motivated us to work harder at improving health literacy and adopting of preventative measure like hand washing, face coverings and social distancing. She also reassured us that we shall overcome the difficult pandemic challenges we were facing through global solidarity.

Secondly, we want to thank Dr Neelam Dhingra, WHO Unit Head, Patient Safety Flagship Decade of Patient Safety 2020-2030. During the chaos of the pandemic, Dr Dhingra worked tirelessly in the best traditions of the WHO to support the World Health Assembly adopt WHA Resolution 72.6. This gifted us a day of our own, the World Patient Safety Day, and the Global Action Plan on Patient Safety Action Plan 2021-2030.

We thank the pharmaceutical industry, medicine and health device regulators, and health technology assessment bodies that worked seamlessly in global solidarity to give us innovative medicines and health devices to address the needs of the patients during the pandemic.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

### **FOR THE YEAR ENDED 31 DECEMBER 2020**

---

At our Global Patients Congress 2020, Thomas Cueni Director General of the International Federation of Pharmaceutical Manufacturers Association (IFPMA) and some of his members gave us great insight into vaccines development and the WHO Solidarity Trials that looked at repurposing of existing drugs to treat COVID-19, especially if they are already approved (for other indications) and have well established safety profiles. IAPO continues to enjoy close relationship with the International Drug Regulators Authority Conference and the European Medicines Agency and the FDA. The regulators have included us within their decision-making processes and have established good patient engagement framework for co-creation.

In 2020 IAPO has been very fortunate in its collaboration programmes through the Memorandums of Understanding and other collaborative relations we have established with International Society for Quality in Health Care (ISQua), The Professional Society for Health Economics and Outcomes Research (ISPOR) and The Union for International Cancer Control (UICC). I thank our partners for their input and direction given to us.

Lastly, I want to thank our healthcare industry partners who have supported us and our member organisations in this difficult challenging time through sponsorship, educational grants, and research projects. Without their support, we could not have reached the audience we have and made the impact we have in 2020.

This Report highlights who we addressed our strategy in 2020 over the three objectives:

1. Empower patient communities globally to advocate effectively for PC-UHC for all.
2. Drive research processes and the development of evidence base for PC-UHC.
3. Shape law, policy and practice in PC-UHC at global, regional and national levels

Our 2022-2024 Strategy was conceived during the pandemic in 2020 through collaboration with all our stakeholders and addresses the key need that we collaborate globally along the entire healthcare value chain to attain a Patient Centred (PC) and Pandemic Prepared (PP) Universal Health Coverage (UHC 2030).

The full 2020 strategy activity impact and the 2022-2024 strategy is listed on our website [www.iapo.org.uk](http://www.iapo.org.uk) and our social media handles <https://twitter.com/iapovoice?lang=en> and <https://www.facebook.com/IAPOvoice/>



Sita Ratna Devi Duddi  
Chair IAPO

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

### *FOR THE YEAR ENDED 31 DECEMBER 2020*

---

#### Governance

The International Alliance of Patients' Organizations has a Board of Trustees and Directors overseeing its governance and direction, supported by a secretariat headed by the Chief Executive Officer.

| BOARD OF TRUSTEES AND DIRECTORS   |              |                 |
|-----------------------------------|--------------|-----------------|
| Name                              | Position     | Country         |
| Dr. Ratna Devi                    | Chair        | India           |
| Dr. Neda Milevska-Kostova         | Vice-Chair   | North Macedonia |
| Mr. Ellos Ellard Lodzeni          | Treasurer    | Malawi          |
| Mrs. Karen Ida Alparce-Villanueva | Secretary    | Philippines     |
| Mrs. Rosalia Liliana Tieri        | Board Member | Argentina       |
| Mrs. Orajitt Bumrungkulswat       | Board Member | Thailand        |
| Mrs. Bisi Bright                  | Board Member | Nigeria         |

#### Report of Activities 1<sup>st</sup> Jan – 31 Dec 2020

In 2020, the second year of our 2019-2021 Strategic Plan, our vision remained to see patient-centred universal health coverage (PC -UHC) established in all countries, and our objective were to ensure that there is a sufficient availability of patient-centric, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each WHO Member State, along with essential and innovative medicines and health devices, which are accessible, acceptable and affordable, and delivered without the patients suffering financial hardship or discrimination. A summary of our achievements is available online

[https://www.iapo.org.uk/sites/default/files/files/IAPO\\_2020%20Highlights.pdf](https://www.iapo.org.uk/sites/default/files/files/IAPO_2020%20Highlights.pdf)

Further reports of the two congresses are also shared online:

Global Patients Congress:

[https://www.iapo.org.uk/sites/default/files/files/GPC%202020%20Report%20\(13\).pdf](https://www.iapo.org.uk/sites/default/files/files/GPC%202020%20Report%20(13).pdf)

Asia Pacific 2020: <https://www.iapo.org.uk/sites/default/files/files/APPC%202020%20report.pdf>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

### ***FOR THE YEAR ENDED 31 DECEMBER 2020***

---

#### **Our 2020 strategy was to:**

1. Empower patient communities globally to advocate effectively for patient-centred universal health coverage for all.
2. Drive research processes and the development of evidence base for patient-centred universal health coverage.
3. Shape law, policy, and practice in patient-centred universal health coverage at global, regional and national levels.

#### **Under our strategic plan IAPO achieved the following in 2020:**

#### **Shape law, policy, and practice in patient centred-universal health coverage at global, regional and national levels**

#### **IAPO's anniversary – 21 years of shaping our healthcare ecosystem**

IAPO was formed in 1999 as a response to developments in healthcare that were increasingly marginalising patients by restricting participation and engagement. IAPO wanted to put the patient back at the centre of all healthcare decision and policymaking. While we have surmounted most of the traditional barriers in healthcare during the past 21 years, the modern healthcare landscape has changed dramatically over the last decade. Rapid globalisation digitised and innovation within healthcare has created new challenges and barriers for us.

While 2020 was to celebrate the year in which IAPO came of age, the COVID-19 pandemic shook every patient organization and health system around the world. The pandemic disrupted all our plans to welcome our members to an amazing anniversary dinner at the National Museum of Scotland in their great exhibition hall, where great scientists like Charles Darwin had developed their scientific theories, and which housed Dolly the sheep (the first cloned animal). We had to curtail all celebrations acknowledging the great global mortality, morbidity and suffering.

In 2020, very early during the pandemic, we sadly lost our Board Member Carol Ossai to COVID-19 (RIP) who was a strong advocate for the improvement of care and treatment for people living with sickle cell diseases.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

To mark our 21<sup>st</sup> anniversary, IAPO and its Board and staff have developed a short video telling IAPO's story: <https://bit.ly/37Akolq>

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### IAPO collaboration with the World Health Organization

#### *73<sup>rd</sup> World Health Assembly*

IAPO participated in perhaps the most important World Health Assembly in the entire 72 years of the World Health Organization (WHO). WHA 73 was a single-issue assembly where all 194 Member States came together in national unity and global solidarity to address the COVID-19 pandemic. More than this, over 200 non-State Actors in official relationship with the WHO took particular care to submit statements as part of their interventions.

IAPO joined WHA 73 through the non-State Actor Office and submitted a comprehensive statement to Agenda Item 73.1 3 COVID-19 Response noting we were appalled to see how lockdowns without plans and lack of patient engagement resulted in great lapses of patient safety, breaches of human rights (police action) and loss of trust in health systems. Patient safety and health professional safety was compromised by lack of healthcare availability, access, acceptance and quality. We urged all WHO Member States to adopt a human rights-based approach to their public health measures. Full statement can read here: <https://bit.ly/3p9mMp6>

#### *WHO Regional Committees*

We participated virtually in the WHO Regional Committees:

- Regional Committee for the Western Pacific
- Regional Committee for Europe
- Regional Committee for Africa
- Regional Committee for South-East Asia
- Regional Committee for the Americas
- Regional Committee for the Eastern Mediterranean Region

#### *AMR Patient Alliance*

IAPO along with patient organizations from different regions and countries has developed a Global Patient Consensus Statement and a Call to Action, that aims to convene civil society groups representing patients, carers and advocates in a global AMR Patient Alliance, which was partly launched in December. The AMR Patient Alliance will be a place where patients can exchange views, be educated, and acquire knowledge and resources that we need to raise awareness about the importance of sustaining the efficacy of antibiotics - for as long as possible, for as many patients as possible. Learn more about the Alliance here: <https://bit.ly/3nE4GLF>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### Fight the Fakes Alliance

IAPO is a founding member of the new Fight the Fakes (FTF) Alliance, a new multi-stakeholder non-profit association registered in Geneva (Switzerland), set up to fight against falsified medicines. Seven years since its first activities as a grass root advocacy campaign, the new formal governance structure will allow the FTF Alliance to take the fight against substandard and falsified medicines to the next level. With over 15 members representing health care professionals, manufacturers, wholesalers, researchers and patients, the Alliance is uniquely positioned to scale up action to prevent falsified medicines from endangering people's health and well-being. More information on this:

<https://bit.ly/2Jc0a8c>

### 10th Asia Regulatory Conference

Ratna Devi, IAPO Chair, participated in the panel discussion 'Patients Perspectives on Regulatory Reliance and Why Patient Engagement is Important'. In order to secure early access to innovative quality and safe medications, it is important that market authorization process is streamlined across Asia. Regulatory Reliance is a process through which national medicines regulatory authorities cooperate and streamline market authorization processes.

### Campaign to ratify the African Medicines Agency Treaty

Two years after we issued our Entebbe Statement on the African Medicines Agency (AMA) in 2017, we had hoped we would have AMA set up by 2019. This has not happened. The IAPO campaign explores the benefits of establishing the African Medicines Agency and what is preventing the signing and ratification of the Treaty to establish the AMA. In partnership with African organizations, WHO and the International Federation of Pharmaceutical and Manufacturers Association, IAPO began the campaign to address this at the Geneva Health Forum. You can watch the session via this link: <https://bit.ly/2J8hLxI>

AMA's main objectives are improving access to safe and affordable medicines, boosting local manufacturing, and taking concerted action to tackle substandard and falsified medicines. It will also help to support the growth of local pharmaceutical companies and drug manufacturing, one of the key aims of the Pharmaceutical Manufacturing Plan for Africa and the Africa Continental Free Trade Area. If it was not a priority before, then with the COVID-19 pandemic, there can be no other priority but AMA to ensure safe vaccines, biotherapeutics and repurposed medicines from WHO.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

**Empower patient communities globally to advocate effectively for patient centred-universal health coverage for all**

### 9th Global Patients Congress

The 9th Global Patients Congress (GPC 2020) held on 16-17 September 2020 was one of the most critical congresses in our 21-year history. Holding a patients congress in the middle of a pandemic was very important to raise the patient voice in all the public health decision-making taking place globally. It was also key that we showed global solidarity with all the stakeholders engaged in controlling and hopefully eliminating COVID-19. The Congress was unique as it invited top scientists, policy makers, and Non-State Actors to speak to our members.

The Congress was also important because it was marking the 2<sup>nd</sup> World Patient Safety Day on 17 September when patient harm and health professional safety had become one urgent and critical issue during the COVID-19 pandemic in all of our health systems. WHO and we concurred that the theme 2020 had to be 'Health Worker Safety, a Priority for Patient Safety'.

GPC 2020 was IAPO's first fully digital congress with a record number of 1300 registered delegates from 101 countries with 338 patient groups, who attended 26 sessions with 64 speakers from 28 countries. The full summary of the Congress was for the first time published in the BMJ:

<https://bit.ly/3mxF9Cs>

The Congress issued a strong call to action urging WHO Member States to urgently engage expert patients in their structures, processes and decisions in co-creating patient-centred public health and shielding programmes. The full statement can be read here: <https://bit.ly/3mB8v2H>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### *IAPO Member participation in GPC 2020*

IAPO Members were invited to showcase their best COVID-19 activities and achievements in supporting their patient communities. IAPO for the first time provided over USD\$ 15,000 in special grants for those organizations who have merited support for their work in this critical phase: Uganda Alliance of Patients' Organizations - UAPO (Uganda), Epilepsy Support Association Uganda (Uganda), Sharecare Ghana (Ghana), Patient and Community Welfare Foundation of Malawi - PAWEM (Malawi), Save Liver - SLAP (North Macedonia), Action Group for Health Human Rights and HIV/AIDS - AGHA (Uganda), Consumer Online Foundation (India) and National Community of Women Living with HIV in Uganda – NACWOLA (Uganda). You can learn more about the deserving awardee organizations here:

<https://bit.ly/38j3wPe>

Also for the first time, IAPO engaged our film-makers to record for posterity what challenges some of our members were facing during the COVID-19 pandemic. This was facilitated by GiJong An from the Korean Alliance of Patient Organizations, who have instituted the Patient Shouting Café, a very important methodology of engaging patients, their healthcare systems, journalists and regulatory agencies in addressing patient harm, patient safety and patient experience issues. You can see how the Patient Shouting Café works in practice here: <https://bit.ly/2Ko6jPb>

### *2nd Asia Pacific Patients Congress*

The 2nd Asia Pacific Patients Congress was held as IAPO's second fully digital congress on 3-4 December 2020 with over 3000 registered from 66 countries with 298 patient groups, who attended 20 sessions with 66 speakers from 16 countries. The Congress aimed at bringing together patient experts and health stakeholders including researchers, nurses, health financiers, regulators, health service providers and pharmaceutical industry representatives to map out how we can all harmonise and align our agendas with national health policies and plans on Universal Health Coverage in the region.

To learn more about the Congress, please visit: <https://bit.ly/3axRPGX>. To view the session recordings, register for free and access the auditorium via this link: <https://bit.ly/3pdz3sQ>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### *COVID-19 activities*

#### *IAPO COVID-19 statement*

IAPO released an official statement on COVID-19 in April posted on our newsletter, website and on all social media platforms. The statement called for a new COVID-19 Patient Engagement Collaborative Framework that puts patient experts at the heart of all COVID-19 related responses and measures: <https://bit.ly/2KHaTYL>

#### *IAPO's COVID-19 resources hub*

To support our members, partners and the grater global health community working to bring this outbreak to a close, we created a web page on IAPO's website to support the distribution of expert and relevant information and share best practices as part of our responsibility as a coordination and cooperation organization: <https://bit.ly/2WBJoCx>

The hub has been the most visited page on our website with over 327 people sharing it on various social media platform. The initiatives on this page have also been shared on our newsletter and social media accounts. We are continually mapping relevant information and updates as it is published for inclusion on the page.

#### *IAPO Members' response to COVID-19*

We created a web page on the IAPO website to showcase a summary of IAPO members' response activities to fight the COVID-19 pandemic and support patients worldwide: <https://bit.ly/2KmYQQg>

#### *IAPO Member Stories on COVID-19*

This is an article series where IAPO members shared their stories on how the pandemic is impacting their work as well as their efforts to continue supporting patients during the pandemic. The series was promoted on IAPO's monthly newsletter and is available on the IAPO website here: <https://bit.ly/3rhmUon>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### *WHO Information Network for Epidemics (EPI-WIN)*

IAPO supported the WHO in fighting the COVID-19 infodemic through being part of the newly formed WHO Information Network for Epidemics (EPI-WIN). The forum exists with the aim of using a series of amplifiers to share timely, accurate and relevant information to all.

### *Stakeholder engagement with partners*

#### *Upjohn (now Viatris)*

Twinning programme on stroke in Asia: IAPO developed a twinning programme on stroke in Low- and Middle-Income countries (LMIC) located in the Asia-Pacific region, Middle East and Latin America.

Survey of patient experience of non-communicable diseases (NCDs) and COVID-19: This survey is a joint proposal with NIHI (National Institute of Health and innovation, Auckland, FIP (International Pharmaceutical Federation), WONCA, and IAPO, where our members in LMICs helped collect data from patients and caregivers to understand the true impact of the pandemic on NCD care.

### *Voices of Safety - World Patient Safety Day 2020 storytelling campaign*

In partnership with BD, IAPO scoped patient stories for our joint storytelling campaign on patients' experiences related to healthcare systems safety to mark World Patient Safety Day 2020 on 17 September. You can watch the campaign videos here: <https://bit.ly/3h87azn>

### *Union for International Cancer Control (UICC)*

IAPO joined UICC and its over 1200 members from more than 170 countries. UICC is the world's leading international cancer organization. UICC's activities are shaped by the World Cancer Declaration which sets out a framework to help reduce the global cancer burden by 2025, including through the adoption of the 2017 Cancer Resolution.

### *Global Self-Care Federation*

IAPO worked with the Global Self-Care Federation to launch their Self-Care Readiness Index Consumer Survey among our network through our newsletter, website and social media. We have also marked the International Self-Care Day on 24th July in collaboration.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### *Global Coalition for Circulatory Health (GCCH)*

We collaborated with GCCH through the COVID-19 webinars series in collaboration with the International Council of Nurses, World Organization of Family Doctors, World Federation of Public Health Associations and WHO. Under the theme 'Joining forces to fight COVID in people with circulatory conditions', IAPO represented the patient view on circulatory risk factors and outcomes associated with COVID-19.

### *Antimicrobial Resistance Patient Advocacy Group*

Health First Europe launched the first European patients' advocacy group on AMR, which aims to raise awareness about antimicrobial resistance and to help reduce antibiotic misuse in Europe. The AMR patient advocacy group includes several national patient associations from across Europe, including IAPO members Fondazione The Bridge (Italy), Save Liver Association for Patients – SLAP (Macedonia), Pelvic Pain Support Network (EU), Malta Health Network (Malta) and The Patients Association (UK).

### *International Federation of Psoriasis Associations (IFPA)*

As part of IFPA's webinar series in 2020, Kawaldip Sehmi, IAPO CEO, spoke at a webinar in October about IAPO's role in the resolution on Global Action on Patient Safety and how other patient associations can use it in their work.

### *Fondazione The Bridge (FTB)*

Kawaldip Sehmi, IAPO CEO, wrote an article for the FTB newsletter in June about the importance of working in a network and how to manage the dialogue between patient associations. Read the article here: <https://bit.ly/2Kln4L0>

### *Global Alliance of Sickle Cell Disease Organisations (GASCO)*

We had a collaborative meeting with GASCO to rethink healthcare system strengthening to reduce the burden of sickle cell disease in underserved populations. This will be followed up in 2021.

### *IAPO Members survey*

IAPO conducted a survey to help identify ways of strengthening collaboration among IAPO members' network and ensure we prioritise our resources and continue to respond to our member organizations' priorities and needs throughout and beyond the pandemic. Results to be launched in 2021.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### Communications

**Newsletter:** Our monthly newsletter reaches out to over 5900 subscribers and has covered the COVID-19 pandemic news and information. It was very inspiring to see that over 30 patient organizations submit high quality articles on various aspects of healthcare globally, especially on how COVID-19 affected them. We are encouraging more patient organizations to submit articles for 2021.

**Twitter:** [@IAPOvoice](#) and [@PatientSolidarityDay](#)

**Facebook:** We operate [IAPOvoice](#), [International Alliance of Patients' Organizations](#), [African page](#) and [PatientSolidarity Day](#)

**Website:** Continues to be the main focal point for IAPO's dissemination and communications activities. We have seen an increase in number of page views: with over 100,000 page views in 2020 compared to 92,154 in 2019. [www.iapo.org.uk](http://www.iapo.org.uk)

### **Drive research processes and development of evidence base for patient centred-universal health coverage**

#### IAPO Scientific Advisory Board

IAPO has set up a new Scientific Advisory Board to support the organization in its scientific programme in ensuring that patients have access to quality safe and evidence based healthcare. The inaugural Scientific Board and its membership can be found here: <https://bit.ly/38scZ6L>

#### Metrodora Award – recognising outstanding women achievers in science and health

IAPO in partnership with Pfizer Upjohn (now Viatris) and the Patient Academy for Innovation and Research (PAIR) introduced the first international Metrodora Awards to empower and recognize women leaders who are delivering positive changes in the care and management of non-communicable diseases (NCDs).

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

Metrodora was a Greek physician who lived between 200 to 400 CE and wrote the first known medical text to be authored by a woman. By studying and working on all aspects of women's health, she defied traditional gender roles during a time when women physicians were limited mainly to childbirth and obstetrics. Among many innovations, she pioneered surgical treatments for breast and uterine cancers – a legacy that has influenced throughout history.

IAPO, for the first time, undertook a consultation with patient organizations to nominate women scientists who patients thought were most deserving. IAPO in acknowledging and thanking these scientists awarded them over USD\$ 15,000 in honorariums. 2020 winners can be seen here:

<https://bit.ly/2KKNZzH>

### IAPO Patients for Patient Safety Observatory

IAPO has established the IAPO Patient for Patient Safety Observatory (P4PS Observatory), a single-point global platform for gathering and analysing patients' expertise and experience that would feed into the national, regional and global policies aimed at improving safety and quality of care for patients and by the patients.

The reason why P4PS Observatory was formed was because patient harm has become a great public health problem, and it now requires expert patient oversight and co-creation. In order to do this, the P4PS Observatory will put patient led research into practice, and patient experience back into research. Patient harm not only causes great suffering, injury and death, it also erodes public trust in healthcare systems and costs billions of USD to address compensation and fines. The WHO Director General in his report and Resolution WHA 72.6 May 2019 Global Action on Patient Safety has asked every WHO Member State to produce plans to implement this resolution in the global consultation WHO Flagship "A Decade of Patient Safety 2020-2030": <https://bit.ly/2KFN1Vg>

### Patient Academy in Innovation and Research (PAIR) collaboration Asia-Pacific

IAPO is participating in the Asia-Pacific region to improve the quality of patient advocacy. The Patient Academy for Innovation and Research is set-up to develop and maintain capacity amongst patients across the globe, in an effort to enable them to engage with their health-systems in a more meaningful and strategic manner. Thus better equipping them to care for themselves and others, by framing their experience with an evidence-based expertise and share with other patients who suffer from the same or similar conditions and diseases. Learn more about PAIR here: <https://bit.ly/3nzYr02>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### ISPOR - The Professional Society for Health Economics and Outcomes Research

Ratna Devi, IAPO Chair was part of the Program Committee of the virtual ISPOR Asia Pacific 2020, themed 'Next Generation Healthcare in Asia Pacific: Where Technology Meets Patients to Improve Care'. The event offered a robust scientific program focused on in-depth studies of the current state of Health economics and outcomes research in the region. Healthcare is being transformed rapidly and dynamically with the rise of cutting-edge technologies that are providing patients with life-changing or curative benefit.

### ISQUA – United to preserve antimicrobials - A joint call for action

Along with the International Hospital Federation, the International Society for Quality in Health Care, and the International Federation of Pharmaceutical Manufacturers and Associations we issued a joint statement calling for antibiotic stewardship and preservation. The statement also calls for the development of more innovative partnerships of healthcare providers, patients and the business sector to tackle the growing AMR threat while improving healthcare safety and quality worldwide.

### Research Papers Published in 2020

- Cancer medicine: a missed opportunity: <https://bit.ly/3nJK3xB>
- A narrative review of the patient journey through the lens of non-communicable diseases in low- and middle-income countries: <https://bit.ly/3rfUvPA>
- Systemic solutions for addressing non-communicable diseases in low- and middle-income countries: <http://bit.ly/3pfdqgh>
- A patient's wish - hospitals that care: <https://bit.ly/3mJvfxE>
- Role of active patient involvement in undergraduate medical education: a systematic review: <https://bit.ly/34yQz2x>
- Mapping the patient journey towards actionable beyond the pill solutions for non-communicable diseases: <https://bit.ly/38usBXq>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

---

### IAPO Membership in 2020

IAPO consolidated its membership in 2020 and sought new members covering rare diseases and non-communicable diseases. IAPO had 289 members at 31<sup>st</sup> December 2020. IAPO is now also actively seeking more members from WHO Eastern Mediterranean Region, South East Asia and the Western Pacific that are under-represented.

| Region                        | %           |
|-------------------------------|-------------|
| African members               | 15%         |
| Eastern Mediterranean members | 4%          |
| European members              | 35%         |
| Latin American members        | 25%         |
| North American members        | 8%          |
| South East Asian member       | 4%          |
| Western Pacific members       | 9%          |
| <b>TOTAL</b>                  | <b>100%</b> |

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

***FOR THE YEAR ENDED 31 DECEMBER 2020***

---

### **IAPO funding transparency**

The Governing Board members declare interests and sign conflict of interest register at the start of each Board meeting. The register is maintained with any changes between meetings.

Reference to IAPO's Code of conduct and policy regulating IAPO's relationship with, and independence from, sponsors can be found at: [www.iapo.org.uk/consensus-framework-ethical-collaboration](http://www.iapo.org.uk/consensus-framework-ethical-collaboration) and [www.iapo.org.uk/healthcare-industry-partners](http://www.iapo.org.uk/healthcare-industry-partners).

The overall proportion of industry to non-industry income for the year was approximately 93%.

### **Public benefit**

In setting our objectives and planning our activities trustees have given consideration to the Charity Commission's general guidance on public benefit (PB1, PB2 and PB3) and have taken these into account in making all decisions. We have not departed from the guidance in 2020.

IAPO objects are the promotion of the relief of sickness and the preservation and protection of health for the public benefit. IAPO pursues this through fostering patient-centred healthcare worldwide and, in particular, by developing the capacity of patients' organisations.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

### ***FOR THE YEAR ENDED 31 DECEMBER 2020***

---

IAPO's services are open to all people and our membership reflects a diverse group of patients' organisations representing patients with communicable and non-communicable diseases, including patients with diseases that are stigmatised in many societies.

IAPO had 289 members comprising umbrella groups and single organisations in 2020 who directly represented views of over 1 million patients in 71 countries across 52 disease areas. The services the charity provides are designed to build the capacity of patients' organisations, allowing them to better assist the needs of patients and carers (and their own member patient organisations in some cases) from across the world.

Access to IAPO's website is freely available to the public. Currently it is in English, with some sections in Spanish. The website contains a wide range of information on IAPO's activities and on patient-centred healthcare, which is of benefit to the public, particularly those who wish to set up local patients' organisations.

By improving access to information, training and other capacity building programmes for patients and their representative organizations, IAPO improves access to healthcare itself. By raising awareness and through capacity building and education of health care providers, we increase access to acceptable services that respect patients' preferences, values, rights and needs.

IAPO has a wealth of evidence, gained from patients' organizations worldwide, which demonstrates that patient involvement in patients' care leads to better health outcomes and lower costs for the whole of society. The charity works with patients' organizations that are not for profit and non-government organisations who demonstrate commitment to improving patient-centred healthcare which is reflected in the charity's membership criteria.

#### **Risk Management**

A risk register is prepared by the CEO and presented annually to the Board to discuss ensuring that there are effective and adequate risk management and internal control systems in place to manage the major risks to which the Charity is exposed. IAPO prepares the risk register by understanding the risk environment of IAPO and its operations and then identifies the key risks. The CEO and the Treasurer then undertake a thorough analysis and evaluation of the risks identified before coming up with a treatment for the risks.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

### ***FOR THE YEAR ENDED 31 DECEMBER 2020***

---

Risks are identified under headings of Financial, Funding, Governance, Operational and Personnel. These are then quantified using a Likelihood/Impact matrix, and mitigation actions detailed. Discussions are underway with the Audit Committee to ensure that the risks are appraised regularly before each board meeting to assess IAPO's risk profile.

IAPO is undertaking a new fundraising strategy to reduce reliance upon the pharmaceutical companies. IAPO will diversify its funding by approaching international trust funds, international development agencies and large programmes to raise non-industry partner funding.

#### **Financial review**

Incoming resources for the year amounted to £509,091(2019: £343,855), which was higher than the previous year as we held two congress.

Expenditure in 2020 was £436,449 (2019: £366,886). Expenditure is also higher than the previous year, in line with the fact that we held two congress.

#### **Reserves Policy**

The IAPO Board approved a Reserves Policy in September 2014, with a target level of free reserves of 6-12 months' running costs for 6 months. This policy was set with due regard to guidance from Charity Commission (CC19 – Charity Reserves) and is reviewed annually.

The level of unrestricted reserves, as at 31<sup>st</sup> December 2020 is £137,648. This is below the target in the reserves policy, and will be reviewed by the Board of Trustees.

#### **Going Concern**

The trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. As they have considered the impact of the COVID-19 pandemic on both its income and expenditure for at least a period of twelve months from the date of approval of these financial statements and are expecting to make a surplus in 2021.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2020**

---

### **Pension arrangements**

With auto-enrolment legislation coming into force in Autumn 2017, we set up an Occupational Pension Scheme.

IAPO also operates a policy of contributions directly into staff members' chosen personal pension schemes, with no obligation for staff to make personal contributions. The issue of pension deficit, which would apply to an occupational scheme, does not therefore arise.

### **Pay and remuneration of senior management**

IAPO has a team of research officers and volunteers led by a Chief Executive.

### **Future Activities**

IAPO's plan of activities for 2021 are listed at:

[https://www.iapo.org.uk/sites/default/files/files/IAPO\\_Planned%20Activities%20in%202021.pdf](https://www.iapo.org.uk/sites/default/files/files/IAPO_Planned%20Activities%20in%202021.pdf)

IAPO's Strategy for 2022-2024 is listed at:

<https://www.iapo.org.uk/sites/default/files/files/IAPO%20Strategy%202022-2024%20Draft.pdf>

Our vision, mission and tactical plans are adapted to build back better a patient centred, pandemic prepared universal health coverage 2030.

- **VISION 2022-24**
  - To ensure through global solidarity and national action that every patient enjoys healthcare that is:
    - Patient centred (PC) (broader definition)
    - Pandemic prepared (PP)
    - A Universal Health Coverage (UHC)
- **MISSION 2022-24**
  - Empower our members with cutting edge knowledge and advocacy skills in bringing about PC & PP UHC 2030.
  - Work with our membership, alliances, partners, and other stakeholders to drive research and policy development activity that establishes the evidence base needed in support of PC & PP UHC 2030 and strengthen patient involvement and co-creation in research.
  - Motivate the empowered patient community into using the evidence base created to shape the institutional, law, policy, practice, and standards framework needed for PC & PP UHC 2030 at global, regional (APEC, AU and EU etc) and national levels.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## TRUSTEES' REPORT

**FOR THE YEAR ENDED 31 DECEMBER 2020**

---

- **TACTICAL PLAN 2022-24**

- To attain PC (Broader Definition) and PP UHC 2030 it is important that IAPO advocates the delivery of:
  - Safe Healthcare
  - Quality Healthcare
  - Accessible Healthcare. Access is across four areas.
  - Non-Discriminatory Healthcare
  - Physically Accessible Healthcare
  - Information Accessibility
  - Affordable Healthcare
  - Acceptable Healthcare: Culturally Competent and Patient Centred (Broader Definition)

In addition to the above, IAPO is collaborating closely in the WHO Work Plan 13 and ensuring that the WHO flagship Global Patient Safety Action Plan 2021-2030 is translated and implemented into national patient safety institutional, legislative, policy, practice and standards through patient and family engagement and cocreation/coproduction.

### **Statement of Trustees' responsibilities**

The Trustees are responsible for preparing the financial statements for each financial period which give a true and fair view of the state of affairs of the company and of the deficit or surplus of the company for that period. In preparing those financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping proper accounting records, which disclose with reasonable accuracy at any time, the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **TRUSTEES' REPORT**

***FOR THE YEAR ENDED 31 DECEMBER 2020***

---

### **Statement as to disclosure to our auditors**

In so far as the trustees are aware at the date of approving this report:-

- there is no relevant audit information, being information needed by the auditor in connection with preparing their report, of which the charity's auditor is unaware; and
- the trustees having made enquiries of fellow directors and the group's auditor that they ought to have individually taken, have each taken all steps that he/she is obliged to take as a director in order to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

### **Reappointment of auditors**

A proposal to reappoint Knox Cropper as the charity's statutory auditors will be put to members at our forthcoming Annual General Meeting.

Approved and authorised for issue by the Board of Trustees on 13<sup>th</sup> December 2021 and signed on their behalf by:-



Sita Ratna Devi Duddi

Chair of the Board

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

---

### Opinion

We have audited the financial statements of International Alliance of Patients' Organization for the year ended 31 December 2020 which comprise the Statement of Financial Activities (including the Income and Expenditure Account), the Balance Sheet and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2020 and of its income and expenditure, for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

### Other information

The other information comprises the information included in the Trustees' Report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

---

### Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report, which includes the directors' report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report, included within the Trustees' Report, has been prepared in accordance with applicable legal requirements.

### Matters on which we are Required to Report by Exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or
- Certain disclosures of Trustees' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit; or
- The trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Trustees' Report.

### Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

### Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- The Charitable Company is required to comply with both company law and charity law and, based on our knowledge of its activities, we identified that the legal requirement to accurately account for restricted funds was of key significance.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2020

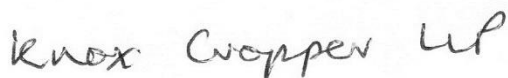
---

- We gained an understanding of how the charitable company complied with its legal and regulatory framework, including the requirement to properly account for restricted funds, through discussions with management and a review of the documented policies, procedures and controls.
- The audit team, which is experienced in the audit of charities, considered the charitable company's susceptibility to material misstatement and how fraud may occur. Our considerations included the risk of management override.
- Our approach was to check that all restricted income was properly identified and separately accounted for and to ensure that only valid and appropriate expenditure was charged to restricted funds. This included reviewing journal adjustments and unusual transactions.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: <https://www.frc.org.uk/auditorsresponsibilities>. This description forms part of our auditor's report.

### Use of our report

This report is made solely to the charitable company's trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



15 December 2021

Simon Goodridge (Senior Statutory Auditor)  
For and on behalf of Knox Cropper LLP (Statutory Auditor)  
65 Leadenhall Street  
London  
EC3A 2AD

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 DECEMBER 2020

|                                                 | Notes | Unrestricted<br>£ | Designated<br>£ | Restricted<br>£ | Total<br>2020<br>£ | Total<br>2019<br>£ |
|-------------------------------------------------|-------|-------------------|-----------------|-----------------|--------------------|--------------------|
| <b>Income from charitable activities:</b>       |       |                   |                 |                 |                    |                    |
| Membership                                      |       | 127               | -               | -               | 127                | 8,569              |
| Healthcare Industry Partners                    |       | 118,808           | -               | -               | 118,808            | 195,186            |
| APPC congress                                   |       |                   | 44,209          |                 | 44,209             | 130,755            |
| GPC congress                                    |       |                   | 270,421         |                 | 270,421            | -                  |
| Special Projects                                |       |                   |                 | 68,556          | 68,556             | 4,611              |
| Other charitable activities                     |       | 6,970             |                 |                 | 6,970              | 4,734              |
| <b>Total</b>                                    | 2     | <b>125,905</b>    | <b>314,630</b>  | <b>68,556</b>   | <b>509,091</b>     | <b>343,855</b>     |
| <b>Expenditure on charitable Activities:</b>    |       |                   |                 |                 |                    |                    |
| Charitable activities:-                         |       |                   |                 |                 |                    |                    |
| • Capacity building, advocacy and collaboration |       | 181,572           | -               | -               | 181,572            | 273,409            |
| • Asia Pacific Patients Congress                |       | -                 | 38,889          | -               | 38,889             | 93,477             |
| • Global Pacific Patients Congress              |       |                   | 154,369         |                 | 154,369            |                    |
| • Special projects                              |       | -                 | -               | 61,619          | 61,619             | -                  |
| <b>Total</b>                                    | 3     | <b>181,572</b>    | <b>193,258</b>  | <b>61,619</b>   | <b>436,449</b>     | <b>366,886</b>     |
| <b>Net income/ (expenditure)</b>                |       | <b>(55,667)</b>   | <b>121,372</b>  | <b>6,937</b>    | <b>72,642</b>      | <b>(23,031)</b>    |
| Transfers                                       |       | 196,625           | (196,625)       | -               | -                  | -                  |
| <b>Net movement in funds</b>                    |       | <b>140,958</b>    | <b>(75,253)</b> | <b>6,937</b>    | <b>72,642</b>      | <b>(23,031)</b>    |
| <b>Reconciliation of funds:</b>                 |       |                   |                 |                 |                    |                    |
| Funds brought forward                           |       | (3,31)            | 89,771          | 80,105          | 166,565            | 189,596            |
| <b>Total funds carried forward</b>              |       | <b>137,647</b>    | <b>14,518</b>   | <b>87,042</b>   | <b>239,207</b>     | <b>166,565</b>     |

All transactions are derived from continuing activities.

All recognised gains and losses are included in the Statement of Financial Activities.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## BALANCE SHEET AS AT 31 DECEMBER 2020

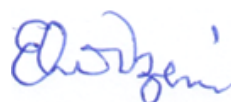
|                                                       | Notes | 2020<br>£      | 2019<br>£      |
|-------------------------------------------------------|-------|----------------|----------------|
| <b>Fixed assets</b>                                   | 6     | 200            | 299            |
| <b>Current assets</b>                                 |       |                |                |
| Debtors                                               | 7     | 127,992        | 151,586        |
| Cash in hand and in bank                              |       | 227,316        | 88,702         |
|                                                       |       | <u>355,308</u> | <u>240,288</u> |
| <b>Creditors: amounts falling due within one year</b> | 8     | (116,301)      | (74,022)       |
|                                                       |       | <u>239,007</u> | <u>166,266</u> |
| <b>Net current assets</b>                             |       |                |                |
|                                                       |       | <u>239,007</u> | <u>166,266</u> |
| <b>Net assets</b>                                     |       | <b>239,207</b> | <b>166,565</b> |
|                                                       |       | <u>239,207</u> | <u>166,565</u> |
| <b>Funds</b>                                          |       |                |                |
| Unrestricted Funds                                    |       | 137,647        | (3,311)        |
| Designated Funds                                      |       | 14,518         | 89,771         |
| Restricted Funds                                      |       | 87,042         | 80,105         |
|                                                       |       | <u>239,207</u> | <u>166,565</u> |
| <b>Total Funds</b>                                    | 10    | <b>239,207</b> | <b>166,565</b> |
|                                                       |       | <u>239,207</u> | <u>166,565</u> |

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies.

These financial statements were approved and authorised for issue by the Board of Trustees on 13<sup>th</sup> December 2021 and signed on their behalf by:-



Sita Ratna Devi Duddi  
Chair



Ellos Ellard Lodzeni  
Treasurer

Registered company number: 08495711 (England and Wales)

The notes on pages 32 to 41 form part of these financial statements

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## CASH FLOW STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2020

|                                                                           |       | 2020    | 2019      |
|---------------------------------------------------------------------------|-------|---------|-----------|
|                                                                           | Notes | £       | £         |
| <b>Cash flows from operating activities:</b>                              |       |         |           |
| Cash generated from operations                                            | 1     | 138,614 | (112,766) |
| <b>Net cash provided by operating activities</b>                          |       | 138,614 | (112,766) |
| <b>Change in cash and cash equivalents in the reporting period</b>        |       | 138,614 | (112,766) |
| <b>Cash and cash equivalents at the beginning of the reporting period</b> |       | 88,702  | 201,468   |
| <b>Cash and cash equivalents at the end of the reporting period</b>       |       | 227,316 | 88,702    |

### 1. RECONCILIATION OF NET INCOME/(EXPENDITURE) TO NET CASH FLOW FROM OPERATING ACTIVITIES

|                                                                                                         | 2020    | 2019      |
|---------------------------------------------------------------------------------------------------------|---------|-----------|
|                                                                                                         | £       | £         |
| <b>Net income/(expenditure) for the reporting period (as per the statement of financial activities)</b> | 72,642  | (23,031)  |
| <b>Adjustments for:</b>                                                                                 |         |           |
| Depreciation Charges                                                                                    | 99      | 146       |
| Decrease/(Increase) in debtors                                                                          | 23,594  | (80,665)  |
| Increase/(Decrease) in creditors                                                                        | 42,279  | (9,216)   |
| <b>Net cash provided by operating activities</b>                                                        | 138,614 | (112,766) |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

---

### 1 Accounting Policies

#### 1.1 Accounting convention

The financial statements of the charitable company, which is a public benefit entity under FRS102, have been prepared in accordance with the 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (SORP) (FRS102 second edition - effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

The financial statements are presented in Sterling (£).

Results for the trading subsidiary, IAPO Trading Limited (Company Number 08863190) are not consolidated on the grounds that it was dormant and not material to the group.

#### Statement on going concern

After reviewing the charity's forecasts and projections, the directors have reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. The charity therefore continues to adopt the going concern basis in preparing its financial statements.

As they have considered the impact of the COVID-19 pandemic on both its income and expenditure for at least a period of twelve months from the date of approval of these financial statements and are expecting to make a surplus in 2021.

#### 1.2 Company status

The parent charity is a company limited by guarantee. The directors of the company are the trustees named on page 1. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity.

#### 1.3 Incoming resources

All incoming resources are included in the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable certainty.

Healthcare Industry Partners: IAPO's Industry Partners are companies, foundations and associations who commit to providing various levels of unrestricted financial support each year, contributing to IAPO's core costs. IAPO's Partners Framework provides a framework for IAPO and industry stakeholders to interact and collaborate in a transparent and accountable way. BMS, Merck EMD Serano and GSK were core partners.

Restricted Project: Pfizer UpJohn Metrodora Awards to honour women scientists (\$58,000) , Pfizer Upjohn Stroke Twinning Project and Study (\$30,000)

Designated Events and Congresses in 2020 were the Global Patients Congress 16<sup>th</sup>-17<sup>th</sup> September 2020 and the 2<sup>nd</sup> Asia Pacific Patients Congress 3<sup>rd</sup>-4<sup>th</sup> December 2020. The Global Patients Congress had nine partners. The Asia Pacific Congress had four partners.

Asia Pacific Patient Congress 2020: The 2020 conference took place in Taipei. Congress income includes grants, sponsorship and delegate registration fees, all of which are recognised in the accounting year in which the event took place. Further information about the Congress including details of sponsors and supporters is available on our website.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

---

GetReal: IAPO is a partner in GetReal, a three-year collaborative European Project exploring how real world research data can be used in the development of drugs, to increase effectiveness and enrich decision-making by regulatory authorities and health technology assessment (HTA) agencies.

IMI Prefer: IAPO is a partner in researching, developing and advocating that patient preferences should be included in decision-making

Other Income: Other income includes "In Kind" support and briefing paper sales, which includes financial support and reimbursement provided to IAPO to attend conferences and meetings around the world.

### 1.4 Expenditure

All expenditure is included on an accruals basis and is inclusive of all VAT, which cannot be reclaimed, and is reported as part of the expenditure to which it relates:

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.
- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.
- All costs are allocated between expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, other costs are apportioned on the basis staff time incurred.

The core elements of charitable expenditure are as follows:-

Capacity Building: Realising active partnerships with patients' organizations, maximising their impact through capacity building.

Advocacy: Advocating internationally with a strong patients' voice on the relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies.

Collaboration: Building cross-sector alliance and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives.

### 1.5 Funds

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Restricted funds are funds, which are to be used in accordance with specific restrictions imposed by the donor. The aim and use of the restricted fund is set out in the notes of the financial statements.

### 1.6 Tangible fixed assets and depreciation

Capital expenditure on items costing £1,000 or higher are recorded as tangible fixed assets. Tangible fixed assets are stated at historical cost less depreciation.

Depreciation is provided to reflect the useful estimated economic life of computer equipment assets at a rate of 33% per annum (reducing balance method).

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

### 2 Incoming resources

|                                 | Charitable<br>Activities &<br>Others | Healthcare<br>Industry<br>Partners | Projects       | Total<br>2020         |
|---------------------------------|--------------------------------------|------------------------------------|----------------|-----------------------|
|                                 | £                                    | £                                  | £              | £                     |
| GSK IHC                         | -                                    | 39,430                             | -              | <b>39,430</b>         |
| EMD Serano                      | -                                    | 30,795                             | -              | <b>30,795</b>         |
| E.R SquiBB                      | -                                    | 11,297                             | -              | <b>11,297</b>         |
| MSD Merck                       | -                                    | 37,286                             | -              | <b>37,286</b>         |
| Congress Sponsorship            | -                                    |                                    | 314,630        | <b>314,630</b>        |
| Novo Nordisk India Private Ltd  | -                                    |                                    | 1,519          | <b>1,519</b>          |
| Pfizer                          | -                                    |                                    | 67,037         | <b>67,037</b>         |
| Other Activities and membership | 7,097                                | -                                  | -              | <b>7,097</b>          |
|                                 | <u>7,097</u>                         | <u>118,808</u>                     | <u>383,186</u> | <u><b>509,091</b></u> |

### Income Resources comparative

|                                 | Charitable<br>Activities &<br>Others | Healthcare<br>Industry<br>Partners | Projects       | Total                 |
|---------------------------------|--------------------------------------|------------------------------------|----------------|-----------------------|
|                                 | £                                    | £                                  | £              | £                     |
| Novo Nordisk                    | -                                    | 18,780                             | -              | <b>18,780</b>         |
| Amgen Global                    | -                                    | 39,714                             | -              | <b>39,714</b>         |
| Pfizerinc                       | -                                    | 38,778                             | -              | <b>38,778</b>         |
| PhRma                           | -                                    | 37,841                             | -              | <b>37,841</b>         |
| Ifpma                           | -                                    | 20,347                             | -              | <b>20,347</b>         |
| Gsk                             | -                                    | 39,726                             | -              | <b>39,726</b>         |
| Congress Sponsorship            | -                                    | -                                  | 130,755        | <b>130,755</b>        |
| Prefer                          | -                                    | -                                  | 4,611          | <b>4,611</b>          |
| Other Activities and membership | 13,303                               |                                    |                | <b>13,303</b>         |
|                                 | <u>13,303</u>                        | <u>195,186</u>                     | <u>135,366</u> | <u><b>343,855</b></u> |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

### Congress Sponsorship 2020

|                      | Asia Pacific Congress | Global Patient Congress | Total          |
|----------------------|-----------------------|-------------------------|----------------|
|                      | £                     | £                       | £              |
| PFizer Inc           | 22,712                | 37,925                  | <b>60,637</b>  |
| Roche Pharma Holding | 7,232                 | 30,164                  | <b>37,396</b>  |
| Leo Pharma           | 14,266                | 39,005                  | <b>53,271</b>  |
| Merck                |                       | 31,572                  | <b>31,572</b>  |
| BD                   |                       | 23,096                  | <b>23,096</b>  |
| Bayer                |                       | 23,029                  | <b>23,029</b>  |
| Johnson Johnson      |                       | 37,136                  | <b>37,136</b>  |
| PhARMA               |                       | 26,487                  | <b>26,487</b>  |
| Novartis Pharma AG   |                       | 22,006                  | <b>22,006</b>  |
|                      | <hr/>                 | <hr/>                   | <hr/>          |
|                      | 44,209                | 270,421                 | <b>314,630</b> |
|                      | <hr/>                 | <hr/>                   | <hr/>          |

### 3 Analysis of support costs

All support costs are allocated directly to charitable activities and as such there are no support costs.

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

---

### 4 Trustees and staff remuneration

The trustees received no remuneration, but 2 Trustees received reimbursements of £1,519 (2019: £14,547) for travel and subsistence expenses incurred on behalf of the charity.

#### Staff remuneration and numbers

|                                                                            | <b>Total<br/>2020<br/>£</b> | <b>Total<br/>2019<br/>£</b> |
|----------------------------------------------------------------------------|-----------------------------|-----------------------------|
| Wages and salaries                                                         | <b>103,754</b>              | 166,517                     |
| Social Security                                                            | <b>14,789</b>               | 20,825                      |
| Pension costs                                                              | <b>1,026</b>                | 6,859                       |
| Other personnel related costs:<br>(recruitment, training, temporary staff) | -                           | 28,263                      |
|                                                                            | <b>119,569</b>              | 222,464                     |

The average number of full and part-time employees during the year was 3. One individual employee received emoluments in excess of £60,000 (2019: one). Key management personnel costs amounted to £63,654 (2019: £63,654).

### 5 Operating Surplus

Operating surplus is stated after charging

|                                         | <b>Total<br/>2020<br/>£</b> | <b>Total<br/>2019<br/>£</b> |
|-----------------------------------------|-----------------------------|-----------------------------|
| Auditors Remuneration                   | <b>4,920</b>                | 4,788                       |
| Depreciation of Assets                  | <b>200</b>                  | 146                         |
| Operating Lease Charges (office rental) | <b>31,277</b>               | 31,277                      |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

### 6 Fixed Assets

|                       | Computer<br>equipment<br>£ |
|-----------------------|----------------------------|
| <b>Cost</b>           |                            |
| Brought forward       | 4,169                      |
| Carried forward       | <u>4,169</u>               |
| <b>Depreciation</b>   |                            |
| Brought forward       | 3,870                      |
| Charge for the year   | 99                         |
| Carried forward       | <u>3,969</u>               |
| <b>Net book value</b> |                            |
| At 31 December 2020   | <u>200</u>                 |
| At 31 December 2019   | <u>299</u>                 |

There are no charges or securities held over any fixed assets. All fixed assets are held in the charity and none in the trading subsidiary. Depreciation of £219 was charged in the accounts for the previous period.

### 7. Debtors

|                | 2020<br>£      | 2019<br>£      |
|----------------|----------------|----------------|
| Debtors        | 97,356         | 35,548         |
| Prepayments    | 6,880          | 6,880          |
| Accrued income | 23,756         | 109,058        |
|                | <u>127,992</u> | <u>151,586</u> |

### 8. Creditors: amount falling due within one year

|                 | 2020<br>£      | 2019<br>£     |
|-----------------|----------------|---------------|
| Creditors       | -              | -             |
| Deferred income | 41,722         | 49,116        |
| Accruals        | 74,579         | 24,906        |
|                 | <u>116,301</u> | <u>74,022</u> |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

### 9. Analysis of net assets between funds

|                                | Unrestricted<br>Fund<br>£ | Designated<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total Funds<br>£      |
|--------------------------------|---------------------------|--------------------------|--------------------------|-----------------------|
| Tangible fixed assets          | 200                       | -                        | -                        | <b>200</b>            |
| Current assets                 | 159,647                   | 14,518                   | 181,143                  | <b>355,308</b>        |
| Current liabilities            | (22,200)                  | -                        | (94,101)                 | <b>(116,301)</b>      |
| Net assets at 31 December 2020 | <u>137,647</u>            | <u>14,518</u>            | <u>87,042</u>            | <u><b>239,207</b></u> |

### 10. Analysis of net assets between funds comparative

|                                | Unrestricted<br>Fund<br>£ | Designated<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total Funds<br>£      |
|--------------------------------|---------------------------|--------------------------|--------------------------|-----------------------|
| Tangible fixed assets          | 299                       | -                        | -                        | <b>299</b>            |
| Current assets                 | 140,667                   | 89,283                   | 10,338                   | <b>240,288</b>        |
| Current liabilities            | (74,022)                  | -                        | -                        | <b>(74,022)</b>       |
| Net assets at 31 December 2019 | <u>66,944</u>             | <u>89,283</u>            | <u>10,338</u>            | <u><b>166,565</b></u> |

### 11. Movements in funds

|                                             | At 31<br>December<br>2019<br>£ | Incoming<br>Resources<br>£ | Resources<br>Expended<br>£ | Transfers<br>£ | At 31<br>December<br>2020<br>£ |
|---------------------------------------------|--------------------------------|----------------------------|----------------------------|----------------|--------------------------------|
| Unrestricted fund                           | (3,311)                        | 125,905                    | (181,572)                  | 196,625        | <b>137,647</b>                 |
| <u>Designated Funds: -</u>                  |                                |                            |                            |                |                                |
| APPC Congress                               | -                              | 44,209                     | (38,889)                   |                | <b>5,320</b>                   |
| GPC Congress                                | 89,771                         | 270,421                    | (154,369)                  | (196,625)      | <b>9,198</b>                   |
| <u>Restricted funds: -</u>                  |                                |                            |                            |                |                                |
| PREFER                                      | 32,512                         | -                          | -                          | -              | <b>32,512</b>                  |
| Special projects - Up john<br>and Metrodora | -                              | 68,556                     | (54,224)                   | -              | <b>14,332</b>                  |
| Other projects                              | 47,593                         | -                          | (7,395)                    | -              | <b>40,198</b>                  |
|                                             | <u>166,565</u>                 | <u>513,287</u>             | <u>(448,040)</u>           | <u>-</u>       | <u><b>239,207</b></u>          |

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

### Movements in funds Comparative

|                            | At 31<br>December<br>2018<br>£ | Incoming<br>Resources<br>£ | Resources<br>Expended<br>£ | Transfers<br>£ | At 31<br>December<br>2019<br>£ |
|----------------------------|--------------------------------|----------------------------|----------------------------|----------------|--------------------------------|
| Unrestricted fund          | 61,609                         | 208,489                    | (273,409)                  | -              | <b>(3,311)</b>                 |
| <u>Designated Funds: -</u> |                                |                            |                            |                |                                |
| APPC Congress              | 52,493                         | 130,755                    | (93,477)                   | -              | <b>89,771</b>                  |
| <u>Restricted funds: -</u> |                                |                            |                            |                |                                |
| PREFER                     | 27,901                         | 4,611                      | -                          | -              | <b>32,512</b>                  |
| PROTECT                    | -                              | -                          | -                          | -              | -                              |
| Other projects             | 47,593                         | -                          | -                          | -              | <b>47,593</b>                  |
|                            | <u>189,596</u>                 | <u>343,855</u>             | <u>(366,886)</u>           | <u>-</u>       | <u><b>166,565</b></u>          |

### Congress Overhead recharge

Congress income and expenditures were originally treated as unrestricted until it was agreed that they should be treated as designated in 2018 accounts onwards. However, although all direct income and cost related to the congress were allocated accordingly the overhead cost, primarily consisting of staff cost, were not. Which is why after careful allocation £196k cost was added to the total congress cost to date, moving cost from unrestricted to designated, to reflect true cost of congress in the past 3years.

### GPC2020 Virtual

Considering the COVID-19 pandemic and in the best interest of participants, we made the difficult but inevitable decision to postpone the 9th Global Patients Congress to a virtual event on 16 -17 September 2020, under the theme of 'Co-creation in Innovative Healthcare during COVID-19'.

The re-imagined 9th Global Patients Congress (GPC 2020) was a moment to reflect on the defining health crisis of COVID-19 and its impact on the global patient community. The Congress was a great opportunity to focus our conversation on the next steps in health system strengthening and preparedness through patient led and co-created innovative solutions in 2020 and beyond.

The Congress brought together 1300 delegates; a number 10 times higher than the previous Global Patients Congress. Benefiting from the advantages of virtual conferences, delegates were based in 101 countries, an increase of 70 countries when compared with IAPO's previous global conference

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

---

### APPC2020 Virtual

The Virtual 2nd Asia-Pacific Patients Congress 2020 (APPC2020) gave us a stark reminder that health in the region must not be considered as a sovereign matter. Health was a collective regional matter and all the patients, the State, and regulators in the region must collaborate across borders. The Congress brought together 3046 delegates from 66 countries, 20 times more than our 1st Asia Pacific Patients Congress, which was held face to face in Taiwan in 2019. In total, 298 patient groups attended APPC 2020, being 61 organizations members of IAPO.

### Metrodora Awards

The first ever international Metrodora Awards – a celebration of women leaders in science and health improving NCD care and management was established by IAPO and Pfizer Upjohn. Over the past few years, the number of women leaders in science and health has grown significantly. However, while there has been progress towards gender equality, women science and health leaders are still under-represented globally. Women constitute only 30% of the world's researchers with too few of them occupying decision-making roles in academic and research institutions, which further hinders their ability to shape the research agenda <https://www.iapo.org.uk/news/2020/oct/27/metrodora-awards>

### Stroke Twinning programme on stroke in LMIC

Twinning programme on stroke in Asia was supported by Pfizer Upjohn and developed as a twinning programme on stroke in Low and Middle Income countries (LMIC) located in the Asia-Pacific region, Middle East and Latin America.

### PREFER

PREFER will run over the next one year and establish recommendations to support development of guidelines for industry, Regulatory Authorities and HTA bodies on how and when to include patient perspectives on benefits and risks of medicinal products.

We have given all our input to patient preference studies run in both academic and industry setting by others. Our perspective has provided a better understanding of what the recommended best-practice approach to patient-preference studies should be in the future. The Recommendations are in consultation and we will disseminate results later to show how patient preference studies can give valuable information to support decision making for regulators and HTA bodies.

### GetReal

Get-Real IMI Project has now concluded and has been set-up as a separate entity the Get Real Institute. We explored how real-world research data could be used in the development of drugs, to increase effectiveness and enrich decision-making by regulatory authorities and health technology assessment (HTA) agencies. IAPO's role is to bring the perspective of patients and patients' organizations to this work and facilitate the input of member organizations into the study. As a partner in this project, IAPO hopes to contribute to improving medicine development process, so patients have access to the drugs that they need. Surplus funds are ringfenced to be spent specifically on this project.

# **INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS**

## **NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020**

---

### **12. Related parties**

There were no related party transactions during the year or prior year.

### **13. Post balance sheet event note**

#### **IMPACT OF COVID-19 PANDEMIC**

The Trustees anticipate that the COVID-19 outbreak in February 2020 and the subsequent events will have a long-term impact on the Charity's incoming resources and resources expended in the coming years and on the fair value of its assets and liabilities. They have considered the likely impact on its incoming resources and how the charity can react to that impact and are confident that it has sufficient reserves and enough flexibility to ensure that it can continue to exist for the foreseeable future.