

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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

FINANCIAL STATEMENTS AND ANNUAL REPORT

FOR THE YEAR ENDED 31 DECEMBER 2020



INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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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 Neda Milevska-Kostova Sita Ratna Devi Duddi (Chair) Ya Hsin Wang (Resigned 15 Dec 2020) Carol Chinwe Nwosu (Resigned 10 April 2020) Rosalia Liliana Tieri (Appointed 16 Dec 2020) Orajitt Bumrungskulswat (Appointed 16 Dec 2020) Adebisi Omolola Bright (Appointed 16 Dec 2020)
Chief Executive	Kawaldip Sehmi
Bankers	NatWest Bank Plc PO Box 12258 1 Princes 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 2020

The directors, who are also the trustees of the charity, are pleased to present their report together with the financial statements of the charity for the year ended 31 December 2020 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

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

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

Aims and objectives of the organisation

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

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

IAPO was first established in 1999 in the Netherlands as a Dutch Stichting and then de-registered in 2014 to be registered in England and Wales as a UK Charity and Company Limited by Guarantee on 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

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FOR THE YEAR ENDED 31 DECEMBER 2020

IAPO's vision and mission

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

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

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

IAPO's activities include:

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

Structure

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

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

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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, 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 31 St December 2020

The year 2020 has been like no other year in living memory. It clearly was like no other year in the entire 21-year history of the International Alliance of Patients Organizations. I would now like to pass on my condolences to all our members, stakeholders and their families who have lost loved ones to the COVID-19 pandemic. We are still not free from the pandemic as we are facing long-COVID and other sequelae of the disease today, not forgetting the disrupted healthcare services and collapsing healthcare systems.

2020 was a year that gave a wakeup call to the global patients' movement that our health systems are all vulnerable to not only national issues, but also global influences. We need to work together in national unity and global solidarity to ensure that we strengthen our global health governance and healthcare delivery systems and address the fault lines that appeared along the entire spectrum of our national healthcare services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course.

Some say that the pandemic was a mixed blessing as it really spurred the WHO Member States, regulators and the global pharmaceutical and biotechnology industry to look at global cooperation in innovative medicines and health device research and development. The raising of the issue of vaccine equity has made it important that all countries have an equitable access to innovative, safe, quality, acceptable and patient centred medicines, health devices and other medical products that they need without suffering financial hardship.

I particularly want to thank all our stakeholders who rallied around the global patient movements and IAPO, and joined us in guiding our member organisations and the world through the complex healthcare ecosystem created by the pandemic.

We firstly thank the World Health Organization and its Director General Dr Tedros Adhanom Ghebreyesus for stepping up in the best traditions of the WHO and providing leadership on this global and grave health matter. Dr Ghebreyesus began very early on in shaping the pandemic healthcare research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing the pandemic threat and trends as they rose. The WHO's fight against the misinformation and infodemic has helped our patient organisations a lot.

We also want to thank two other WHO scientists who supported IAPO in 2020. We firstly thank WHO's Chief Scientist Dr Soumya Swaminathan for having graciously accepted our invitation and addressed and reassured over 1500 patient delegates on the progress of the pandemic at our Global Patients Congress 2020. Dr. Swaminathan motivated us to work harder at improving health literacy and adopting of preventative measure like hand washing, face coverings and social distancing. She also reassured us that we shall overcome the difficult pandemic challenges we were facing through global solidarity.

Secondly, we want to thank Dr Neelam Dhingra, WHO Unit Head, Patient Safety Flagship Decade of Patient Safety 2020-2030. During the chaos of the pandemic, Dr Dhingra worked tirelessly in the best traditions of the WHO to support the World Health Assembly adopt WHA Resolution 72.6. This gifted us a day of our own, the World Patient Safety Day, and the Global Action Plan on Patient Safety Action Plan 2021-2030.

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

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At our Global Patients Congress 2020, Thomas Cueni Director General of the International Federation of Pharmaceutical Manufacturers Association (IFPMA) and some of his members gave us great insight into vaccines development and the WHO Solidarity Trials that looked at repurposing of existing drugs to treat COVID-19, especially if they are already approved (for other indications) and have well established safety profiles. IAPO continues to enjoy close relationship with the International Drug Regulators Authority Conference and the European Medicines Agency and the FDA. The regulators have included us within their decision-making processes and have established good patient engagement framework for co-creation.

In 2020 IAPO has been very fortunate in its collaboration programmes through the Memorandums of Understanding and other collaborative relations we have established with International Society for Quality in Health Care (ISQua), The Professional Society for Health Economics and Outcomes Research (ISPOR) and The Union for International Cancer Control (UICC). I thank our partners for their input and direction given to us.

Lastly, I want to thank our healthcare industry partners who have supported us and our member organisations in this difficult challenging time through sponsorship, educational grants, and research projects. Without their support, we could not have reached the audience we have and made the impact we have in 2020.

This Report highlights who we addressed our strategy in 2020 over the three objectives:

1. Empower patient communities globally to advocate effectively for PC-UHC for all.
2. Drive research processes and the development of evidence base for PC-UHC.
3. Shape law, policy and practice in PC-UHC at global, regional and national levels

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

The full 2020 strategy activity impact and the 2022-2024 strategy is listed on our website www.iapo.org.uk and our social media handles <https://twitter.com/iapovoice?lang=en> and <https://www.facebook.com/IAPOvoice/>



Sita Ratna Devi Duddi
Chair IAPO

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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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. Ratna Devi	Chair	India
Dr. Neda Milevska-Kostova	Vice-Chair	North Macedonia
Mr. Ellos Ellard Lodzeni	Treasurer	Malawi
Mrs. Karen Ida Alparce-Villanueva	Secretary	Philippines
Mrs. Rosalia Liliana Tieri	Board Member	Argentina
Mrs. Orajitt Bumrungskulswat	Board Member	Thailand
Mrs. Bisi Bright	Board Member	Nigeria

Report of Activities 1st Jan – 31 Dec 2020

In 2020, the second year of our 2019-2021 Strategic Plan, our vision remained to see patient-centred universal health coverage (PC -UHC) established in all countries, and our objective were to ensure that there is a sufficient availability of patient-centric, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each WHO Member State, along with essential and innovative medicines and health devices, which are accessible, acceptable and affordable, and delivered without the patients suffering financial hardship or discrimination. A summary of our achievements is available online

https://www.iapo.org.uk/sites/default/files/files/IAPO_2020%20Highlights.pdf

Further reports of the two congresses are also shared online:

Global Patients Congress:

[https://www.iapo.org.uk/sites/default/files/files/GPC%202020%20Report%20\(13\).pdf](https://www.iapo.org.uk/sites/default/files/files/GPC%202020%20Report%20(13).pdf)

Asia Pacific 2020: <https://www.iapo.org.uk/sites/default/files/files/APPC%202020%20report.pdf>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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FOR THE YEAR ENDED 31 DECEMBER 2020

Our 2020 strategy was to:

1. Empower patient communities globally to advocate effectively for patient-centred universal health coverage for all.
2. Drive research processes and the development of evidence base for patient-centred universal health coverage.
3. Shape law, policy, and practice in patient-centred universal health coverage at global, regional and national levels.

Under our strategic plan IAPO achieved the following in 2020:

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

[IAPO's anniversary – 21 years of shaping our healthcare ecosystem](#)

IAPO was formed in 1999 as a response to developments in healthcare that were increasingly marginalising patients by restricting participation and engagement. IAPO wanted to put the patient back at the centre of all healthcare decision and policymaking. While we have surmounted most of the traditional barriers in healthcare during the past 21 years, the modern healthcare landscape has changed dramatically over the last decade. Rapid globalisation digitised and innovation within healthcare has created new challenges and barriers for us.

While 2020 was to celebrate the year in which IAPO came of age, the COVID-19 pandemic shook every patient organization and health system around the world. The pandemic disrupted all our plans to welcome our members to an amazing anniversary dinner at the National Museum of Scotland in their great exhibition hall, where great scientists like Charles Darwin had developed their scientific theories, and which housed Dolly the sheep (the first cloned animal). We had to curtail all celebrations acknowledging the great global mortality, morbidity and suffering.

In 2020, very early during the pandemic, we sadly lost our Board Member Carol Ossai to COVID-19 (RIP) who was a strong advocate for the improvement of care and treatment for people living with sickle cell diseases.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

To mark our 21st anniversary, IAPO and its Board and staff have developed a short video telling IAPO's story: <https://bit.ly/37Akolq>

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

[IAPO collaboration with the World Health Organization](#)

73rd World Health Assembly

IAPO participated in perhaps the most important World Health Assembly in the entire 72 years of the World Health Organization (WHO). WHA 73 was a single-issue assembly where all 194 Member States came together in national unity and global solidarity to address the COVID-19 pandemic. More than this, over 200 non-State Actors in official relationship with the WHO took particular care to submit statements as part of their interventions.

IAPO joined WHA 73 through the non-State Actor Office and submitted a comprehensive statement to Agenda Item 73.1.3 COVID-19 Response noting we were appalled to see how lockdowns without plans and lack of patient engagement resulted in great lapses of patient safety, breaches of human rights (police action) and loss of trust in health systems. Patient safety and health professional safety was compromised by lack of healthcare availability, access, acceptance and quality. We urged all WHO Member States to adopt a human rights-based approach to their public health measures. Full statement can read here: <https://bit.ly/3p9mMp6>

WHO Regional Committees

We participated virtually in the WHO Regional Committees:

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

AMR Patient Alliance

IAPO along with patient organizations from different regions and countries has developed a Global Patient Consensus Statement and a Call to Action, that aims to convene civil society groups representing patients, carers and advocates in a global AMR Patient Alliance, which was partly launched in December. The AMR Patient Alliance will be a place where patients can exchange views, be educated, and acquire knowledge and resources that we need to raise awareness about the importance of sustaining the efficacy of antibiotics - for as long as possible, for as many patients as possible. Learn more about the Alliance here: <https://bit.ly/3nE4GLF>

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Fight the Fakes Alliance

IAPO is a founding member of the new Fight the Fakes (FTF) Alliance, a new multi-stakeholder non-profit association registered in Geneva (Switzerland), set up to fight against falsified medicines. Seven years since its first activities as a grass root advocacy campaign, the new formal governance structure will allow the FTF Alliance to take the fight against substandard and falsified medicines to the next level. With over 15 members representing health care professionals, manufacturers, wholesalers, researchers and patients, the Alliance is uniquely positioned to scale up action to prevent falsified medicines from endangering people's health and well-being. More information on this:

<https://bit.ly/2Jc0a8c>

10th Asia Regulatory Conference

Ratna Devi, IAPO Chair, participated in the panel discussion 'Patients Perspectives on Regulatory Reliance and Why Patient Engagement is Important'. In order to secure early access to innovative quality and safe medications, it is important that market authorization process is streamlined across Asia. Regulatory Reliance is a process through which national medicines regulatory authorities cooperate and streamline market authorization processes.

Campaign to ratify the African Medicines Agency Treaty

Two years after we issued our Entebbe Statement on the African Medicines Agency (AMA) in 2017, we had hoped we would have AMA set up by 2019. This has not happened. The IAPO campaign explores the benefits of establishing the African Medicines Agency and what is preventing the signing and ratification of the Treaty to establish the AMA. In partnership with African organizations, WHO and the International Federation of Pharmaceutical and Manufacturers Association, IAPO began the campaign to address this at the Geneva Health Forum. You can watch the session via this link: <https://bit.ly/2J8hLxI>

AMA's main objectives are improving access to safe and affordable medicines, boosting local manufacturing, and taking concerted action to tackle substandard and falsified medicines. It will also help to support the growth of local pharmaceutical companies and drug manufacturing, one of the key aims of the Pharmaceutical Manufacturing Plan for Africa and the Africa Continental Free Trade Area. If it was not a priority before, then with the COVID-19 pandemic, there can be no other priority but AMA to ensure safe vaccines, biotherapeutics and repurposed medicines from WHO.

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Empower patient communities globally to advocate effectively for patient centred-universal health coverage for all

9th Global Patients Congress

The 9th Global Patients Congress (GPC 2020) held on 16-17 September 2020 was one of the most critical congresses in our 21-year history. Holding a patients congress in the middle of a pandemic was very important to raise the patient voice in all the public health decision-making taking place globally. It was also key that we showed global solidarity with all the stakeholders engaged in controlling and hopefully eliminating COVID-19. The Congress was unique as it invited top scientists, policy makers, and Non-State Actors to speak to our members.

The Congress was also important because it was marking the 2nd World Patient Safety Day on 17 September when patient harm and health professional safety had become one urgent and critical issue during the COVID-19 pandemic in all of our health systems. WHO and we concurred that the theme 2020 had to be 'Health Worker Safety, a Priority for Patient Safety'.

GPC 2020 was IAPO's first fully digital congress with a record number of 1300 registered delegates from 101 countries with 338 patient groups, who attended 26 sessions with 64 speakers from 28 countries. The full summary of the Congress was for the first time published in the BMJ:

<https://bit.ly/3mxF9Cs>

The Congress issued a strong call to action urging WHO Member States to urgently engage expert patients in their structures, processes and decisions in co-creating patient-centred public health and shielding programmes. The full statement can be read here: <https://bit.ly/3mB8v2H>

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IAPO Member participation in GPC 2020

IAPO Members were invited to showcase their best COVID-19 activities and achievements in supporting their patient communities. IAPO for the first time provided over USD\$ 15,000 in special grants for those organizations who have merited support for their work in this critical phase: Uganda Alliance of Patients' Organizations - UAPO (Uganda), Epilepsy Support Association Uganda (Uganda), Sharecare Ghana (Ghana), Patient and Community Welfare Foundation of Malawi - PAWEM (Malawi), Save Liver - SLAP (North Macedonia), Action Group for Health Human Rights and HIV/AIDS - AGHA (Uganda), Consumer Online Foundation (India) and National Community of Women Living with HIV in Uganda – NACWOLA (Uganda). You can learn more about the deserving awardee organizations here:

<https://bit.ly/38j3wPe>

Also for the first time, IAPO engaged our film-makers to record for posterity what challenges some of our members were facing during the COVID-19 pandemic. This was facilitated by GiJong An from the Korean Alliance of Patient Organizations, who have instituted the Patient Shouting Café, a very important methodology of engaging patients, their healthcare systems, journalists and regulatory agencies in addressing patient harm, patient safety and patient experience issues. You can see how the Patient Shouting Café works in practice here: <https://bit.ly/2Ko6jPb>

2nd Asia Pacific Patients Congress

The 2nd Asia Pacific Patients Congress was held as IAPO's second fully digital congress on 3-4 December 2020 with over 3000 registered from 66 countries with 298 patient groups, who attended 20 sessions with 66 speakers from 16 countries. The Congress aimed at bringing together patient experts and health stakeholders including researchers, nurses, health financiers, regulators, health service providers and pharmaceutical industry representatives to map out how we can all harmonise and align our agendas with national health policies and plans on Universal Health Coverage in the region.

To learn more about the Congress, please visit: <https://bit.ly/3axRPGX>. To view the session recordings, register for free and access the auditorium via this link: <https://bit.ly/3pdz3sQ>

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COVID-19 activities

IAPO COVID-19 statement

IAPO released an official statement on COVID-19 in April posted on our newsletter, website and on all social media platforms. The statement called for a new COVID-19 Patient Engagement Collaborative Framework that puts patient experts at the heart of all COVID-19 related responses and measures: <https://bit.ly/2KHaTYL>

IAPO's COVID-19 resources hub

To support our members, partners and the grater global health community working to bring this outbreak to a close, we created a web page on IAPO's website to support the distribution of expert and relevant information and share best practices as part of our responsibility as a coordination and cooperation organization: <https://bit.ly/2WBJoCx>

The hub has been the most visited page on our website with over 327 people sharing it on various social media platform. The initiatives on this page have also been shared on our newsletter and social media accounts. We are continually mapping relevant information and updates as it is published for inclusion on the page.

IAPO Members' response to COVID-19

We created a web page on the IAPO website to showcase a summary of IAPO members' response activities to fight the COVID-19 pandemic and support patients worldwide: <https://bit.ly/2KmYQQg>

IAPO Member Stories on COVID-19

This is an article series where IAPO members shared their stories on how the pandemic is impacting their work as well as their efforts to continue supporting patients during the pandemic. The series was promoted on IAPO's monthly newsletter and is available on the IAPO website here:

<https://bit.ly/3rhmUon>

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WHO Information Network for Epidemics (EPI-WIN)

IAPO supported the WHO in fighting the COVID-19 infodemic through being part of the newly formed WHO Information Network for Epidemics (EPI-WIN). The forum exists with the aim of using a series of amplifiers to share timely, accurate and relevant information to all.

Stakeholder engagement with partners

Upjohn (now Viartis)

Twinning programme on stroke in Asia: IAPO developed a twinning programme on stroke in Low- and Middle-Income countries (LMIC) located in the Asia-Pacific region, Middle East and Latin America.

Survey of patient experience of non-communicable diseases (NCDs) and COVID-19: This survey is a joint proposal with NIHI (National Institute of Health and innovation, Auckland), FIP (International Pharmaceutical Federation), WONCA, and IAPO, where our members in LMICs helped collect data from patients and caregivers to understand the true impact of the pandemic on NCD care.

Voices of Safety - World Patient Safety Day 2020 storytelling campaign

In partnership with BD, IAPO scoped patient stories for our joint storytelling campaign on patients' experiences related to healthcare systems safety to mark World Patient Safety Day 2020 on 17 September. You can watch the campaign videos here: <https://bit.ly/3h87azn>

Union for International Cancer Control (UICC)

IAPO joined UICC and its over 1200 members from more than 170 countries. UICC is the world's leading international cancer organization. UICC's activities are shaped by the World Cancer Declaration which sets out a framework to help reduce the global cancer burden by 2025, including through the adoption of the 2017 Cancer Resolution.

Global Self-Care Federation

IAPO worked with the Global Self-Care Federation to launch their Self-Care Readiness Index Consumer Survey among our network through our newsletter, website and social media. We have also marked the International Self-Care Day on 24th July in collaboration.

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Global Coalition for Circulatory Health (GCCH)

We collaborated with GCCH through the COVID-19 webinars series in collaboration with the International Council of Nurses, World Organization of Family Doctors, World Federation of Public Health Associations and WHO. Under the theme 'Joining forces to fight COVID in people with circulatory conditions', IAPO represented the patient view on circulatory risk factors and outcomes associated with COVID-19.

Antimicrobial Resistance Patient Advocacy Group

Health First Europe launched the first European patients' advocacy group on AMR, which aims to raise awareness about antimicrobial resistance and to help reduce antibiotic misuse in Europe. The AMR patient advocacy group includes several national patient associations from across Europe, including IAPO members Fondazione The Bridge (Italy), Save Liver Association for Patients – SLAP (Macedonia), Pelvic Pain Support Network (EU), Malta Health Network (Malta) and The Patients Association (UK).

International Federation of Psoriasis Associations (IFPA)

As part of IFPA's webinar series in 2020, Kawaldip Sehmi, IAPO CEO, spoke at a webinar in October about IAPO's role in the resolution on Global Action on Patient Safety and how other patient associations can use it in their work.

Fondazione The Bridge (FTB)

Kawaldip Sehmi, IAPO CEO, wrote an article for the FTB newsletter in June about the importance of working in a network and how to manage the dialogue between patient associations. Read the article here: <https://bit.ly/2Kln4L0>

Global Alliance of Sickle Cell Disease Organisations (GASCDO)

We had a collaborative meeting with GASCDO to rethink healthcare system strengthening to reduce the burden of sickle cell disease in underserved populations. This will be followed up in 2021.

IAPO Members survey

IAPO conducted a survey to help identify ways of strengthening collaboration among IAPO members' network and ensure we prioritise our resources and continue to respond to our member organizations' priorities and needs throughout and beyond the pandemic. Results to be launched in 2021.

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Communications

Newsletter: Our monthly newsletter reaches out to over 5900 subscribers and has covered the COVID-19 pandemic news and information. It was very inspiring to see that over 30 patient organizations submit high quality articles on various aspects of healthcare globally, especially on how COVID-19 affected them. We are encouraging more patient organizations to submit articles for 2021.

Twitter: [@IAPOvoice](#) and [@PatientSolidarityDay](#)

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

Website: Continues to be the main focal point for IAPO's dissemination and communications activities. We have seen an increase in number of page views: with over 100,000 page views in 2020 compared to 92,154 in 2019. www.iapo.org.uk

Drive research processes and development of evidence base for patient centred-universal health coverage

IAPO Scientific Advisory Board

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

Metrodora Award – recognising outstanding women achievers in science and health

IAPO in partnership with Pfizer Upjohn (now Viatrix) and the Patient Academy for Innovation and Research (PAIR) introduced the first international Metrodora Awards to empower and recognize women leaders who are delivering positive changes in the care and management of non-communicable diseases (NCDs).

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Metrodora was a Greek physician who lived between 200 to 400 CE and wrote the first known medical text to be authored by a woman. By studying and working on all aspects of women's health, she defied traditional gender roles during a time when women physicians were limited mainly to childbirth and obstetrics. Among many innovations, she pioneered surgical treatments for breast and uterine cancers – a legacy that has influenced throughout history.

IAPO, for the first time, undertook a consultation with patient organizations to nominate women scientists who patients thought were most deserving. IAPO in acknowledging and thanking these scientists awarded them over USD\$ 15,000 in honorariums. 2020 winners can be seen here:

<https://bit.ly/2KKNZzH>

IAPO Patients for Patient Safety Observatory

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

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

Patient Academy in Innovation and Research (PAIR) collaboration Asia-Pacific

IAPO is participating in the Asia-Pacific region to improve the quality of patient advocacy. The Patient Academy for Innovation and Research is set-up to develop and maintain capacity amongst patients across the globe, in an effort to enable them to engage with their health-systems in a more meaningful and strategic manner. Thus better equipping them to care for themselves and others, by framing their experience with an evidence-based expertise and share with other patients who suffer from the same or similar conditions and diseases. Learn more about PAIR here: <https://bit.ly/3nzYr02>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

ISPOR - The Professional Society for Health Economics and Outcomes Research

Ratna Devi, IAPO Chair was part of the Program Committee of the virtual ISPOR Asia Pacific 2020, themed 'Next Generation Healthcare in Asia Pacific: Where Technology Meets Patients to Improve Care'. The event offered a robust scientific program focused on in-depth studies of the current state of Health economics and outcomes research in the region. Healthcare is being transformed rapidly and dynamically with the rise of cutting-edge technologies that are providing patients with life-changing or curative benefit.

ISQUA – United to preserve antimicrobials - A joint call for action

Along with the International Hospital Federation, the International Society for Quality in Health Care, and the International Federation of Pharmaceutical Manufacturers and Associations we issued a joint statement calling for antibiotic stewardship and preservation. The statement also calls for the development of more innovative partnerships of healthcare providers, patients and the business sector to tackle the growing AMR threat while improving healthcare safety and quality worldwide.

Research Papers Published in 2020

- Cancer medicine: a missed opportunity: <https://bit.ly/3nJK3xB>
- A narrative review of the patient journey through the lens of non-communicable diseases in low- and middle-income countries: <https://bit.ly/3rfUvPA>
- Systemic solutions for addressing non-communicable diseases in low- and middle-income countries: <http://bit.ly/3pfdqgh>
- A patient's wish - hospitals that care: <https://bit.ly/3mJvfxE>
- Role of active patient involvement in undergraduate medical education: a systematic review: <https://bit.ly/34yQz2x>
- Mapping the patient journey towards actionable beyond the pill solutions for non-communicable diseases: <https://bit.ly/38usBXq>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

IAPO Membership in 2020

IAPO consolidated its membership in 2020 and sought new members covering rare diseases and non-communicable diseases. IAPO had 289 members at 31st December 2020. IAPO is now also actively seeking more members from WHO Eastern Mediterranean Region, South East Asia and the Western Pacific that are under-represented.

Region	%
African members	15%
Eastern Mediterranean members	4%
European members	35%
Latin American members	25%
North American members	8%
South East Asian member	4%
Western Pacific members	9%
TOTAL	100%

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

IAPO funding transparency

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

Reference to IAPO's Code of conduct and policy regulating IAPO's relationship with, and independence from, sponsors can be found at: www.iapo.org.uk/consensus-framework-ethical-collaboration 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 2020.

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

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

IAPO had 289 members comprising umbrella groups and single organisations in 2020 who directly represented views of over 1 million patients in 71 countries across 52 disease areas. The services the charity provides are designed to build the capacity of patients' organisations, allowing them to better assist the needs of patients and carers (and their own member patient organisations in some cases) from across the world.

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

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

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

Risk Management

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

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

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

Financial review

Incoming resources for the year amounted to £509,091(2019: £343,855), which was higher than the previous year as we held two congress.

Expenditure in 2020 was £436,449 (2019: £366,886). Expenditure is also higher than the previous year, in line with the fact that we held two congress.

Reserves Policy

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

The level of unrestricted reserves, as at 31st December 2020 is £137,648. This is below the target in the reserves policy, and will be reviewed by the Board of Trustees.

Going Concern

The trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern. As they have considered the impact of the COVID-19 pandemic on both its income and expenditure for at least a period of twelve months from the date of approval of these financial statements and are expecting to make a surplus in 2021.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

Pension arrangements

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

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

Pay and remuneration of senior management

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

Future Activities

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

https://www.iapo.org.uk/sites/default/files/files/IAPO_Planned%20Activities%20in%202021.pdf

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

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

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

- **VISION 2022-24**
 - To ensure through global solidarity and national action that every patient enjoys healthcare that is:
 - Patient centred (PC) (broader definition)
 - Pandemic prepared (PP)
 - A Universal Health Coverage (UHC)
- **MISSION 2022-24**
 - Empower our members with cutting edge knowledge and advocacy skills in bringing about PC & PP UHC 2030.
 - Work with our membership, alliances, partners, and other stakeholders to drive research and policy development activity that establishes the evidence base needed in support of PC & PP UHC 2030 and strengthen patient involvement and co-creation in research.
 - Motivate the empowered patient community into using the evidence base created to shape the institutional, law, policy, practice, and standards framework needed for PC & PP UHC 2030 at global, regional (APEC, AU and EU etc) and national levels.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 DECEMBER 2020

- **TACTICAL PLAN 2022-24**

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

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

Statement of Trustees' responsibilities

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

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

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2020

Statement as to disclosure to our auditors

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

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

Reappointment of auditors

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

Approved and authorised for issue by the Board of Trustees on 13th December 2021 and signed on their behalf by:-



Sita Ratna Devi Duddi
Chair of the Board

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31ST DECEMBER 2020

Opinion

We have audited the financial statements of International Alliance of Patients' Organization for the year ended 31 December 2020 which comprise the Statement of Financial Activities (including the Income and Expenditure Account), the Balance Sheet and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2020 and of its income and expenditure, for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Conclusions relating to going concern

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

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

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

Other information

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

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

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31ST DECEMBER 2020

Opinion on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are Required to Report by Exception

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

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

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

Responsibilities of Trustees

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

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

Auditor's responsibilities for the audit of the financial statements

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

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

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31ST DECEMBER 2020

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

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

Use of our report

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

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 DECEMBER 2020

	Notes	Unrestricted £	Designated £	Restricted £	Total 2020 £	Total 2019 £
Income from charitable activities:						
Membership		127	-	-	127	8,569
Healthcare Industry Partners		118,808	-	-	118,808	195,186
APPC congress			44,209		44,209	130,755
GPC congress			270,421		270,421	-
Special Projects				68,556	68,556	4,611
Other charitable activities		6,970			6,970	4,734
Total	2	125,905	314,630	68,556	509,091	343,855
Expenditure on charitable Activities:						
Charitable activities:-						
• Capacity building, advocacy and collaboration		181,572	-	-	181,572	273,409
• Asia Pacific Patients Congress		-	38,889	-	38,889	93,477
• Global Pacific Patients Congress			154,369		154,369	
• Special projects		-	-	61,619	61,619	-
Total	3	181,572	193,258	61,619	436,449	366,886
Net income/ (expenditure)		(55,667)	121,372	6,937	72,642	(23,031)
Transfers		196,625	(196,625)	-	-	-
Net movement in funds		140,958	(75,253)	6,937	72,642	(23,031)
Reconciliation of funds:						
Funds brought forward		(3,31)	89,771	80,105	166,565	189,596
Total funds carried forward		137,647	14,518	87,042	239,207	166,565

All transactions are derived from continuing activities.

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

BALANCE SHEET AS AT 31 DECEMBER 2020

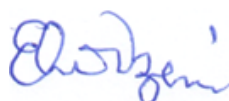
	Notes	2020 £	2019 £
Fixed assets	6	200	299
Current assets			
Debtors	7	127,992	151,586
Cash in hand and in bank		227,316	88,702
		<hr/>	<hr/>
		355,308	240,288
Creditors: amounts falling due within one year	8	(116,301)	(74,022)
		<hr/>	<hr/>
Net current assets		239,007	166,266
		<hr/>	<hr/>
Net assets		239,207	166,565
		<hr/> <hr/>	<hr/> <hr/>
Funds			
Unrestricted Funds		137,647	(3,311)
Designated Funds		14,518	89,771
Restricted Funds		87,042	80,105
		<hr/>	<hr/>
Total Funds	10	239,207	166,565
		<hr/> <hr/>	<hr/> <hr/>

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 2021 and signed on their behalf by:-



Sita Ratna Devi Duddi
Chair



Ellos Ellard Lodzeni
Treasurer

Registered company number: 08495711 (England and Wales)

The notes on pages 32 to 41 form part of these financial statements

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

CASH FLOW STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2020

		2020	2019
	Notes	£	£
Cash flows from operating activities:			
Cash generated from operations	1	138,614	(112,766)
Net cash provided by operating activities		138,614	(112,766)
Change in cash and cash equivalents in the reporting period		138,614	(112,766)
Cash and cash equivalents at the beginning of the reporting period		88,702	201,468
Cash and cash equivalents at the end of the reporting period		227,316	88,702

1. RECONCILIATION OF NET INCOME/(EXPENDITURE) TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2020	2019
	£	£
Net income/(expenditure) for the reporting period (as per the statement of financial activities)	72,642	(23,031)
Adjustments for:		
Depreciation Charges	99	146
Decrease/(Increase) in debtors	23,594	(80,665)
Increase/(Decrease) in creditors	42,279	(9,216)
Net cash provided by operating activities	138,614	(112,766)

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

1 Accounting Policies

1.1 Accounting convention

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

The financial statements are presented in Sterling (£).

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

Statement on going concern

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

As they have considered the impact of the COVID-19 pandemic on both its income and expenditure for at least a period of twelve months from the date of approval of these financial statements and are expecting to make a surplus in 2021.

1.2 Company status

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

1.3 Incoming resources

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

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

Restricted Project: Pfizer UpJohn Metrodora Awards to honour women scientists (\$58,000) , Pfizer Upjohn Stroke Twinning Project and Study (\$30,000)

Designated Events and Congresses in 2020 were the Global Patients Congress 16th-17th September 2020 and the 2nd Asia Pacific Patients Congress 3rd-4th December 2020. The Global Patients Congress had nine partners. The Asia Pacific Congress had four partners.

Asia Pacific Patient Congress 2020: The 2020 conference took place in Taipei. Congress income includes grants, sponsorship and delegate registration fees, all of which are recognised in the accounting year in which the event took place. Further information about the Congress including details of sponsors and supporters is available on our website.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

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

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

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

1.4 Expenditure

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

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

The core elements of charitable expenditure are as follows:-

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

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

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

1.5 Funds

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

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

1.6 Tangible fixed assets and depreciation

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

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

2 Incoming resources

	Charitable 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>

Income Resources comparative

	Charitable Activities & Others	Healthcare Industry Partners	Projects	Total
	£	£	£	£
Novo Nordisk	-	18,780	-	18,780
Amgen Global	-	39,714	-	39,714
Pfizerinc	-	38,778	-	38,778
PhRma	-	37,841	-	37,841
Ifpma	-	20,347	-	20,347
Gsk	-	39,726	-	39,726
Congress Sponsorship	-	-	130,755	130,755
Prefer	-	-	4,611	4,611
Other Activities and membership	13,303	-	-	13,303
	<u>13,303</u>	<u>195,186</u>	<u>135,366</u>	<u>343,855</u>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

Congress Sponsorship 2020

	Asia Pacific Congress	Global Patient Congress	Total
	£	£	£
Pfizer Inc	22,712	37,925	60,637
Roche Pharma Holding	7,232	30,164	37,396
Leo Pharma	14,266	39,005	53,271
Merck		31,572	31,572
BD		23,096	23,096
Bayer		23,029	23,029
Johnson Johnson		37,136	37,136
PhARMA		26,487	26,487
Novartis Pharma AG		22,006	22,006
	<hr/>	<hr/>	<hr/>
	44,209	270,421	314,630
	<hr/>	<hr/>	<hr/>

3 Analysis of support costs

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

4 Trustees and staff remuneration

The trustees received no remuneration, but 2 Trustees received reimbursements of £1,519 (2019: £14,547) for travel and subsistence expenses incurred on behalf of the charity.

Staff remuneration and numbers

	Total 2020 £	Total 2019 £
Wages and salaries	103,754	166,517
Social Security	14,789	20,825
Pension costs	1,026	6,859
Other personnel related costs: (recruitment, training, temporary staff)	-	28,263
	119,569	222,464

The average number of full and part-time employees during the year was 3. One individual employee received emoluments in excess of £60,000 (2019: one). Key management personnel costs amounted to £63,654 (2019: £63,654).

5 Operating Surplus

Operating surplus is stated after charging

	Total 2020 £	Total 2019 £
Auditors Remuneration	4,920	4,788
Depreciation of Assets	200	146
Operating Lease Charges (office rental)	31,277	31,277

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

6 Fixed Assets

	Computer equipment £
Cost	
Brought forward	4,169
Carried forward	<u>4,169</u>
Depreciation	
Brought forward	3,870
Charge for the year	99
Carried forward	<u>3,969</u>
Net book value	
At 31 December 2020	<u>200</u>
At 31 December 2019	<u>299</u>

There are no charges or securities held over any fixed assets. All fixed assets are held in the charity and none in the trading subsidiary. Depreciation of £219 was charged in the accounts for the previous period.

7. Debtors

	2020 £	2019 £
Debtors	97,356	35,548
Prepayments	6,880	6,880
Accrued income	23,756	109,058
	<u>127,992</u>	<u>151,586</u>

8. Creditors: amount falling due within one year

	2020 £	2019 £
Creditors	-	-
Deferred income	41,722	49,116
Accruals	74,579	24,906
	<u>116,301</u>	<u>74,022</u>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

9. Analysis of net assets between funds

	Unrestricted 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)
	<hr/>	<hr/>	<hr/>	<hr/>
Net assets at 31 December 2020	137,647	14,518	87,042	239,207
	<hr/>	<hr/>	<hr/>	<hr/>

10. Analysis of net assets between funds comparative

	Unrestricted Fund £	Designated Funds £	Restricted Funds £	Total Funds £
Tangible fixed assets	299	-	-	299
Current assets	140,667	89,283	10,338	240,288
Current liabilities	(74,022)	-	-	(74,022)
	<hr/>	<hr/>	<hr/>	<hr/>
Net assets at 31 December 2019	66,944	89,283	10,338	166,565
	<hr/>	<hr/>	<hr/>	<hr/>

11. Movements in funds

	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
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	166,565	513,287	(448,040)	-	239,207

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

Movements in funds Comparative

	At 31 December 2018 £	Incoming Resources £	Resources Expended £	Transfers £	At 31 December 2019 £
Unrestricted fund	61,609	208,489	(273,409)	-	(3,311)
<u>Designated Funds: -</u>					
APPC Congress	52,493	130,755	(93,477)	-	89,771
<u>Restricted funds: -</u>					
PREFER	27,901	4,611	-	-	32,512
PROTECT	-	-	-	-	-
Other projects	47,593	-	-	-	47,593
	189,596	343,855	(366,886)	-	166,565

Congress Overhead recharge

Congress income and expenditures were originally treated as unrestricted until it was agreed that they should be treated as designated in 2018 accounts onwards. However, although all direct income and cost related to the congress were allocated accordingly the overhead cost, primarily consisting of staff cost, were not. Which is why after careful allocation £196k cost was added to the total congress cost to date, moving cost from unrestricted to designated, to reflect true cost of congress in the past 3years.

GPC2020 Virtual

Considering the COVID-19 pandemic and in the best interest of participants, we made the difficult but inevitable decision to postpone the 9th Global Patients Congress to a virtual event on 16 -17 September 2020, under the theme of 'Co-creation in Innovative Healthcare during COVID-19'.

The re-imagined 9th Global Patients Congress (GPC 2020) was a moment to reflect on the defining health crisis of COVID-19 and its impact on the global patient community. The Congress was a great opportunity to focus our conversation on the next steps in health system strengthening and preparedness through patient led and co-created innovative solutions in 2020 and beyond.

The Congress brought together 1300 delegates; a number 10 times higher than the previous Global Patients Congress. Benefiting from the advantages of virtual conferences, delegates were based in 101 countries, an increase of 70 countries when compared with IAPO's previous global conference

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

APPC2020 Virtual

The Virtual 2nd Asia-Pacific Patients Congress 2020 (APPC2020) gave us a stark reminder that health in the region must not be considered as a sovereign matter. Health was a collective regional matter and all the patients, the State, and regulators in the region must collaborate across borders. The Congress brought together 3046 delegates from 66 countries, 20 times more than our 1st Asia Pacific Patients Congress, which was held face to face in Taiwan in 2019. In total, 298 patient groups attended APPC 2020, being 61 organizations members of IAPO.

Metrodora Awards

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

Stroke Twinning programme on stroke in LMIC

Twinning programme on stroke in Asia was supported by Pfizer Upjohn and developed as a twinning programme on stroke in Low and Middle Income countries (LMIC) located in the Asia-Pacific region, Middle East and Latin America.

PREFER

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

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

GetReal

Get-Real IMI Project has now concluded and has been set-up as a separate entity the Get Real Institute. We explored how real-world research data could be used in the development of drugs, to increase effectiveness and enrich decision-making by regulatory authorities and health technology assessment (HTA) agencies. IAPO's role is to bring the perspective of patients and patients' organizations to this work and facilitate the input of member organizations into the study. As a partner in this project, IAPO hopes to contribute to improving medicine development process, so patients have access to the drugs that they need. Surplus funds are ringfenced to be spent specifically on this project.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2020

12. Related parties

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

13. Post balance sheet event note

IMPACT OF COVID-19 PANDEMIC

The Trustees anticipate that the COVID-19 outbreak in February 2020 and the subsequent events will have a long-term impact on the Charity's incoming resources and resources expended in the coming years and on the fair value of its assets and liabilities. They have considered the likely impact on its incoming resources and how the charity can react to that impact and are confident that it has sufficient reserves and enough flexibility to ensure that it can continue to exist for the foreseeable future.