

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	Page 1
Trustees Report	2-22
Independent Auditor's Report	23-25
Statement of Financial Activities	26
Balance Sheet	27
Notes to the Financial Statements	28-38

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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

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 Karen Alparce-Villanueva (Resigned 22 Feb 2022) Neda Milevska-Kostova (Chair) Sita Ratna Devi Duddi (Resigned 22 Feb 2022) Rosalia Liliana Tieri (Appointed 16 Dec 2020) Orajitt Bumrungkulswat Adebisi Omolola Bright 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
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	www.iapo.org.uk

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 30th 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 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.

BOARD OF TRUSTEES AND DIRECTORS		
Name	Position	Country
Dr. Neda Milevska-Kostova	Chair	North Macedonia
Mr. Ellos Ellard Lodzeni	Board Member	Malawi
Mrs. Rosalia Liliana Tieri	Board Member	Argentina
Mrs. Orajitt Bumrungkulswat	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 3rd 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 3rd 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 3rd 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](#)

74th 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 Viatris 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

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

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 31st 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%
TOTAL	100%

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 and 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 31st 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

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 13th 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 31ST 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 31ST 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

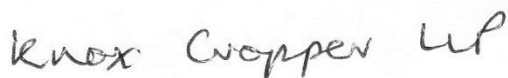
INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31ST DECEMBER 2021

- 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 £	Designated £	Restricted £	Total 2021 (year) £	Total 2020 (year) £
Income from charitable activities:						
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
Total	2	241,235	82,202	57,269	380,706	509,091
Expenditure on charitable Activities:						
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
Total	3	114,857	134,832	20,967	270,656	436,449
Net income/(expenditure)		126,378	(52,630)	36,302	110,050	72,643
Transfers		-	-	-	-	-
Net movement in funds		126,378	(52,630)	36,302	110,050	72,643
Reconciliation of funds:						
Funds brought forward		137,647	14,518	87,042	239,207	166,565
Total funds carried forward		264,025	(38,112)	123,344	349,257	239,207

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 £	2020 £
Fixed assets	6	134	200
Current assets			
Debtors	7	6,958	127,992
Cash in hand and in bank		435,290	227,316
		<u>442,248</u>	<u>355,308</u>
Creditors: amounts falling due within one year	8	(93,125)	(116,301)
		<u>349,123</u>	<u>239,007</u>
Net current assets			
		<u>349,123</u>	<u>239,007</u>
Net assets		349,257	239,207
Funds			
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>
Total Funds	9	349,257	239,207

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 13th 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 20th -21st July 2021 and the 3rd Asia Pacific Patients on the 16-17th 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 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
	<u>16,694</u>	<u>224,541</u>	<u>139,471</u>	<u>380,706</u>

Income Resources comparative

	Charitable Activities & Others	Healthcare Industry Partners	Projects	Total 2020
	£	£	£	£
GSK IHC	-	39,430	-	39,430
EMD Serano	-	30,795	-	30,795
E.R SquiBB	-	11,297	-	11,297
MSD Merck	-	37,286	-	37,286
Congress Sponsorship	-	-	314,630	314,630
Novo Nordisk India Private Ltd	-	-	1,519	1,519
Pfizer	-	-	67,037	67,037
Other Activities and membership	7,097	-	-	7,097
	<u>7,097</u>	<u>118,808</u>	<u>383,186</u>	<u>509,091</u>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

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/> 43,314 <hr/>	<hr/> 38,887 <hr/>	<hr/> 82,202 <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

	Total 2021 £	Total 2020 £
Wages and salaries	124,338	103,754
Social Security	13,754	14,789
Pension costs	1,362	1,026
	<hr/>	<hr/>
	139,454	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

	Total 2021 £	Total 2020 £
Auditors Remuneration	5,040	4,920
Depreciation of Assets	66	99
Operating Lease Charges (office rental)	12,213	31,277

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

6 Fixed Assets

	Computer equipment £
Cost	
Brought forward	4,169
Carried forward	<u>4,169</u>
Depreciation	
Brought forward	3,969
Charge for the year	66
Carried forward	<u>4,035</u>
Net book value	
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 £	2020 £
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 £	2020 £
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 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	<u>264,025</u>	<u>(38,112)</u>	<u>123,344</u>	<u>349,257</u>

10. Analysis of net assets between funds comparative

	Unrestricted Fund £	Designated Funds £	Restricted Funds £	Total Funds £
Tangible fixed assets	200	-	-	200
Current assets	159,647	14,518	181,143	355,308
Current liabilities	(22,200)	-	(94,101)	(116,301)
Net assets at 31 December 2020	<u>137,647</u>	<u>14,518</u>	<u>87,042</u>	<u>239,207</u>

11. Movements in funds

	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>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

Movements in funds Comparative

	At 31 December 2019 £	Incoming Resources £	Resources Expended £	Transfers £	At 31 December 2020 £
Unrestricted fund	(3,311)	125,905	(181,572)	196,625	137,647
<u>Designated Funds: -</u>					
APPC Congress	-	44,209	(38,889)		5,320
GPC Congress	89,771	270,421	(154,369)	(196,625)	9,198
<u>Restricted funds: -</u>					
PREFER	32,512	-	-	-	32,512
Special projects - Up john and Metrodora	-	68,556	(54,224)	-	14,332
Other projects	47,593	-	(7,395)	-	40,198
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
	166,565	513,287	(448,040)	-	239,207

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 £	Designated £	Restricted £	Total 2020 £
Income from charitable activities:				
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
Total	125,905	314,630	68,556	509,091
Expenditure on charitable Activities:				
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
Total	181,572	193,258	61,619	436,449
Net income/(expenditure)	(55,667)	121,372	6,937	72,642
Transfers	196,625	(196,625)	-	-
Net movement in funds	140,958	(75,253)	6,937	72,642
Reconciliation of funds:				
Funds brought forward	(3,31)	89,771	80,105	166,565
Total funds carried forward	137,647	14,518	87,042	239,207