

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 2017



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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)	Penney Cowan (Chair) Jolanta Bilinska (Previous Chair) Andrew Spiegel Androulla Eleftheriou Bejon Misra Ellos Ellard Lodzeni (Appointed 23rd May 2018) Hussain Jafri Joshua Wamboga (Resigned 20 th October 2017) Karen Alparce-Villanueva (Appointed 23rd May 2018) Matthias Wienold (Resigned 18 th August 2017) Migdalia Denis Neda Milevska-Kostova (Appointed 11 th August 2017) Ratna Duddi (Appointed 11 th August 2017) Ya Hsin Wang (Appointed 23rd May 2018)
Chief Executive	Kawaldip Sehmi
Bankers	NatWest Bank Plc PO Box 12258 1 Prices Street LONDON EC2R 8BP
Lawyers	Bates Wells & Brathwaite LLP 2-6 Cannon St LONDON EC4M 6YH
Independent auditor	Knox Cropper 8/9 Well Court LONDON EC4M 9DN
Website	www.iapo.org.uk

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2017

The trustees present their report and financial statements of the charity for the year ended 31st December 2017. 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 SORP (SORP 2015 – "Statement of Recommended Practice", FRS 102 version), which became applicable for charities with year ends starting or commencing on 1st January 2015.

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 established in 1999 and has a membership of 282 organizations across 71 countries covering 51 diseases groups. IAPO is in official relations with the World Health Organization (WHO) and has official partnerships 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) amongst many others.

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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. 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; 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.

Message from the Chair

This year (2017) was the culminating year of our three year strategy 2015-17. IAPO has performed well and our achievements can be found on our website. <https://bit.ly/2GiJAwr>

In 2017 IAPO had set itself three objectives and achieved them as follows:

1) Leading the patient voice on global healthcare issues

IAPO took the lead on identifying key issues in healthcare on which to advocate at all levels of decision-making. IAPO then undertook research and produced briefings and toolkits for its members. We ensured that the patient voice was heard in global, regional and national fora. IAPO spoke out on these key issues with a clear voice and sought to make its voice strongest where it can have most impact.

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2) Advancing patient engagement

IAPO developed and disseminated models of healthcare advocacy and practice, drawn from our membership experience, of what effective patient engagement looks at all levels of healthcare decision-making. IAPO demonstrated to our stakeholders and healthcare policy makers that patient engagement leads to more effective healthcare. This was especially useful when engaging with the formation and establishment of the African medicines agency.

3) Empowering the global patient movement

IAPO used the three years to develop the ability of our members to understand the key healthcare issues identified, and advocate effectively and clearly. We used briefings, resources, webinars, and opportunities for face to face sharing and learning from each other at events like the African Meeting in Entebbe, The World Health Assembly Side-Events and at other global forums. IAPO also empowered strengthened its regional networks, recognising that each region had different ways to develop, and ensured Latin America and African members were given the appropriate IAPO support in their events.

I recognise that none of the work of IAPO or the delivery of its goals could have happened without the organization itself being strong, sustainable and committed. 2017 was used to strengthen IAPO itself to ensure that as a responsible global organization we can work together with our membership to achieve our vision and mission.

I will be stepping down in August 2018 and want to thank the Board, members and staff of IAPO for having given me the opportunity and support to ensure we achieve patient centred healthcare globally. I wish the new incoming Chair Penney Cowan all the success in 2018 and beyond.

For a detailed insight of our 2017 out-turn please visit our website www.iapo.org.uk and look at our Twitter account (@IAPOvoice) and Facebook Page (IAPOvoice and our Latin American and African pages).

Jolanta Bilinska
Chair

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Achievements in 2017

1. Leading the patient voice on global healthcare issues

- World Health Assembly (Geneva, 22-31 May). Being in an official relationship with the World Health Organization, IAPO was able to submit three comments on items of the official agenda of the World Health Assembly (WHA): Health emergencies (Agenda item 12.1); Donation and management of blood (Agenda item 13.2); Prevention and control of non-communicable diseases (Agenda item 15.1).
- In addition, IAPO held 6 side-events co-hosting with a number of State and non-State Actors and our Industry Partners on important topics
- **Biotherapeutics & the next 70 years:** Delivering on their potential for patients globally, 23 May 2017, International Red Cross and Red Crescent Museum. Co-hosted by IFPMA (International Federation of Pharmaceutical Manufacturers and Associations) and IAPO, this event looked at the current issues of access and the variation in regulatory regimes in the approval of biosimilars (especially within Latin America). It brought together the International Federation of Pharmacists (IFP), prescribers, payers and patients to discuss the practice of switching and substitution between the originators and their biosimilars and the impact on the public budget and public health (patient safety pharmacovigilance). The take home messages were:
 - Biotherapeutics have transformed modern medicine through innovative and targeted therapies;
 - They have transformed lives of patients with chronic conditions (e.g. diabetes Type1);
 - Brought relief and reduced severity of symptoms for many rare conditions;
- **Displaced people with chronic conditions** – How to tackle the pandemic on the move, 24 May 2017, Musée Ariana. Co-hosted by IAPO, the Kenya Red Cross Society, Novartis and Novo Nordisk, this event debated the burden of noncommunicable diseases in displaced populations and the specific health challenges they face. It called upon actors from all sectors to share experiences and ideas on how to address the unmet needs. Multi-stakeholder partnerships and innovative financing models are needed to cope with the situation at hand. Joshua Wamboga our chair-elect spoke about South Sudan and its refugee population in Uganda and the impact on a struggling health system.

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- **Access and care of patients with polychronic conditions:** An expert dialogue meeting, 24 May 2017, Restaurant Vieux Bois. Co-hosted by TEVA and IAPO, this event convened experts on the issues of patients with polychronic conditions, aspiring to unite the health care, policy and patient communities to address siloes between sectors and align policy agendas; highlighted the interconnections between the major global risks in the context of sustainable development goals 3 and the post-2015 development agenda, with particular focus on people suffering from polychronic conditions; and establish synergistic opportunities in polychronic, specifically highlighting 'what works' in the co-benefits approach to advance sustainable development and reducing risks and enhancing effective management of polychronic conditions. IAPO Board Secretary Penney Cowan launched the International Pain Awareness Month (September each year) in the occasion. Pain management is often conducted within polychronic disease management settings.
- **Addressing sepsis - the unrecognized number one cause of preventable deaths from infection / WHA Resolution A70/13,** 24 May 2017, Domain de Penthes. The dialogue, co-hosted by the Global Sepsis Alliance (GSA), the German Ministry of Health and IAPO, was shadowing the recommendation of the WHO Executive Board to the 70th World Health Assembly to adopt a resolution WHA A70/13 - Improving the prevention, diagnosis and clinical management of sepsis that urges member states to develop training for all health professionals on infection prevention and patient safety. The meeting heard from patients and carers who called to highlight and help in understanding that infections which may lead to sepsis can often be prevented through appropriate hygiene, access to vaccination programs, to improved sanitation and water availability. The Resolution was adopted unanimously.
- **Global heart health and the road to 2025: Supporting a heart healthy agenda for the age of longevity,** 24 May 2017, InterContinental Hotel. This event was co-hosted by the World Heart Federation, DEVEX and IAPO, and was supported by Novartis. The event acted as a platform to share new data from 'Global Heart Health: Evaluating Efforts to Promote Healthy Hearts', a comprehensive report and scorecard of country progress in heart health, created by The Economist Intelligence Unit. A panel of health and innovation experts with Bejon Misra, our Board Member from South Asia, discussed where countries stand on the road to reducing premature mortality due to cardiovascular diseases by 2025. Experts will highlight the major challenges they face and discuss the available opportunities to unleash innovation in disease prevention, management and treatment in an ageing world.

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- **Safeguarding blood safety for the multi-transfused patients**, 26 May 2017, UN Headquarters. Organized by IAPO and the blood and blood product using patients' organizations Thalassaemia International Federation (TIF), World Federation of Hemophilia (WFH), International Society of Blood Transfusion (ISBT), Worldwide Network for Blood & Marrow Transplantation (WBMT) and International Patient Organisation for Primary Immunodeficiencies (IPOPI) to enhance discussion on the WHA Resolution A70/19 - Principles for global consensus on the donation and management of blood, blood components and other medical products of human origin. The event focussed on raising discussion on blood safety for the multi-transfused patients and the patient perspective on the principles of global consensus on donation and management of blood and blood products. Multi-transfused patients are exposed to more risks from infections and adverse immunological response after a mismatched blood transfusion than any other blood recipients. Giving blood is like giving medication and the Medication Without Harm-the 3rd Global Patient Safety Challenge offers some systemic issues we need to address to strengthen patient safety in blood donations and transfusions.
- **IAPO supported a rapid mapping survey led by the WHO Patient for Patient Safety Geneva** Office with its WHO Country Offices on mapping national patient safety strategies and the existence of national patient safety institutional, legal and the policy and practice framework. The CEO provided support on the NHS Patient Safety Agency and the NHS policy framework lessons learnt. WHO has produced a draft landmark map of what is in place in each country and shared this with us. We are taking this work forward and have produced our own mini-survey to assess what our members are doing (pending release).
- IAPO took part and actively contributed input in to the WHO consultation on its newly released Framework of Interaction with **Non-State Actors (FENSA)**, to a WHO consultation on the prequalification programme for similar **biotherapeutics products**, and a WHO consultation on the **WHO 13th Programme 2019-2023**.
- IAPO continues its work within the **Patients' and Consumers' Working Party** aimed at enhancing patient engagement in medicines development and appears in **EMA's list of European Expert**, enabling us to participate in specific initiatives concerning document review and scientific advice. Kawaldip Sehmi attended PCWP roundtable on improving messaging and naming biosimilars and two TCs to re-write a health professional fact sheet.

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- **IMI-GetReal** has officially ended on 31 March 2017. The consortium is back at work to apply for an IMI exploitation call so as to be able to continue the work that has been carried out within the consortium. Some of the consortium's key outputs in 2017 to which IAPO has contributed include:
 - Real-world evidence navigator: Putting real-world healthcare data to work
 - PragMagic: Pragmatic Trial Resources
 - Online course: "Real-World Evidence in Medicine Development"
 - 15 Journal articles
- **IMI-PREFER.** IAPO is part of the research consortium "IMI-PREFER", a 5-year research project aimed at exploring effective ways of incorporating patient preferences in the drug development process. The project is in its first year. IAPO is working with other patients organisations (European Cancer Patients Coalition, European Patients Forum, and Muscular Dystrophy UK) in the Patient Advisory Group. In particular we are leading the work stream on methodology.
- IAPO has been added to the NHS **National Institute for Health Research** pool of reviewers.
- IAPO and The **Economist Intelligence Unit** collaboration is progressing on a research proposal on the gap between legal consent and informed consent.
- **International Forum Safe Online Pharmacies New Delhi India** 1-2 March 2017 Alliance for Safe Online Pharmacies (ASOP Global) brought together 160 key international stakeholders and local India partners for "Patient Safety and Access to Safe Online Pharmacies," an international forum in New Delhi, India.

Forum speakers included representatives from the Government of India (GoI) officials; India Consumer Online Federation; U.S. Food and Drug Administration (FDA); U.S. Pharmacopeial Convention; Great Britain; Indonesia; France; INTERPOL; the National Association of Boards of Pharmacy (NABP); International Alliance of Patient Organizations (IAPO); International Institution of Research Against Counterfeit Medicines (IIRACM); PhRMA; Pharmaceutical Security Institute; Partnership for Safe Medicines (PSM) India Office; Digital Health Platform (an association of Indian Internet pharmacies); the U.S. Embassy; and WHO SEARO and WHO SERO Office.

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2. Advancing patient engagement

- IAPO's Board Member, attended **FIFARMA's Capacity Building Strategy** meeting in Miami. The meeting aimed at gaining understanding of the current regional and in-country needs of Patient Advocacy Groups, as well as of the efforts key stakeholders are doing. FIFARMA aims to develop a strategic plan for capacity building, based on capability levels of the Patient Advocacy Groups in Latin America.
- IAPO Chair and IAPO Policy Manager attended the **HTAi International Conference** in Rome, 20-22 June 2017 and presented on multiple topics related to patient engagement in HTA.
Outcome: IAPO continues its work in HTAi's patients and citizens working group.
- IAPO signed an MOU with the The International Prevention Research Institute (**iPRI**) to mark the World Cancer Day

3. Empowering the global patient movement

- Development of IAPO-industry collaborative projects (Empowerment Toolkit and the Biosimilars Toolkit) aimed at increasing patient advocates' knowledge as to how to develop cross-stakeholder collaborations in healthcare
- We are currently participating in the EPF-led Task Force on patient safety, represented by our Chair Jolanta Bilinska.
- 3rd African Regional Meeting, held on 4th – 5th July 2017 in Entebbe, Uganda, the meeting brought together over 30 of IAPO's member organizations and collaborators, representing ten African countries. The meeting, which focused on the on-going African Medicines Regulatory Harmonization (AMRH) initiative, culminated in delegates making a united call for a patient-centred African Medicines Agency (AMA) in which patients are meaningfully engaged.
- African programme development. Following the regional meeting in Uganda, IAPO is working with members and other patient advocates in the region to lobby and influence decision-makers to ensure that patients are recognised as key partners in the African Medicines Agency. IAPO is seeking to formalise its relationship with the New Partnership for Africa's Development (NEPAD) through the form of a Memorandum of Understanding.
- 3rd Biennial Scientific Conference on Medical Products Regulation in Africa, 27 – 28 November 2017, Ghana. The New Partnership for Africa's Development (NEPAD) invited IAPO to send a patient advocate from the region to represent the patient movement by speaking at a session on civil society engagement in harmonisation. This will be an opportunity to continue pushing the calls for patient engagement in the African Medicines Agency.

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- Alianza Latina Meeting, 26-27 October 2017, Rio de Janeiro. Alianza Latina and IAPO Forum – Best practices for the Third Sector in health. The event will be held on 26-27 October in Rio de Janeiro, Brazil. IAPO will hold a specific session on the second day entitled 'Clinical Research in Latin America' to discuss the following topics: i) what are the rights and benefits of the patients who participate on clinical trials?; ii) the importance on considering the voice of the patients on the development of clinical trials; and iii) the clinical research being conducted in Latin America.
- 2nd TAG meeting, Universal Health Coverage meeting, WHO Western Pacific Region, 13-15 November 2017, Manila, Philippines. After IAPO's successful representation at the 1st TAG meeting in 2016, IAPO will be represented by the Philippines Alliance of Patient Organizations for the 2nd convening on the topic.
- Policy Manager is representing IAPO in the core group of the newly launched Rare Diseases International Advocacy and Policy Committee. The committee was established in September 2017 and has already delivered an output (response to WHO consultation on 13th programme 2019-2023).
- IAPO Research Unit is moving on and its concept note, operational document, and strategy have been developed.
- PRE - Patient Research Exchange. We have now fully taken over this resource. The 'exchange' will form an important part of our Research Unit and its information dissemination strategy. We are inviting our pharma partners to submit articles and research results that could benefit our members. Patient Research Exchange's mission is to provide a platform that delivers high-quality information and enhances cross-stakeholder dialogue on how to best pursue and put in practice meaningful patient engagement in medical research.
- The Member Engagement and Empowerment plan. At the start of 2017, IAPO launched an engagement plan to facilitate members' engagement with IAPO's work. We focused on four overarching themes for the year, which were patient-centred healthcare, access, transparency and accountability and Empowerment (Patient Solidarity Day theme). Each month, we have focused on a sub-theme, exploring the issues through policy briefings (see further detail below), engagement with members internally and on social media, and through a thematic newsletter edition. By focusing in this way we have facilitated greater participation from IAPO's membership and wider network, for example through contributions to the monthly newsletter and networking between members.

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- The Policy Briefing Series, which forms a key part of the Member Empowerment and Engagement plan, aims at providing IAPO members, partners and stakeholders with a systematic overview of how key global healthcare issues impact patients and the role patients can play in policy making and shaping. The briefings published to date cover topics such as Patient-centred healthcare, Patient Information and health literacy, High-quality access to care, Patient involvement in HTA, Patient safety, Medicines regulatory harmonization, Pain management, patient empowerment.
- In the first quarter of the Member Engagement and Empowerment plan, we held a webinar to develop the capacity of IAPO's member organizations, which explored practical approaches for finding and assessing the most credible health evidence to help patient organizations to build a strong case when advocating for change. The speaker Fiona Morgan, a Systematic Reviewer and Lecturer at Cardiff University, shared tips and tools on how to navigate the range of health evidence available to effectively assess the credibility and value of a source. She also presented strategies, techniques and tools for carrying out this assessment. To provide for IAPO's large membership in Latin America, we facilitated simultaneous Spanish translation.
- IAPO has starting filming for a new empowerment initiative – the Patient Voice platform. This will be an online space for members to highlight and share powerful stories on innovations in patient advocacy relating to the work of their organizations, that they can share with others in the network. It will act as a platform for sharing and disseminating best practice in patient advocacy, as well as assisting networking and engagement between members and other stakeholders.
- Patient Solidarity Day, Saturday 2nd December 2017, will be centred on the theme "Globally Empowered Patients. Power Through Knowledge". Earlier in the year, IAPO conducted a consultation with all members and stakeholders, asking for theme suggestions for the upcoming day and all members had the opportunity to vote on the final theme. A PSD 2017 Grant Scheme was launched in September, which provides a small amount of financial support to members in their advocacy activities. These grants will assist members in holding activities, such as hosting seminars, conferences, marches and lobbying. Once again, we will use the social media tool, Thunderclap, to maintain momentum on the campaign.
- Meet the Members series. To encourage networking between members and to highlight the diverse and significant expertise evident among IAPO's members, each month we have published a video interview with one of IAPO's member organisations. This also acts as a platform for showcasing the work of members.

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- International Pain Awareness Month. In September, IAPO dedicated the Engagement and Empowerment plan to International Pain Awareness Month, as led by the American Chronic Pain Association. The campaign gained traction from members and the wider network, securing engagement globally, notably from patient advocates in India, Australia, Bulgaria, UK, Ireland, Croatia, Venezuela. The IAPO secretariat also took part in the 'Give a Squat 4 Pain' element of the month, by posing for a 'squat' photo, which was posted on social media.
- WHO 13th General Programme of Work 2019-2023. IAPO conducted a survey with its members on WHO's consultation 2019-2023 programme. An IAPO submission was made, reflecting comments from members in Uganda, Venezuela, Kenya and the Philippines.

Empowering global patient movement

IAPO has increased and diversified its membership in 2017. We now have over 250 member organizations.

Region	%
African members	14%
Eastern Mediterranean members	4%
European members	37%
Latin American members	23%
North American members	10%
South East Asian member	3%
Western Pacific members	9%
TOTAL	100%

Members were consulted in the development of IAPO's 2017 Work Plan in Africa. The Patient Solidarity Day 2017 consultation was a great opportunity to engage with members, and collect information about activities and get support for the initiative. Members are now being consulted on the Global Patients Congress 2018 to assess key issues and priorities for them.

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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 2017.

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' organization representing patients with communicable and non-communicable diseases, including patients with diseases that are stigmatised in many societies.

IAPO has 282 members who represent around 365 million patients and carers across the world. 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 and going forward the aim is to translate sections of the website to increase access to patients and their carers from around the world. 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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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.

At this early stage of the year, as we have to re-establish relationships with some of the old funders and by the appointment of a project officer the efforts have doubled on widening income from the research unit's engagement in project work, the 2017/18 budget has been prepared using a 'worst-case' scenario in order for Trustees to fully understand the level of financial risk. With the WHO collaborative and the African Congress breaking even, and having three new Pharmaceutical companies become our gold industry partners, it is therefore anticipated that focused fund raising activity will result in an improved financial situation. Periodic financial reports to the Board will enable risks to the organization's sustainability to be easily identified and addressed in good time.

Financial review

Incoming resources for the year amounted to £491,311 (2016: £493,722), which was higher than the previous period due to being a Congress year.

Expenditure in 2017 was £434,855 (2016: £478,854). Expenditure is higher in Congress years, which happen every two years. 2017 was not a Congress 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. This policy was set with due regard to guidance from Charity Commission (CC19 – Charity Reserves) and is reviewed annually.

The level of unrestricted reserves at 31st December 2017 increased to £244,633. The Trustees have deemed that funding requirements are sufficient for the forthcoming year to operate a going concern budget through and into 2018.

The Global Patients Congress reserve at 31st December 2017 has a deficit of £18,219 due to spending related to the 2018 Congress. No income was received in connection with the event until after the year end.

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Pension arrangements

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

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

Pay and remuneration of senior management

IAPO has a team of research officers and volunteers led by a Chief Executive. With natural wastage IAPO has been downsizing by not replacing staff who left in 2017, which has streamlined service delivery considerably.

FUTURE ACTIVITY 2017/18

We are now in the fourth year of delivery against Strategic Plan published online. In 2017 we are consolidating and building on our successes from 2017 to achieve our three Strategic Objectives:

1. Leading the patient voice on global healthcare issues
2. Advancing patient engagement
3. Empowering the global patient movement

The main outward facing activities are:

- Participate in the WHO Executive Board
- Participate in the World Health Assembly May 2017
- Host the African Patients Congress in Jul 2017
- Participate in the WHO Regional Committees in Aug 17
- Host the Latin American Regional Congress in Nov 17
- Hosts the Patient Solidarity Day in Dec 17
- Continue collaboration with IMI in the GetReal project
- Develop and launch an Advocacy Empowerment Toolkit
- Update our Biosimilars Toolkit

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2017

The inward facing membership engagement and development activities in are:

Membership development & capacity-building:

- 2-year African regional plan developed in Jan 2017
- A Latin American Plan developed in Jan 2017
- Patient-centered content, training and support developed for members
- Monthly patient briefings on key patient-centered principles
- Informative resources completed/circulated to members and other interested organizations

Communications:

- Publicise patient-centered healthcare (and key policy messages) with decision-makers and health professionals
- External authors/ experts in IAPO communications
- IAPO attendance and profile at targeted events

2018-20 strategic plan:

- Develop our 2018-20 strategic plan with targets and objectives for engagement, assessing collaboration opportunities which fit with IAPO key objectives
- Develop potential projects in line with key objectives; discuss with stakeholders and possible partners
- 2018 Global Patient Congress
- Consult and plan the 2018 GPC

Trustee Board, Governance & Finance:

- Board meetings (2) and sub-Committee meetings (audit, membership, etc.)
- Gold Health Industry Partner meetings (2)
- Annual external audit; Companies House & Charity Commission compliance

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2017

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 21st September 2018 and signed on their behalf by:-


P. Cowan - Trustee & Director
Chair

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31ST DECEMBER 2017

Opinion

We have audited the financial statements of International Alliance of Patients' Organization for the year ended 31 December 2017 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 2017 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.

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.

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.

Opinion on other matters prescribed by the Companies Act 2006

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS FOR THE YEAR ENDED 31ST DECEMBER 2017

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.

Kevin Lally

Kevin Lally FCA (Senior Statutory Auditor)
For and on behalf of Knox Cropper (Statutory Auditor)
8/9 Well Court
London
EC4M 9DN

21st September 2018

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 DECEMBER 2017

	Notes	Unrestricted £	Restricted £	Total 2017 (year) £	Total 2016 (year) £
Income from charitable activities:					
Membership		5,832	-	5,832	6,245
Healthcare Industry Partners		292,119	-	292,119	345,955
Global Patients Congress		-	-	-	137,136
Special Projects		-	190,249	190,249	-
Other charitable activities		3,111	-	3,111	4,436
Total	2	301,062	190,249	491,311	493,772
Expenditure on charitable Activities:					
Charitable activities:-					
• Capacity building, advocacy and collaboration		199,862	-	199,862	348,321
• Global Patients Congress		-	18,219	18,219	14,125
• Special projects		-	216,774	216,774	189,147
Total	3	199,862	234,993	434,855	478,854
Net income/(expenditure)		101,200	(44,744)	56,456	14,918
Transfers		(7,092)	7,092	-	-
Net movement in funds		94,108	(37,652)	56,456	14,918
Reconciliation of funds:					
Funds brought forward		150,525	19,433	169,958	155,040
Total funds carried forward		244,633	(18,219)	226,414	169,958

All transactions are derived from continuing activities.
The notes on pages 24 to 30 form part of these financial statements

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

BALANCE SHEET AS AT 31 DECEMBER 2017

	Notes	2017 £	2016 £
Fixed assets	6	664	991
Current assets			
Debtors	7	84,839	13,314
Cash in hand and in bank		157,476	195,653
		<hr/>	<hr/>
		242,315	208,967
Creditors: amounts falling due within one year			
	8	(16,565)	(40,000)
		<hr/>	<hr/>
Net current assets		225,750	168,967
		<hr/>	<hr/>
Net assets		226,414	169,958
		<hr/> <hr/>	<hr/> <hr/>
Funds			
Unrestricted fund		244,633	150,525
Restricted funds		(18,219)	19,433
		<hr/>	<hr/>
Total funds	10	226,414	169,958
		<hr/> <hr/>	<hr/> <hr/>

These financial statements were approved and authorised for issue by the Board of Trustees on 21st September 2018 and signed on their behalf by:-


P Cowan - Trustee & Director
Chair


H Jafri - Trustee & Director
Treasurer

Registered company number: 08495711 (England and Wales)

The notes on pages 24 to 30 form part of these financial statements

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

1 Accounting Policies

1.1 Accounting convention

The financial statements of the charitable company, which is a public benefit entity, are prepared in accordance with the Statement of Recommended Practice: Accounting and reporting by charities (SORP 2015 – FRS 102 version), applicable accounting standards and the Companies Act 2006. The charity has taken advantage of the Small Entity provisions of FRS 102. The financial statements are presented in Sterling (£).

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

Statement on going concern

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

1.2 Company status

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

1.3 Incoming resources

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

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

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

Latin America Regional Programme: for the support of activities for members in the Latin America region, including the holding of a regional meeting and the production of an online platform on biological and biosimilar medicines.

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

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 £100 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 2017

2 Incoming resources

	Healthcare Industry Partners £	Projects £	Total £
AbbVie UK	-	18,453	18,453
Amgen	37,136	-	37,136
Eli Lilly	18,216	-	18,216
GSK	39,279	-	39,279
Janssen	29,740	-	29,740
J.C. General Services	-	19,459	19,459
Medtronic	23,550	-	23,550
Merck	37,608	-	37,608
Novartis	-	43,048	43,048
Novo Nordisk	37,875	-	37,875
PhRMA	38,715	-	38,715
Roche	-	68,509	68,509
Tekeda	30,000	-	30,000
Congress Sponsorship	-	40,000	40,000
Other	-	780	780
	<hr/>	<hr/>	<hr/>
	292,119	190,249	482,368
	<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 2017

4 Trustees and staff remuneration

The trustees received no remuneration but received reimbursements of £20,165 (2016: £5,237) for travelling and subsistence expenses incurred on behalf of the charity.

Staff remuneration and numbers

	Total 2017	Total 2016
	£	£
Wages and salaries	187,772	175,205
Social Security costs	20,934	19,464
Pension costs	3,979	5,657
Other personnel related costs: (recruitment, training, temporary staff)	19,896	13,410
	<hr/> 232,582 <hr/>	<hr/> 213,736 <hr/>

The average number of full and part-time employees during the year was between 5 and 8. Senior Management Personnel costs amounted to £63,000 (2016: £63,000). One member of staff received emoluments between £60,000 - £70,000 (2016: 1).

5 Operating surplus

Operating surplus is stated after charging

	Total 2017	Total 2016
	£	£
Auditors remuneration (including VAT) (all audit services)	4,788	4,560
Depreciation of assets	495	328
Operating lease charges (office rental)	41,572	38,976
	<hr/> 46,855 <hr/>	<hr/> 43,864 <hr/>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

6 Fixed Assets

	Computer equipment £
Cost	
Brought forward	4,169
Additions	-
Carried forward	<u>4,169</u>
Depreciation	
Brought forward	3,177
Charge for the year	328
Carried forward	<u>3,505</u>
Net book value	
At 31 December 2017	<u>664</u>
At 31 December 2016	<u>992</u>

There are no charges or securities held over any fixed assets. Depreciation of £328 was charged in the accounts for the previous period.

7. Debtors

	2017 £	2016 £
Debtors	-	-
Prepayments	25,099	13,314
Accrued income	59,740	-
	<u>84,839</u>	<u>13,314</u>

8. Creditors: amount falling due within one year

	2017 £	2016 £
Creditors	14,565	-
Deferred income	-	40,000
Accruals	2,000	-
	<u>16,565</u>	<u>40,000</u>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

9. Analysis of net assets between funds

	Unrestricted Fund £	Restricted Funds £	Total Funds £
Tangible fixed assets	664	-	664
Current assets	260,534	(18,219)	242,315
Current liabilities	(16,565)	-	(16,565)
Net assets at 31 December 2017	<u>244,633</u>	<u>(18,219)</u>	<u>226,414</u>

10. Movements in funds

	At 31 December 2016 £	Incoming Resources £	Resources Expended £	Transfers £	At 31 December 2017 £
Unrestricted fund	150,525	301,062	(199,862)	(7,092)	244,633
<u>Restricted funds:-</u>					
Biotookit	-	42,295	(42,295)	-	-
GetReal	19,566	-	(26,525)	6,959	-
Global Patients Congress	(133)	-	(18,219)	133	(18,219)
Patient research website	-	43,048	(43,048)	-	-
PROTECT	-	-	-	-	-
Universal Health Coverage Day (70 th Anniversary)	-	26,214	(26,214)	-	-
Other projects	-	78,692	(78,692)	-	-
	<u>169,958</u>	<u>491,311</u>	<u>(434,855)</u>	<u>-</u>	<u>226,414</u>

INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

Biotoolkit

This toolkit provides patients' organizations with up-to-date, evidence-based information on the science, technology and regulatory information relevant to biologic originator and their biosimilar medicines, as well as tips on advocacy. More information can be found here: <https://www.iapo.org.uk/biosimilars-toolkit>. The fund was fully spent during the year.

GetReal

GetReal (continuing in 2018 through "Get Real 2") 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. More information can be found here: <https://www.iapo.org.uk/getreal>

Global Patients Congress

The Global Patients Congress is our flagship event where we bring together our global membership with a variety of high level healthcare stakeholders to discuss important issues for patients worldwide. There was no Congress in 2017 but an amount of £18,219 was expensed in advance to secure the accommodation for the 2018 Congress in Miami. More information can be found here: <https://www.iapo.org.uk/global-patients-congress>

Patient Research Website

IAPO now manages The Patient Research Exchange, which a group of people representing many different experiences and geographies who are dedicated to exploring how the patient perspective can improve participation in and the effectiveness of research. This website is a place for people interested in active patient-centered research to exchange ideas, experiences, resources, and perspectives. More information can be found here: <https://www.patientresearchexchange.org/>

PROTECT

The goal of PROTECT was to strengthen the monitoring of the benefit-risk of medicines in Europe. This was 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. PROTECT was completed in 2016 but completion work incurred costs funded out of unrestricted funds.

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.

More information can be found here: <https://www.iapo.org.uk/protect>

Universal Health Coverage Day (70th Anniversary)

Universal Health Coverage Day has become the annual rallying point for the growing movement for health for all. It marks the anniversary of the United Nations' historic and unanimous endorsement of universal health coverage in 2012. For more information, access the campaign website here: <https://www.iapo.org.uk/events/universal-health-coverage-day>

Other projects

There are a number of other projects in the pipeline as described in the Trustees Report about.

11. Related parties

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