

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**

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# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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

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

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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.

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### 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.

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### 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

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### 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.

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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

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### 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

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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

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### 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

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### 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.

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### 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

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### 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.

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### 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

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### [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).



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### 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.

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### 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*

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### [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 Scientific Board and its membership can be found here: <https://bit.ly/38scZ6L>

# INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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### 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

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### 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*

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### [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

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### 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](#), [Patient Solidarity 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

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### 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

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### 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

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*FOR THE YEAR ENDED 31 DECEMBER 2022*

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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

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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

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### 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*

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### · 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*

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### 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

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### 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

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### 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

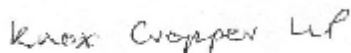
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- We gained an understanding of how the charitable company complied with its legal and regulatory framework, including the requirement to properly account for restricted funds, through discussions with management and a review of the documented policies, 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 2022	Total 2021
	N o t e s	Unrestricted	Designated	Restricted	(year)	(year)
		£	£	£	£	£
<b>Income from charitable activities:</b>						
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
<b>Total</b>	<b>2</b>	<b>241,805</b>	<b>82,973</b>	<b>257,863</b>	<b>582,642</b>	<b>380,706</b>
<b>Expenditure on charitable Activities:</b>						
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
<b>Total</b>	<b>3</b>	<b>187,933</b>	<b>113,519</b>	<b>97,674</b>	<b>399,126</b>	<b>270,656</b>
<b>Net income/(expenditure)</b>		<b>53,872</b>	<b>-30,546</b>	<b>160,189</b>	<b>183,516</b>	<b>110,050</b>
Transfers		-30,546	30,546			
<b>Net movement in funds</b>		<b>23,326</b>	<b>-</b>	<b>160,189</b>	<b>183,516</b>	<b>110,050</b>
<b>Reconciliation of funds:</b>						
Funds brought forward		264,025	-38,112	123,344	349,257	239,208
<b>Total funds carried forward</b>		<b>287,351</b>	<b>-38,112</b>	<b>283,533</b>	<b>532,772</b>	<b>349,257</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 2022

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

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### 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

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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 Industry 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
	7,404	575,238	-	582,642

### Income Resources comparative

	Charitable Activities & Others £	Healthcare Industry Partners £	Projects £	Total £
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
Other Activities and membership	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 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 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

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### 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 2021 £	Total 2021 £
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 2021 £	Total 2021 £
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 equipment £
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 £	2021 £
Debtors	1,235	78
Prepayments	6,880	6,880
Accrued income	-	-
	8,115	6,958

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

	2021 £	2021 £
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 Fund £	Designated Funds £	Restricted Funds £	Total Funds £
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 Fund £	Designated Funds £	Restricted Funds £	Total Funds £
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 December 2021 £	Incoming Resources £	Resources Expended £	Transfers £	At 31 December 2022 £
Unrestricted fund	264,025	241,805	(187,933)	(30,546)	287,351
<u>Designated Funds: -</u>					
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)
<u>Restricted funds: -</u>					
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 December 2020	Incoming Resources	Resources Expended	Transfers	At 31 December 2021
	£	£	£	£	£
Unrestricted fund	137,647	241,235	(114,857)	-	264,025
<u>Designated Funds: -</u>					
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)
<u>Restricted funds: -</u>					
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

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### 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 £	Designated £	Restricted £	Total 2021 (year) £
<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>					
Charitable activities:-					
· 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>
Transfers		-	-	-	-
<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>