

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 2019



INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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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)	Penney Cowan (Resigned 15 May 2019) Jolanta Bilinska (Resigned 15 May 2019) Andrew Spiegel (Resigned 15 May 2019) Androulla Eleftheriou (Resigned 17 November 2019) Ellos Ellard Lodzeni Hussain Jafri (Resigned 17 November 2019) Karen Alparce-Villanueva Neda Milevska-Kostova Sita Ratna Devi Duddi (Chair) Ya Hsin Wang
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 2019

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The directors, who are also the trustees of the charity, are pleased to present their report together with the financial statements of the charity for the year ended 31 December 2019 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 267 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) and the International Prevention Research Institute (iPRI) partnerships with many other non-State Actors.

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IAPO's vision and mission

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

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

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

IAPO's activities include:

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

Structure

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

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

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Appointment and Induction of Governing Board

Every member of the IAPO Governing Board is elected by IAPO's members, through a process defined in the [Memorandum and Articles of Association](#), [By Laws](#) and [Election Code of Conduct](#) . Every year, in advance of the Annual General Meeting, 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.

Chairs report

This year 1999 was the start of our new three strategy (Strategy Documents <https://bit.ly/2TSNPZR>) Our vision remains to see patient-centred health care established in all countries. This would now mean the establishment of patient-centred universal health coverage (UHC) in all 194 United Nations Member States (MS) by 2030.

Our objective aims to ensure that there is a sufficient availability of patient-centred, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each World Health Organization 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 strategy in 2019 was:

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

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Empower patient communities globally to advocate effectively for PC-UHC for all

Health finance is critical to improve access to a sufficient quantity of promotive, preventive, curative, rehabilitative and palliative healthcare services in each WHO Member State. Health finance will improve access to essential and innovative medicines and health devices without the patients suffering financial hardship.

However, health finance and universal health coverage will not address all of the barriers preventing access. There needs to be other concomitant programmes that improve patient safety, quality, health literacy and communications within the healthcare system.

In order that healthcare is truly accessible, it has to be patient-centred and non-discriminatory.

Drive research processes and the development of evidence base for PC-UHC.

In order for a healthcare policy to be adopted, you must be able to provide evidence and best practice to support it. We have a relatively good understanding that patient centred UHC (PC-UHC) will improve access and healthcare outcomes. However, we need to undertake research to develop this evidence to support PC-UHC.

Expert-Patients as co-creators of research evidence is now well-established approach in improving healthcare. They are putting research into practice, and practice into research.

Shape law, policy and practice in PC-UHC at global, regional and national levels

Once you have empowered the patient advocates and have the research and best practice evidence in support of PC-UHC, you then need to ensure you cement this into institutions, laws, policy, practice and standards.

IAPO needs to shape laws, policy, practice and standards in PC-UHC

I hope you will join us next year at our Global Patients Congress 2020 and other notable events.

Regards



Sita Ratna Devi Duddi

Chair

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Governance review

IAPO is now marking its 21st Anniversary, having changed its governance jurisdiction from a Dutch Stichting (Foundation) and association to that of being a UK based charity and operating within the UK charity governance regime in 30 January 2014.

In 2019, our 20 Anniversary, The Board reviewed and harmonised IAPO's policies, by-laws and memoranda and articles of association, not just with the aim of achieving best governance standards, but with the aim to meet current international standards and best practice to attain results that our members want over the next 20 years. We have observed the *Charity and Voluntary Organisations' Good Governance Code* and its standards by undertaking board level training and development to ensure that the board members:

- Recognise and meet legal requirements
- Know how well the organisation is meeting its aims
- Make good, timely decisions
- Explain where, why and how money has been spent
- Provide strong leadership
- Treat people fairly and equally

IAPO has integrated new communication technologies (Zoom Webinars) during the pandemic to allow for greater membership engagement in the decision-making processes.

A vibrant and active membership organization like IAPO continues to ensure that international good governance and management standards are adopted by all its members in their governance and practice.

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Introduction

The International Alliance of Patients' Organizations' vision is to see patient-centred healthcare established globally.

IAPO's three year Strategic Plan (2019-2021) was approved at the Global Patients' Congress in Miami 2018. IAPO members wanted to advocate the pursuit of the establishment patient-centred universal health coverage within all WHO Member States.

In 2019, IAPO's main programme engaged with UHC2030 Global Partnership on advocacy targeted at the *United Nations High Level Meeting on Universal Health Coverage* and participate in the process to formalise an acceptable *Political Declaration on Universal Health Coverage*.

Our 2019 programme and activities focussed on getting across the message that the attainment of the *United Nations Sustainable Development Goals Target 3.8 Universal Health Coverage* requires a Member State to adopt patient-centred healthcare in the heart of its healthcare policy and decision-making. It was important that all State and non-State advocate patient engagement and an acceleration of the momentum to establish patient-centric universal health coverage (PC-UHC) for all by 2030.

In 2019, IAPO Strategy built upon the achievements of 2018 and pursued a multi-agency and cross-stakeholder global effort to support our 3 strategic goals:

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

IAPO believes that a comprehensive PC-UHC will ensure the availability of a sufficient quantity of patient-centric, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each country. These healthcare services, along with the essential and innovative medicines and health devices that compliment them, must be accessible, acceptable and affordable, and delivered without the patients suffering financial hardship or discrimination.

YEAR 1 OF STRATEGIC PLAN 2019

Goal 1 Empower patient communities globally to advocate effectively for PC-UHC for all.

Asia-Pacific Patient's Congress 13-14 Nov 2019 Taipei Taiwan

IAPO's Asia-Pacific Patient Congress was envisaged as a great two-day platform to bring together the regional patient movement in Asia-Pacific closer together and:

- To bring together all patients groups and key high level stakeholders in the region to discuss important issues concerning patients specifically from the Asia region
- To highlight IAPO's vision to see patients at the centre of healthcare throughout the world and its mission is to help build patient-centred healthcare and UHC worldwide
- To inspire patient groups to establish national patient alliances that will align and become members of IAPO

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The APPC targeted:

- Patient advocates
- Government and policy makers
- Industry representatives
- Healthcare professionals
- Academics and researchers
- Regulators

The Congress was organized and co-delivered by IAPO's regional members Psoriasis Association of Taiwan (PAT) and the Taiwan Alliance of Patient Organizations (TAPO).

7th Patient Solidarity Day 2019: 'Accelerating Progress for Safe Patient-Centred Universal Health Coverage.'

On Friday 6th December 2019, health stakeholders from all over the world came together, united in a celebration of Patient Solidarity Day (PSD). This was seventh year running that we have joined hands to mark the Day. On PSD 2019, IAPO members, patients, various healthcare organizations, policymakers, academia, industry and other stakeholders came together to call for '*Accelerating Progress for Safe Patient-Centred Universal Health Coverage*' to guarantee safe healthcare for all.

2019 has been a great year for global health advocacy. There was a global commitment to achieve safe and quality Universal Health Coverage (UHC). Heads of State and Health Ministers made two ambitious and comprehensive commitments:

On 24th May 2019, the World Health Organization Member States unanimously adopted Resolution 72.6 Global Action on Patient Safety in Geneva to address global patient safety in concerted manner.

On 23rd September 2019, The United Nations General Assembly adopted the Political Declaration of the high-level meeting on universal health coverage in New York, strongly recommitting to achieving UHC by 2030 scaling up the global effort to build a healthier world for all.

On PSD2019, we called on all leaders to act on the promises they have made in 2019 to guarantee safe patient-centred universal health coverage for all.

On PSD2019 patient advocates raised their voices to share the stories of the millions of people still waiting for health, to call on leaders to make bigger and smarter investments in health, and to remind the world that a safe Health for All is imperative to create the world we want.

<https://www.iapo.org.uk/2019-theme-0>

Membership Engagement

One of the main membership engagement activities this year was to reinforce our commitments on the main healthcare issues that needed to be addressed within IAPO's Strategy 2018-2020 and specify the goals and activities for the next three years. IAPO engaged its members and the wider stakeholder community to see how we can:

- Empower patient communities globally to advocate effectively for PC-UHC for all
- To drive research processes and strengthen patient involvement in research

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- Shape law, policy and practice in PC-UHC at global, regional and national levels.

IAPO's 2019 membership engagement activity involved providing information, advice and support to our members on various issues during the year. During 2019 there were a number of issues that we engaged our members on.

- PATIENT SAFETY
 - WHA Resolution 76. 2 and 1st World Patient Safety Day
- INNOVATION
 - Biotherapeutics -Biologic and Biosimilar Medicines
 - Gene and cell therapy
 - Oncology and monoclonal antibodies and chimeras
 - Rare Diseases and Disorders
 - Antimicrobial Resistance
- SUPPLY CHAIN, SAFETY and REGULATIONS
 - Substandard & Falsified Medicines (Fight the Fakes)
 - WHO Patients for Patient Safety
 - Quality and Safety (Medication without errors)
 - Regulation and pharmacovigilance-African Medicines Agency and EMA
- ACCESS
 - Access Survey- Structural and Social Determinants of Health
 - Access to Clinical Trials and Ethics
 - Health Technology Assessment and Health Finance
 - Non-communicable diseases
 - Primary Healthcare
 - Value Based Outcomes (VBO)
 - Carers and Self-Care
 - Multi-Chronic Conditions and Polypharmacy

Goal 2 Drive research processes and the development of evidence base for PC-UHC.

IAPO believes that early patient participation in research activity allows IAPO to incorporate patient perspectives within it. Any evidence base and good practice emerging from this participatory approach will help us develop patient-centric healthcare and medicines, and ultimately realise our vision for a PC-UHC by 2030.

In 2019 we conducted our 1st Access Survey to determine the role that structural and social determinants played in shaping access for our members.

In 2018 IAPO has been involved in strengthening patient involvement in research to get to our primary objective of PC-UHC through three interventions:

- GetReal Initiative IMI
- PREFER IMI
- IAPO in-house research initiative

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Since June 2018, IAPO has been involved in the GetReal Initiative. This is a two-year project of the Innovative Medicines Initiative (IMI). The IMI is a public-private consortium comprising researchers from the pharmaceutical companies, academia, HTA agencies, medicines regulators, patient organisations and other small to medium research enterprises.

GetReal Initiative's primary goal is to research upon and drive the adoption of evidence-based tools, methodologies and best practices to increase the quality of real-world evidence (RWE) generation in medicines development and regulatory/HTA processes across Europe. This helps IAPO as it will influence universal health coverage providers in planning their health finance, essential medicines lists and priorities far better.

PREFER initiative aims to 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. This is very important in ensuring a safe and quality PC-UHC.

Over the next five years, PREFER will run patient preference studies in both academic and industry settings. This patient voice and experience will provide industry, Regulatory Authorities and HTA bodies a better understanding of what is the recommended best-practice approach in patient-preference studies. It will also show how patient preference studies can give valuable information to support decision making for regulators and HTA bodies.

IAPO in-house research: From time to time, IAPO has collaborated with a number of research partners and written up joint speculative research proposals in partnership with these important research institutions. The collaboration in 2018 was with:

- **The Economic Intelligence Unit** (part of the magazine The Economist) - developed a collaborative research proposal patient electronic patient consent. The proposal has been finalised and we are waiting for a suitable research funding opportunity.
- **Institute for Prevention Research (IPRI)**- collaborated on two research proposal with them:
 - Bridging scientific Evidence, applications for Learning, policy Initiatives and public engagement for improving Vaccination among the Elderly
 - African Oncology- Follow up to their report: State of Oncology in Africa
- **TransCelerate BioPharma Inc (TCBP)**. IAPO is having ongoing discussions on the ASPIRE project (a collaboration with Novo Nordisk) to help patients engage with clinical trials and are building IAPO's relationship with TCBP
- **International Society for Quality in Health Care (ISQua)**. ISQua is a member-based, not-for-profit community and organisation dedicated to promoting quality improvement in health care. IAPO is working with them to improve the quality and safety of health care worldwide. IAPO endorses and supports ISQUA's education, knowledge sharing, external evaluation, supporting health systems worldwide and connecting like-minded people through our health care networks.

IAPO has also been working on developing some in-house membership surveys to support us to empower patient communities globally to advocate effectively for PC UHC for all. IAPO has ongoing work on:

- Systemic and Structural Factors affecting member organization's access to health
- Planning the policy research for 2019 in relation to the PC-UHC at global, regional and national levels.

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Shape law, policy and practice in PC-UHC.

In order to shape law, policy and practice on a safe and quality PC-UHC, IAPO needed to engage a number of global and national institutions and use a range of policy instruments to support advocacy.

Engaging Institutions

Engaging the United Nations

Health is a political choice (WHO Euro). The United Nations Security Council and its five permanent members (China, France, Russia, the United Kingdom, and the United States) have considerable power and resources to influence global health issues. The 2014 Ebola outbreak in West Africa signified this power when the global impasse and inaction was broken by President Barack Obama, acting as a UN Permanent Member of the Security Council, when he mobilised the Centres for Disease Control and the United States Army.

UNGA 2018. The United Nations General Assembly is the next most powerful global entity that can impact global health. In September 2018, IAPO attended the 73rd United Nations General Assembly and participated in the third High-Level Meeting called to review the implementation of the 2011 Political Declaration of the High-Level Meeting of the UN General Assembly on the Prevention and Control of Non-communicable Diseases.

IAPO advocated that patient participation and engagement within the comprehensive review of the global and national progress achieved in putting measures in place that protect patients from dying too young from heart and lung diseases, cancers and diabetes was extremely important.

IAPO reiterated that while most of the NCD control strategy has been driven by public health bodies in changing laws and regulations on sugar, fats, tobacco and sedentary lifestyles, secondary prevention measures like statins and diabetic management clinics have been under appreciated. Patients living with these conditions, especially expert patients, can make a great impact if they are engaged and supported appropriately in primary and secondary healthcare decision-making.

UN CoNGO Rare Diseases. The Conference of NGOs in Consultative Relationship with the United Nations (CoNGO) is an umbrella body of all non-State actors engaged with the UN. The NGO Committee for Rare Diseases (NGO CRD) of the EURODIS Rare Diseases International is a member. IAPO has a seat on NGO CRD and has collaborated in 2018 in setting the agenda, theme and programme of the UN Congo high level meeting in Feb 2019.

UN Political Declaration Universal Health Coverage 2019. IAPO will support UNGA and the Member States in their high level meeting to endorse their political commitment and declaration in supporting Universal Health Coverage to be made at the UNGA 2019.

Engaging WHO

WHO was created by the United Nations Member States as the directing and coordinating authority on international health, enabling the nations of the world to act together for the health of all people. IAPO is aware that health still remains a sovereign matter and that the role of WHO is confined to providing scientific evidence and support to Member States to engage in evidence-based decision-making in healthcare. IAPO members still have to engage with their own national parliaments and healthcare agencies to ensure that they have access to safe and quality PC-UHC in their own countries. We made three interventions at the WHA and five at their regional assemblies.

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WHO General Programme of Work (GPW) 2019-2023. WHO GWP is a planning and coordinating mechanism to fulfil WHO's global mission. IAPO has participated in planning the WHO thirteenth general programme of work 2019–2021 Promote health, keep the world safe, and serve the vulnerable. http://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_4-en.pdf?ua=1

IAPO worked upon and submitted its own collaboration plan to support the 13th GPW 2019-2021. IAPO GPW 13 collaboration plan works supports IAPO 2018-2020 strategy and promotes safe and quality PC-UHC by 2030. The WHO will announce the renewal of IAPO non-State actor's status and the acceptance of IAPO plan at the Executive Board in January 2019.

As Patients for Patient Safety members, IAPO commitments to the earlier WHO GPW 12 2016-2018 to lead, participate and contribute towards the patient safety programme and decision-making in the WHO. IAPO is a member of the WHO Expert Consultation: Patient Safety Assessments within the context of UHC. IAPO responds to its consultations and attends its meeting (face-to-face and remotely via web-ex).

IAPO is supporting the WHO Global Ministerial Summits on Patient Safety. IAPO engaged with the Third Global Ministerial Summit on Patient Safety (2018) Tokyo, Japan and joined some 500 participants representing high-level government delegations from Ministries of Health of 44 countries across the world and key international organizations to press home how important patient safety is with national health policy. <https://www.who.int/patientsafety/policies/ministerial-summits/en/>

IAPO endorsed the Tokyo Declaration on Patient Safety <https://www.mhlw.go.jp/file/06-Seisakujouhou-10800000-Iseikyoku/0000204005.pdf>

Medication safety has become a big global issue. In a lead up to IAPO's Patient Solidarity Day 2018, In November 2018 IAPO participated and engaged with WHO Consultative Meeting on '*Implementing WHO's Global Patient Safety Challenge: Medication Without Harm Country Guidance*'. We presented our ideas and approaches to medication safety and briefed the Member States about our Patient Solidarity Day 2018.

IAPO is also providing input and comment to the WHO on its new initiative to develop a national patient safety assessment tool that will allow each Member State to assess its own patient safety institutions, legislation, policy, practice, standards and national patient safety surveillance and ombudsmen systems to a recognised standard and report on it. This will help ensure safe and quality universal health coverage.

IAPO continues to engage with the WHO Regional Committees and attended six WHO Regional Committee meetings in WHO AFR (Dakar Sep 2018), WHO EMR (Khartoum-Oct 2018), WHO EUR (Rome Sep 2018), WHO PAH (Washington-Sep 2018), WHO SEAR (Delhi Sep 2018), WHO WPR (Manila-Oct 2018).

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IAPO engaged the health legislators and policy makers on the inclusion of expert patients in the non-communicable diseases agenda and to engage patients on a law, policy and practice in universal health coverage, patient safety and patient-centric healthcare systems.

IAPO has a seat on the International Advisory Group on Primary Health Care for universal health coverage and it collaborated with the WHO on the WHO Global Conference on Primary Health Care and Astana Declaration (Alma Ata 40) in Kazakhstan.

IAPO joined over 100 Member States present to renew our commitment to primary health care to achieve universal health coverage and the Sustainable Development Goals. The Conference was held at the Palace of Independence and was co-hosted by the Government of Kazakhstan, WHO and UNICEF with over 500 high-level health policy delegates and legislators meeting to discuss a road-map to UHC 2030. IAPO was the invited organization and advocated on dismantling of silos in healthcare and encouraged Member States to utilise expert-patients as the great underutilised resource in primary healthcare planning and decision making. Expert-patients could also be employed within the frontline as phlebotomists, community health workers and within other roles where their insight would be a great asset.

WHO/UNESCO Council for International Organizations of Medical Sciences (CIOMS)

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

IAPO has been collaborating with its newly launched working group with the purpose of involving patients as key stakeholders in the development and safe use of medicines. CIOMS has given a seat to one of our African Members on its working group.

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IAPO Membership in 2019 IAPO consolidated its membership in 2019 and sought new members covering rare diseases and non-communicable diseases. IAPO had 269 members at 31st December 2019. 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%

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IAPO funding transparency

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

Reference to IAPO's Code of conduct and policy regulating IAPO's relationship with, and independence from, sponsors can be found at: www.iapo.org.uk/consensus-framework-ethical-collaboration 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 2019.

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.

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

IAPO had 267 members comprising umbrella groups and single organisations in 2019 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.

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FOR THE YEAR ENDED 31 DECEMBER 2019

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 £343,855 (2018: £510,218), which was lower than the previous year.

Expenditure in 2019 was £366,886 (2018: £547,037). Expenditure is also lower than the previous year.

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, including designated funds, at 31st December 2019 decreased to £86,161. This is below the target in the reserves policy, however the Trustees have deemed that funding requirements are enough for the forthcoming year to operate a going concern budget, especially in light of the confirmed projects going ahead in 2020.

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 2020.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 DECEMBER 2019

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

Goal 1: Empower patient communities globally to advocate effectively for PC-UHC for all

- Action 1 - Build the evidence-based knowledge to support effective patient advocacy
 - a) Establish the evidence base and best practices to promote patient centricity worldwide and effectively advocate for PC-UHC:
 - b) Research and establish the policy instruments, strategies and approaches that have had the largest reach, effectiveness and impact on overcoming the resistors and enhancing the drivers to patient empowerment;
 - c) Use an IAPO membership survey to test accuracy, relevancy, and currency of research findings;
 - d) Map the required knowledge and skills needed for patients to advocate effectively for PC-UHC.

- Action 2 - Design, develop and deliver capacity building aimed at ensuring patients are equipped with the necessary skills to advocate for PC-UHC
 - a) Partner with other organizations to design the appropriate curriculum, toolkits and resources to deliver the training, based on adult learning and community practice settings. The findings of Line of Action 1 will inform the training:
 - b) Use appropriate online and webinar technologies, and face-to-face workshops for training;
 - c) Develop a policy education programme aimed at promoting patient empowerment.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 DECEMBER 2019

Goal 2: To drive research processes and strengthen patient involvement in research

- Action 1 - Strengthen the IAPO research activities, where IAPO and its members will develop patient-led research.
 - a) Work with IAPO members to set research priorities and engage them in the design, implementation and dissemination of research findings.
- Action 2 -Improve IAPO's quality of research dissemination:
 - a. Review IAPO's communication network and the digital platforms used to communicate and disseminate information;
 - b. Work in partnership with other organizations to develop an 'information highway' for 'expert patients' within our membership so that they are able to become research-literate and have resources and support.
 - i. Identify and map research opportunities for IAPO members.
 - ii. Undertake capacity building in partnership with other organizations to improve member engagement in research as reviewers, assessors, and patient-centricity experts.
 - iii. Work with academic partners, policy research teams and industry to undertake various research projects.

Goal 3: Shape law, policy and practice in PC-UHC at global, regional and national levels.

- Action 1 - Build the evidence-based knowledge to understand the policy context that drives PC-UHC.
 - a. Map the regional and global legislative, policy and institutional frameworks underpinning the drive towards a PC-UHC globally;
 - b. Develop partnerships with international law and pro bono legal services and health law research institutions to map the frameworks underpinning PC-UHC;
 - c. Segment regions, countries, partners and patient organizations affected by health legislation, policy and practice supporting PC-UHC;
 - d. Define the policy instruments that have been effectively used to reach and impact patient centricity and universal health coverage;
 - e. Engage IAPO members in the WHO report on UHC.
 - f. Undertake policy research and policy implementation evaluations and modelling to identify the alternative policies that might facilitate achievement of PC-UHC.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT

FOR THE YEAR ENDED 31 DECEMBER 2019

- g. Implement IAPO-WHO Collaboration Plan 2019-2021. Undertake a review of IAPO membership to assess its reach and impact to support the implementation of the IAPO-WHO Collaboration Plan 2019-2021.
- Action 2 - Fuel and strengthen IAPO's official collaboration with the World Health Organization (WHO) and ensure that patients' voices are adequately represented in the global arena by playing a leading role in relevant events, policy consultations, educational programmes, and research activities.
- Action 3 - Lead outcome-oriented collaborations with state and non-state actors and strategic international partners to advocate for PC-UHC.
 - a. Actively promote and engage in cross-stakeholder alliances in which IAPO members can contribute to health services design and delivery:
 - i. Build relationships with regulatory bodies to become more strongly involved in new regulations focused on quality of life, psycho-social burden of disease and treatment;
 - ii. Engage with initiatives aimed at promoting patient centricity in the processes of generation, development and dissemination of information in healthcare (medicines, technologies, research);
 - iii. Engage in initiatives advocating for increased financing and strengthening of systems of health to reduce health disparities across the world;
 - iv. Design collaboration plans with strategic partners.
- Action 4 - Place a PC-UHC resolution before the World Health Assembly by 2021.
 - a. Produce a needs assessment of partnerships of what is required for a WHO Resolution on PC-UHC by 2021:
 - b. Gain support from 3 WHO member states for the resolution;
 - c. Gain support from member states and other organizations in an official relation with WHO.
 - d. Work collaboratively with multi-stakeholders to produce the draft of the PC-UHC Resolution.
 - e. Gather support from the WHO Executive Board and Secretariat to place the PC-UHC Resolution before the 2021 World Health Assembly (WHA).

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2019

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.

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 11th December 2020 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 2019

Opinion

We have audited the financial statements of International Alliance of Patients' Organization for the year ended 31 December 2019 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 2019 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

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

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 2019

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.

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

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

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 2019

	Notes	Unrestricted £	Designated £	Restricted £	Total 2019 (year) £	Total 2018 (year) £
Income from charitable activities:						
Membership		8,569	-	-	8,569	20,072
Healthcare Industry Partners		195,186	-	-	195,186	223,221
APPC congress		-	130,755	-	130,755	200,722
Special Projects		-	-	4,611	4,611	65,821
Other charitable activities		4,734	-	-	4,734	382
Total	2	208,489	130,755	4,611	343,855	510,218
Expenditure on charitable Activities:						
Charitable activities:-						
• Capacity building, advocacy and collaboration		273,409	-	-	273,409	364,453
• Asia Pacific Patients Congress		-	93,477	-	93,477	130,010
• Special projects		-	-	-	-	52,574
Total	3	273,409	93,477	-	366,886	547,037
Net income/(expenditure)		(64,920)	37,278	4,611	(23,031)	(36,819)
Transfers		-	-	-	-	-
Net movement in funds		(64,920)	37,278	4,611	(23,031)	(36,819)
Reconciliation of funds:						
Funds brought forward		61,609	52,493	75,494	189,596	226,414
Total funds carried forward		(3,311)	89,771	80,105	166,565	189,596

All transactions are derived from continuing activities.
All recognised gains and losses are included in the Statement of Financial Activities.
The notes on pages 27 to 34 form part of these financial statements

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

BALANCE SHEET AS AT 31 DECEMBER 2019

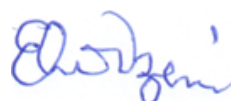
	Notes	2019 £	2018 £
Fixed assets	6	299	445
Current assets			
Debtors	7	151,586	70,921
Cash in hand and in bank		88,702	201,468
		<u>240,288</u>	<u>272,389</u>
Creditors: amounts falling due within one year	8	(74,022)	(83,238)
		<u>166,266</u>	<u>189,151</u>
Net current assets			
		<u>166,266</u>	<u>189,151</u>
Net assets		<u>166,565</u>	<u>189,596</u>
Funds			
Unrestricted Funds		(3,311)	61,609
Designated Funds		89,771	52,493
Restricted Funds		80,105	75,494
		<u>166,565</u>	<u>189,596</u>
Total Funds	10	<u>166,565</u>	<u>189,596</u>

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

These financial statements were approved and authorised for issue by the Board of Trustees on 11th December 2020 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 27 to 34 form part of these financial statements

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2019

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 2020.

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.

Project Funding: IAPO has received restricted funding for the following projects:

Asia Pacific Patient Congress 2019: The 2019 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 2019

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.

PROTECT: IAPO is a partner in a European project, the Pharmacoepidemiological Research on Outcomes of Therapeutics by a European Consortium (PROTECT). PROTECT aims to strengthen the monitoring of the benefit-risk of medicines, and IAPO currently supports work on two parts (work packages) of the project.

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 2019

2 Incoming resources

	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
Pfizer	-	4,611	4,611
	<hr/>	<hr/>	<hr/>
	195,186	135,366	330,552
	<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 2019

4 Trustees and staff remuneration

The trustees received no remuneration, but 6 Trustees received reimbursements of £14,547 (2018: £32,986 for travel and subsistence expenses incurred on behalf of the charity).

Staff remuneration and numbers

	Total 2019	Total 2018
	£	£
Wages and salaries	166,517	169,584
Social Security	20,825	16,692
Pension costs	6,859	2,538
Other personnel related costs: <i>(recruitment, training, temporary staff)</i>	28,263	24,990
	222,464	213,804

The average number of full and part-time employees during the year was 4 (plus two on maternity leave). One individual employee received emoluments in excess of £60,000 (2018: one). Key management personnel costs amounted to £63,654 (2018: £63,654).

5 Operating Surplus

Operating surplus is stated after charging

	Total 2019	Total 2018
	£	£
Auditors Remuneration	4,788	4,788
Depreciation of Assets	146	219
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 2019

6 Fixed Assets

	Computer equipment £
Cost	
Brought forward	4,169
Additions	-
Carried forward	<u>4,169</u>
Depreciation	
Brought forward	3,724
Charge for the year	146
Carried forward	<u>3,870</u>
Net book value	
At 31 December 2019	<u>299</u>
At 31 December 2018	<u>445</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

	2019 £	2018 £
Debtors	35,548	38,551
Prepayments	6,880	6,880
Accrued income	109,058	25,490
	<u>151,586</u>	<u>70,921</u>

8. Creditors: amount falling due within one year

	2019 £	2018 £
Creditors	-	-
Deferred income	49,116	49,116
Accruals	24,906	34,122
	<u>74,022</u>	<u>83,238</u>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2019

9. Analysis of net assets between funds

	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)
Net assets at 31 December 2019	<u>66,944</u>	<u>89,283</u>	<u>10,338</u>	<u>166,565</u>

Analysis of net assets between funds 2018

	Unrestricted Fund £	Designated Funds £	Restricted Funds £	Total Funds £
Tangible fixed assets	445	-	-	445
Current assets	144,402	52,493	75,494	272,389
Current liabilities	(83,238)	-	-	(83,238)
Net assets at 31 December 2018	<u>61,609</u>	<u>52,493</u>	<u>75,494</u>	<u>189,596</u>

10. Movements in funds

	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
	<u>189,596</u>	<u>510,218</u>	<u>(547,037)</u>	<u>-</u>	<u>166,565</u>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2019

Movements in funds 2018

	At 31 December 2017 £	Incoming Resources £	Resources Expended £	Transfers £	At 31 December 2018 £
Unrestricted fund	244,634	243,675	(364,453)	(62,247)	61,609
<u>Designated Funds: -</u>					
Global Patients Congress	(18,219)	200,722	(130,010)	-	52,493
<u>Restricted funds: -</u>					
PREFER	-	14,014	-	13,887	27,901
PROTECT	-	-	(48,360)	48,360	-
Other projects	-	51,807	(4,214)	-	47,593
	<u>226,415</u>	<u>510,218</u>	<u>(547,037)</u>	<u>-</u>	<u>189,596</u>

APPC

The first Asia Pacific Patient Congress (APPC) was held on 13th -14th November 2019, in Taipei Taiwan (ROC) at the Sheraton Grand Taipei Hotel. 150 member organizations and stakeholders, representing 25 countries in the Asia Pacific Region, came together to look at how patient engagement can support harmonisation of patient-centred Universal Health Coverage (UHC) in the Region. Co-hosted with IAPO's regional members, the Psoriasis Association of Taiwan (PAT) and the Taiwan Alliance of Patient Organizations (TAPO-ROC), the APPC created an enabling environment within which delegates could actively contribute to a wide range of interactive sessions, workshops, and networking activities to improve healthcare in the Asia-Pacific Region.

PROTECT

The goal of PROTECT was to strengthen the monitoring of the benefit-risk of medicines in Europe. This will be achieved by developing a set of innovative tools and methods to enhance the early detection and assessment of adverse drug reactions and enable the integration and presentation of data on benefits and risks.

These methods will be tested in real-life situations in order to provide all stakeholders (patients, prescribers, public health authorities, regulators and pharmaceutical companies) with accurate and useful information supporting risk management and continuous benefit-risk assessment.

PROTECT was completed in 2016 but completion work incurred costs funded out of unrestricted funds. Thus in 2018 £48,360 of unrestricted reserves was transferred into the restricted funds to cover for the repayment.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2019

PREFER

PREFER will run over the next five years 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 will Give our input to patient preference studies run in both academic and industry setting by others. Our perspective will provide a better understanding of what the recommended best-practice approach to patient-preference studies should be in the future. We will disseminate results later to show how patient preference studies can give valuable information to support decision making for regulators and HTA bodies.

A prefinancing amount of £13,887 was received in 2016 but misallocated as unrestricted income. This has been corrected in the year by transferring this amount from unrestricted to restricted funds.

GetReal

GetReal is 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. 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.

Other projects; Gene Therapy Project

This project started at the Miami Congress and looks at the role gene and cell therapies will play in future healthcare. The project is particularly important for patients with rare genetic diseases. The project held webinars, and has produced a draft tool kit. We will release this in May 2019 at the World Health Assembly and form new partnerships with Rare Diseases International.

11. Related parties

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

12. 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.