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 2016
# 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)
Jolanta Bilinska (Current Chair)
Joshua Wamboga (Chair elect)
Hussain Jaffri (New Treasurer, Appointed 1 August 2016)
Matthias Wienold (Former Treasurer, Resigned 1 August 2016)
Andrew Spiegel (Appointed, 1 August 2016)
Androulla Eleftheriou (Appointed, 1 August 2016)
Bejon Misra (Appointed, 1 August 2016)
Migdalia Denis (Appointed, 1 August 2016)
Penney Cowan (Secretary)
Robert Johnstone (stepped down 31 July 2016)

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
The trustees present their report and financial statements of the charity for the year ended 31st December 2016. 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, at the end of 2016, had a membership in the region of 280 organizations across 71 countries covering 51 disease groups. IAPO is in official relationships 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

As the Chair of the Board of IAPO, stepping down in August 2017, I am delighted to introduce this annual report and accounts for 2016 to the Chair Elect Joshua Wamboga, our Board and membership, and discuss our outlook for 2017. 2016 began in challenging times as we recovered from a transition period during which we had registered as a new entity in the UK, overseen changes of staff, while welcoming a new Board.

In 2016 we not only had to deliver the 7th Global Patients Congress 2016, but also re-establish relationships with some of the newly appointed patient-liason officers at our industry partners. The sector had seen many partners restructure their operations after mergers and acquisitions. Our staff managing relationships with our industry partners had left and we had not recruited new staff as the deficit in 2015 put considerable pressure on our resources. We had to re-structure and work creatively to reengage the industry partners, making fundraising every one’s business. Fortunately, 2016 started well for our Industry partners as many appointed new enthusiastic patient engagement teams and they worked proactively with us to re-establish the lost relationships with a new vigour.
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At the end of 2015 we had 250 members in 67 countries across 47 disease groups. 2016 ended well as in December 2016 we had 282 members in 71 countries across 51 disease groups.

We delivered a great Global Patients Congress (GPC) in Apr 2016 Innovation Improving Sustainable Access: boosting your reach and impact that kept to its ethos of: by the patients, for the patients. Many patient organizations were given a platform for the first time to show-case their best practice and unique skill in patient advocacy. 136 delegates from across the world attended the Congress.

The Global Patient Solidarity Day, Leave no-one behind, on 3rd December 2016 was another great opportunity to advocate for patient-centric healthcare and a platform for capacity building, sharing experience and recruiting new members in 2016. 172 organizations from 44 countries actively celebrated the event and advocated for sustainable patient-centric universal health coverage (UHC) in all countries. Patients and their representatives marched in support of UHC, lobbied politicians, provided free health screenings and stood together in solidarity. The campaign reached over 120,000 people via social media and dozens wrote articles and blog posts to mark the occasion.

In departure from 2015, our Latin American Programme in 2016 concentrated on quality rather than quantity and we did not hold a large Latin American Congress. We started delivery capacity building training in smaller country cluster settings where the participating organizations could be more engaged with the trainers, process and fellow delegates. Our first cluster meeting in November 2016 in Bogota Columbia went very well. 40 stakeholders from 26 patients’ organizations from Colombia, Ecuador, Panama, Peru and Venezuela attended the event.

I would now like to thank our staff team and the volunteers for their tireless hard work for IAPO during the transitional period. The staff helped us deliver the 2016 GPC and an extensive programme of capacity building and training. Our new staff members have overseen the full incorporation and registration of IAPO UK and have started moving IAPO into new directions and opportunities to achieve patient centred health care globally. Our team includes a policy and research manager, a members engagement manager, a project manager focusing on medical issues within Africa and Latin America, an office manager and three interns serving managing communications, research and WHO collaboration.

As the retiring Chair, I would take this opportunity to thank my fellow board members for their support and contributions made in 2016 to advance our objectives in a difficult year. It is also important at this point to thank our industry partners and their patient engagement teams; without their advice and support, we could not have achieved these results. Your support helped us reach even more vulnerable patient communities around the world in 2016.
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Lastly, but most importantly, I would like to pay tribute to IAPO’s members who have worked very hard in 2016 to the benefit of patients the world over. It is your dedication which has advanced patient engagement and patient-centred health care over the past year. We will once again call upon you for your support over the next 3 years as we set about formulating our new Strategic Plan 2018-2020 and IAPO enters the next exciting phase of its life.

Governance review

IAPO is now in its third year as a UK based charity and appreciating with the UK charity governance regime.

The Board has begun the process of harmonising 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 standards that attain results internationally in order achieve our members overall requested objectives. 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

The board conducts continuous consultation with members in 2017 to bring our by-laws into harmony with best practice and new regulations, amending bye-laws as necessary. IAPO has integrated new communication technologies (Skype and Webinars) 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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Meeting our objectives in 2016

2016 was the 3rd year of IAPO’s Strategic Plan. The overall theme for the year was *leading, advancing and empowering*. The Strategic Plan grouped activities under 3 strategic objectives:

- Leading patient voice on global health issues
- Advancing patient engagement
- Empowering global patient movement

Outcomes in 2016

1) World Health Organization-Executive Board Geneva-Jan 25-30, 2016. Jolanta Bilińska (Chair) and Hussain Jafri attended the event.
   - Reach: 194 ministers of health and 160 NGOs. World Media live broadcast of NGO interventions.
   - Activity: Networking and made a statement on the Framework of engagement with non-State actors
   - Outcome: EB resolution to continue IAPO’s status as an NGO in official relationship with WHO

2) World Health Assembly 69th Geneva May 23-29 2016. Chair Jolanta Bilińska, Board Member Matthias Wienold and Hussain Jafri attended the event. Supported by Kawaldip Sehmi
   - Reach: 194 ministers of health and 160 NGOs. World Media live broadcast.
   - Activity: Held three side-events and made three interventions: i) health of migrant and refugee patients, ii) health in sustainable development 2030 –patient focus on UHC, iii) health of patients during large scale emergencies and health system collapse (natural disasters and Ebola)
   - Outcome: WHA acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Social media recognition that IAPO is the first patients’-group championing patients’ engagement in humanitarian and relief planning.

3) UN General Assembly Summit Pre-meeting Refugees/ Migrants health and welfare July 18 2016 (Physically Hussain Jafri) and 9th September 2016 remotely via Webex Link Kawaldip Sehmi
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- Reach: UN Agencies and NGOs involved with refugees and migrants.
- Outcome: IAPO placed patient-centred approaches and seamless health care on the agenda of all humanitarian bodies dealing with refugee and migrant issues. Patients’ right to health must be respected by all belligerent parties.

4) WHO Afro 66th Regional Committee Addis Ababa Ethiopia 19 to 23 August 2016 Chair-elect Joshua Wamboga
- Reach: 44 ministers of health and 40 NGOs. African Media live broadcast.
- Activity: Two interventions: i) health of migrant and refugee patients, ii) health in sustainable development 2030 –patient focus on UHC
- Outcome: WHO Afro acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Social media recognition that IAPO is the first patients-group championing African patients’ engagement in humanitarian and relief planning.

5) WHO SEARO 66th Regional Committee 5-9 September 2016, Colombo, Sri Lanka Chair-Jolanta Bilinska and Board Member Bejon Misra
- Reach: 12 ministers of health and 40 NGOs. South Asian Media live broadcast.
- Activity: Two interventions: i) health of migrant and refugee patients, ii) Access to patient-centred health and fitness programmes
- Outcome: WHO SEARO acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Health and wellbeing programmes should be accessible to all. Social media recognition that IAPO is the first patients-group championing South Asian patients’ engagement in humanitarian and relief planning.

6) PAHO and WHO Americas 68th Regional Committee 26-30 September 2016, Washington, USA Board Member Migdalia Denis
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- Reach: 35 ministers of health and 80 NGOs. US and LatAm Media live broadcast.
- Activity: Two interventions: i) Resilient Health Systems ii) WHO Framework Engagement non-State Actors (Fensa)
- Outcome: WHO PAHO and Americas acknowledges patient-centric health systems are resilient health systems and that UHC needs health system strengthening. SDG 2030 Goal 3.8 attainment needs health system strengthening. WHO engagement of non-state actors from the NGO sector needs a light-touch engagement to encourage participation.

7) WHO Western Pacific 67th Regional Committee 10-14 October 2016, Manila, Philippines Karen Villanueva (Manila PAPO) and 2 other Philippines member organizations from Manila were attending event.
- Reach: 29 ministers of health and 30 NGOs. Asian and Australian Media live broadcast.
- Activity: Two interventions: i) SDG 2030 and UHC ii) WPRO Emerging Diseases Strategy
- Outcome: WHO WPRO acknowledges that patient-centric approaches are needed to (achieve?) the SDG 2030 Goal 3.8 attainment. WPRO needs to place patient best interest and engagement in emerging diseases strategy.

8) Prince Mahidol Award Conference & NICE Intl-priority setting Thailand Jan 2016: Ryan Lee (NICE IAPO Designate) & Kawaldip Sehmi.
- Reach: Health Ministers from 26 SE Asian Countries and 1200 delegates from global public health and patient advocacy.
- Activity: Joint presentation with NICE Int on patient group engagement and embedding in HTA process, having permanent patient presence on NICE International and national HTA boards. Participation in WHO workshop and session with DTA on Quality and Compassion in UHC. Sharing a panel with Sir Marmot on health inequality and patient engagement.
- Outcome: Our expertise on patient involvement in HTA recognised and our presence in the region acknowledged.

- Reach: World Bank UHC Forum (120 key health finance stakeholders)
- Activity: Advocated in panel discussions that patient-centred UHC critical for all. IAPO UHC principles promoted. Advocated that a patient-centred UHC is core to achieving sustainable development goals 2030. Financing alone is not enough.
- Impact: Acknowledgement that patient-centred UHC central to SDG 2030
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10) Global Forum on Incontinence Berlin Germany April 29 2016 Panel Kawaldip Sehmi CEO
   • Reach: 250 State and non-State Global Stakeholders involved in Continence Care
   • Activity: Presentation and panel on patient-centred continence care. Devices, care products and care should be acceptable and patient-centred.
   • Outcome: IAPO interest in patient-centred continence care acknowledged by all. Patient-centred continence care touches many disease groups and ages, not only elderly. Products must be acceptable and fit for young active patients too.

11) European Conference on Rare Diseases and Orphan Products May 27 2016 Edinburgh Panel Durhane Wong-Rieger and Kawaldip Sehmi CEO
   • Reach: 800 participants and 86 patient organizations involved in rare diseases.
   • Activity: Panel-chair on advocating for a public health response on rare diseases at the international level
   • Outcome: IAPO leadership in rare diseases and orphan drugs in low and middle income countries acknowledged.

12) State of Oncology in Africa Report Launch and iPRI National Cancer Institute’s Directors Meeting July 11-13 2016 Jolanta Bilińska and Joshua Wamboga
   • Reach: 50 directors of National Cancer Institutes from low and middle income countries. 20 Oncology organizations and national Ministry of Health Agencies.
   • Activity: Jolanta advocated Patient Centred Oncology a priority. Joshua expanded on oncology in Africa. Uganda’s only radiotherapy machine is not working.
   • Outcome: IAPO leadership in patient-centred oncology low and middle income countries acknowledged. Professor Boyle may collaborate with us on an African project.

13) FIFARMA meeting Panama City July 26-27 2016
Latin American Pharmaceutical Manufacturers-Kawaldip Sehmi
   • Reach: 80 Pharmaceutical heads in Latin America
   • Activity: Presented our plan as to how we can collaborate with FIFARMA to benefit patients’ in LATAM.
   • Outcome: Latin American funding strategy and country cluster workshop idea developed. November launch opportunities

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14) The BIO International Convention (BIO) FIFARMA meeting 6-9 June 2016

- Reach: Attracts over 15,000 biotechnology and pharma leaders
- Activity: Held a booth in Patient Forum Arena and intensive networking to discover new opportunities and promising partnerships with a wide spectrum of Biotech firms.
- Outcome: Opened dialogue with a number of organizations on biotherapeutics. Biosimilars toolkit update funding secured.

15) UN NGO Committee for Rare Diseases inauguration in New York. 11 November 2016 Migdalia Denis and Durhane Wong-Reiger joined Anders Olason, Agenska Foundation, to bring visibility and understanding of rare diseases to the United Nations.

- Reach: UN and WHO policy makers and over 2000 patient groups
- Activity: Live Stream debate to the world.
- Outcome: IAPO recognised as a part of the global strategy on rare diseases at UN level.

16) Health of 1.2 billion people 11th National Quality Conclave, Quality Council of India and Indian Alliance of Patient Groups (IAPG) Roundtable 18-20th August 206, New Delhi, India Bejon Misra and Matthias Wienold

- Reach: Over 200 allopathic medicine and traditional aryuvedic treatment quality regulators and health policy makers in India
- Activity: Led seminars and workshops on Quality of Care in UHC
- Outcome: IAPO recognised as a patient leader in UHC quality issues

17) Association for Medical Education in Europe (AMEE) International Congress, Workshop Co-Chair and speaker 29-30th August 2016 Barcelona, Spain Matthias Wienold and Stijnije Dijk IFMSA Liaison Officer for Medical Education

- Reach: Over 3200 delegates from academia, industry and other NGO sectors engaged in medical education
- Activity: Led seminars and workshops on Patient involvement in teaching and the medical curriculum
- Outcome: Patient centric medical education curriculum recognised as a policy issue and IAPO as a leader in developing it.
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18) 1st World Sepsis Congress Online Workshop Matthias Wienold led inaugural online Seminar marking WSD 2016

- Reach: Over 8000 patients, health care professionals and other stakeholders online
- Activity: Led seminar on sepsis and challenges of patients and families
- Outcome: IAPO recognised as the patient group with a sepsis care interest.

19) World Health Summit, Berlin Germany 10th Oct 2016 Panel
The Contribution of Biologic Medicines to Public Health Matthias Weinold Co-chair and Speaker: and Durhane Wong-Rieger

- Reach: Over 15000 participants includes ministers of health, health policy makers and patient organizations
- Activity: Matthias Wienold co-chaired the panel on biotherapeutic medicines
- Outcome: IAPO recognised as opinion leader and patient voice on biotherapeutics


- Reach: Report being prepared; 172 groups from 44 countries participated.
- Activity: Walks, social media, health screenings and meetings.

21) Think Health Romania’s Health Conference 13th October 2016 Board Member Androulla Eleftheriou attended this event in Romania.

- Reach: Nearly 100 Central and Eastern European Health Policy Makers
- Activity: Participated in CE Europe Health Strategy. Live stream of debates and workshops
- Outcome: Improved IAPO standing in Central and Eastern Europe

22) WHO African Region WHO Global Dialogue Meeting NCDs and SDG 2030 Balaclava, Mauritius, 19–21 October 2016 Dalilah Kalia from Lupus Alert Mauritius attended two meetings on our behalf
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• Reach: 54 African Countries represented through 40 civil society organizations.
• Activity: Participated in two workshops.
• Outcome: IAPO now part of the African non-State actors’ network and the regional Framework for the prevention and control of Non-communicable Diseases (NCDs)

23) Pre-ICDRA at International Conference of Drug Regulatory Authorities Cape Town 27th Nov-29th Nov 16
• Reach: 100 National Medicines Regulatory Authorities Present, including the 54 African NMRA and over 50 NGOs in official relationship with WHO and other non-State Actors organizations.
• Activity: Participated in one side-meeting and two workshops on patient engagement in strengthening and harmonising medicines regulation, especially access to biotherapeutics.
• Outcome: NMRAs recognise IAPO as a representative patient body that they can engage with in strengthening and harmonizing medicines and health device regulation. African NMRAs, Regional Economic Bodies and non-State actors aware of IAPO’s patient-centric approaches.

24) WHO WRPO Technical Advisory Group 1st meeting for the Universal Health Coverage Manila Philippines 12 Dec 2016 IAPO member Josef De Guzman President Psoriasis Philippines attended on or behalf
• Reach: 28 WHO WPRO Member States and their National Health Authorities and over 20 NGOs in official relationship with WHO and other non-State Actors organizations.
• Activity: Participated in workshops and discussions on UHC to learn from each other and work together, along with distinguished experts and other advisers, to identify priorities for the way forward.
• Outcome: IAPO now an official member of the WHO UHC Technical Group

25) Other achievements:–
• The Chair and Migdalia Dennis represented IAPO at the Alianza Latina Conference in November 2016
• Penney Cowan, Durhane Wong-Reiger and the CEO represented IAPO at the 2016 Bio International Convention in June 2016
• The CEO participated in two panels at The International Conference of Drug Regulatory Authorities (ICDRA) Cape Town in November 2016 on patient perspectives on the regulation of biotherapeutics and health devices.
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- Novo Nordisk is promoting a collaborative project that will engage all pharmaceutical partners to set-up a web portal that will use a ‘Trivago Style’ algorithm that will highlight all the most important patient-centric health literature, clinical trials and opportunities for patients to engage with national research programmes.
- IAPO has set-up a research unit in 2016 under Prof Kathy Kovacs-Burns and Hussain Jafri to identify and carry out research on issues that are relevant and important to patients.

Toolkits and Surveys

Our phase one of the joint survey on patients’, regulators’, prescribers’ and pharmacists’ perspectives on biotherapeutics (Biologic and Biosimilar) with IFPMA was completed by the Health Policy Partnership (London) in November 2016 and handed over to the Institute for Optimizing Health Outcomes to write up a report on. This report will be launched in Autumn 2017 and we will then continue developing capacity amongst Patients Organizations, Regulators, Physicians, Prescribers and Pharmacists to bring about patient-centricity approaches to the bio-therapeutics (biologics and biosimilars) regulation, clinical practice and prescription practice.

IFPMA and IAPO are planning a series of workshops and other events to develop and test a new robust Biosimilars toolkit, starting with Africa.

GetReal

IAPO finished the patient research stream within GetReal in December 2016. GetReal is a multi-stakeholder research project in which IAPO investigated patient acceptability and perceived usefulness of research methods and the use of Real World Evidence in the drug development process. We developed a wide range of research activities with the aim of exploring patient acceptability of pragmatic trials and will be sharing this in 2017 with our membership via peer-reviewed papers and capacity building workshops at regional meetings to develop their awareness, capacity and efficacy to effectively engage in clinical research. https://www.iapo.org.uk/getreal

PREFER

IAPO has started his work in IMI-PREFER, an IMI-funded project which is currently in its first year. IAPO is working in close collaboration with other patient organisations (European Cancer Patients Coalition, European Patients Forum, Muscular Dystrophy UK) within the Patient Advisory Group (PAG) with the aim of providing meaningful input into the research team as to how to best collect, analyse, and use patient preferences in the medicines development process. IAPO is leading the workstream on methodology.
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SDG 2030, UHC and right to health
In 2016 we are worked with a consortium of international lawyers to develop a joint-brief and a programme for patient advocates on how to use the right to health and the Sustainable Development Goals 2030 to get access to treatment and universal health coverage. Right-to-health was developed by the Committee on Economic, Social and Cultural Rights in its General Comment 14 in 2000. In 2015 SDG 2030 were brought in and they have opened a new avenue in advocacy and renewed interest in human rights based approaches to health. This briefing will be developed and tested at the African Patients Congress in 2017.

IAPO Research Unit:
The IAPO Research Unit was set up in August 2016 and has already taken off within the clinical trials world. The unit’s involvement in research activities as a more active participant has been appreciated. The BMJ and the Economists Intelligence Unit has started collaborative work. Our industry partners are very supportive and we will in 2017 continue working on joint initiatives. The overarching aim is to establish ourselves as initiators of research processes, which will also enable us to be part of the conversation from the beginning and identify relevant research questions and objectives.

Other projects
IAPO’s involvement in multi-stakeholders research programmes continues with our involvement in a number of initiatives that will help our membership. Thanks to these projects, we can continue promoting evidence-based patient centricity, and at the same time our members have increasing opportunities to make their voice stronger.

WHO HTA and rival MCDM – Health Technology Assessment and Multiple Criteria Decision Making are two prioritization methods fighting it out in health care planning today. The issue is especially critical with high-cost medicines. IAPO was a part of the Value for Money Event in Geneva, and is now part of a WHO working group that will be producing guidelines as to how to best conduct health technology assessment. IAPO to provide input regarding patient involvement.

Collaborations have been going on lately with a wide range of diverse stakeholders, including:
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- Novo Nordisk (ASPIRE project) on patient engagement in research
- Academy of Social Sciences
- Economist Intelligence Unit
- EUPATI
- IPRI

Communication and Education

Newsletter—These have been published every month and distributed electronically. Google Analytics and e-mail requests show that individual articles and news items are being accessed by an even wider audience in 2016 than in 2015, with specialist articles on health system strengthening and capacity building being the most popular.

Empowering global patient movement

- IAPO has increased and diversified its membership in 2016. At the end of the year we had 282 fully paid-up organizations (31st December 2016). Our African Congress in 2017 will help us recruit even more membership in 2017.

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<td>9%</td>
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</table>

Members were consulted in the development of IAPO’s 2017 Work Plan in Africa. The Patient Solidarity Day 2016 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 strategic plan for 2018-20 to assess key issues and priorities for them.
INTERNATIONAL ALLIANCE OF PATIENTS’ ORGANIZATIONS

TRUSTEES’ REPORT
FOR THE YEAR ENDED 31 DECEMBER 2016

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 2016.

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

TRUSTEES' REPORT
FOR THE YEAR ENDED 31 DECEMBER 2016

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.
INTERNATIONAL ALLIANCE OF PATIENTS’ ORGANIZATIONS

TRUSTEES’ REPORT
FOR THE YEAR ENDED 31 DECEMBER 2016

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 £493,772 (2015: £305,506), which was higher than the previous period due to being a Congress year.

Expenditure in 2016 was £478,854 (2015: £574,075). Expenditure is higher in Congress years, which happen every two years. 2016 was not a Congress year.

As shown in Note 11, one restricted fund was in deficit at the year end being Global Patients Congress (£133). The deficit on the Global Patients Congress is expected to be made good following successful fundraising for the 2018 Congress.

Reserves Policy
The IAPO Board approved a Reserves Policy in September 2014, with a target level of free reserves of 6-12 months’ running costs. 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 2016 was increased to £150,524. The Trustees have deemed that funding requirements are sufficient for the forthcoming year to operate a going concern budget through and into 2018.
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 2016, 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 2016 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

In 2017, 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 2016

The inward facing membership engagement and development activities in 2017 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
- Development of a Patient Voice Platform for members
- 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 2016

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 12th September 2017 and signed on their behalf by:-

Jolanta Bilinska, 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 2016

We have audited the accounts of International Alliance of Patients’ Organizations for the year ended 31 December 2016 which comprise the Statement of Financial Activities, the Balance Sheet and related notes. The financial reporting framework that has been applied in their preparation is applicable law and the small entity provisions of Financial Reporting Standard 102.

This report is made solely to the charity’s members, 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 charity’s members those matters we are required to state to them in an auditor’s 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 charity and the charity’s members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of the trustees and auditors
As explained more fully in the Statement of Trustees’ Responsibilities, set out in the Trustees Report, 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.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board’s (APB’s) Ethical Standards for Auditors.

Scope of the audit of the financial statements
An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company’s circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Trustees Annual Report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.
Opinion on financial statements

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 2016 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Opinion on other matter prescribed by the Companies Act 2006

In our opinion the information given in the Trustees' Annual Report for the financial year for which the financial statements are prepared is consistent with the financial statements and the Trustees' Annual Report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where 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.

Kevin Lally
(Final Statutory Auditor)
For and on behalf of Knox Cropper, Statutory Auditors
8/9 Well Court, LONDON, EC4M 9DN
29th September 2017
INTERNATIONAL ALLIANCE OF PATIENTS’ ORGANIZATIONS

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2016

<table>
<thead>
<tr>
<th>Notes</th>
<th>Unrestricted £</th>
<th>Restricted £</th>
<th>Total 2016 (year) £</th>
<th>Total 2015 (year) £</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income from charitable activities:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Membership</td>
<td>6,245</td>
<td>-</td>
<td>6,245</td>
<td>17,826</td>
</tr>
<tr>
<td>Healthcare Industry Partners</td>
<td>345,955</td>
<td>-</td>
<td>345,955</td>
<td>215,319</td>
</tr>
<tr>
<td>Global Patients Congress</td>
<td>-</td>
<td>137,136</td>
<td>137,136</td>
<td>-</td>
</tr>
<tr>
<td>Special Projects</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>69,140</td>
</tr>
<tr>
<td>Other charitable activities</td>
<td>4,436</td>
<td>-</td>
<td>4,436</td>
<td>3,221</td>
</tr>
<tr>
<td>Total</td>
<td>356,636</td>
<td>137,136</td>
<td>493,772</td>
<td>305,506</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expenditure on charitable Activities:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Charitable activities:-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Capacity building</td>
<td>116,107</td>
<td>-</td>
<td>116,107</td>
<td>141,091</td>
</tr>
<tr>
<td>• Advocacy</td>
<td>116,107</td>
<td>-</td>
<td>116,107</td>
<td>73,817</td>
</tr>
<tr>
<td>• Collaboration</td>
<td>116,107</td>
<td>-</td>
<td>116,107</td>
<td>155,625</td>
</tr>
<tr>
<td>• Global Patients Congress</td>
<td>-</td>
<td>130,533</td>
<td>130,533</td>
<td>14,125</td>
</tr>
<tr>
<td>• Special projects</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>189,147</td>
</tr>
<tr>
<td>Total</td>
<td>348,321</td>
<td>130,533</td>
<td>478,854</td>
<td>574,075</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Net income/(expenditure)</td>
<td>8,315</td>
<td>6,603</td>
<td>14,918</td>
<td>(268,569)</td>
</tr>
<tr>
<td>Transfers</td>
<td>14,526</td>
<td>(14,526)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Net movement in funds</td>
<td>22,841</td>
<td>(7,923)</td>
<td>14,918</td>
<td>(268,569)</td>
</tr>
<tr>
<td>Reconciliation of funds:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funds brought forward</td>
<td>127,684</td>
<td>27,356</td>
<td>155,040</td>
<td>423,609</td>
</tr>
<tr>
<td>Total funds carried forward</td>
<td>150,525</td>
<td>19,433</td>
<td>169,958</td>
<td>155,040</td>
</tr>
</tbody>
</table>

All transactions are derived from continuing 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 2016**

<table>
<thead>
<tr>
<th>Notes</th>
<th>2016 £</th>
<th>2015 £</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fixed assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>991</td>
<td>1,487</td>
</tr>
<tr>
<td><strong>Current assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>13,314</td>
<td>127,940</td>
</tr>
<tr>
<td></td>
<td>195,653</td>
<td>49,268</td>
</tr>
<tr>
<td></td>
<td>208,967</td>
<td>177,208</td>
</tr>
<tr>
<td>8</td>
<td>(40,000)</td>
<td>(23,655)</td>
</tr>
<tr>
<td><strong>Creditors: amounts falling due within one year</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>168,967</td>
<td>153,553</td>
</tr>
<tr>
<td><strong>Net current assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>169,958</td>
<td>155,040</td>
</tr>
<tr>
<td><strong>Net assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>169,958</td>
<td>155,040</td>
</tr>
<tr>
<td><strong>Funds</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>150,525</td>
<td>127,684</td>
</tr>
<tr>
<td>Unrestricted fund</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>19,433</td>
<td>27,356</td>
</tr>
<tr>
<td>Restricted funds</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>169,958</td>
<td>155,040</td>
</tr>
<tr>
<td><strong>Total funds</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

These financial statements were approved and authorised for issue by the Board of Trustees on 12th September 2017 and signed on their behalf by:-

J Bilinska – Trustee & Director  
Chair

H Jeffri – Trustee & Director  
Treasurer

Registered company number: 08495711 (England and Wales)

The notes on pages 27 to 34 form part of these financial statements
1 Accounting Policies

1.1 Accounting convention
The financial statements 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 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 received restricted funding in 2015 and 2016 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.

Global Patients Congress: The biennial 2015 conference took place in the UK. Congress income includes grants, sponsorship and delegate registration fees, all of which are recognised in the accounting year in which the event took place.
INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2016

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 of 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 2016

2 Incoming resources

<table>
<thead>
<tr>
<th>Healthcare Industry Partners</th>
<th>Global Patients Congress</th>
<th>Total £</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amgen</td>
<td>33,562</td>
<td>33,562</td>
</tr>
<tr>
<td>GSK</td>
<td>39,317</td>
<td>39,317</td>
</tr>
<tr>
<td>IFPMA</td>
<td>7,773</td>
<td>7,773</td>
</tr>
<tr>
<td>Janssen</td>
<td>27,499</td>
<td>27,499</td>
</tr>
<tr>
<td>J.C. General Services</td>
<td>20,356</td>
<td>20,356</td>
</tr>
<tr>
<td>Novartis</td>
<td>19,020</td>
<td>19,020</td>
</tr>
<tr>
<td>Novo Nordisk</td>
<td>17,133</td>
<td>17,133</td>
</tr>
<tr>
<td>Pfizer</td>
<td>34,639</td>
<td>34,639</td>
</tr>
<tr>
<td>UMC Utrecht</td>
<td>2,399</td>
<td>2,399</td>
</tr>
<tr>
<td>Uppsala University</td>
<td>13,887</td>
<td>13,887</td>
</tr>
<tr>
<td>Teva Pharmaceutical</td>
<td>24,993</td>
<td>24,993</td>
</tr>
<tr>
<td>IMI (European Union)</td>
<td>11,648</td>
<td>11,648</td>
</tr>
<tr>
<td>Other</td>
<td>93,730</td>
<td>93,730</td>
</tr>
<tr>
<td>Congress Sponsorship</td>
<td>137,136</td>
<td>137,136</td>
</tr>
</tbody>
</table>

345,956 137,136 483,092

3 Analysis of charitable activities

<table>
<thead>
<tr>
<th>Activities undertaken directly</th>
<th>Support Costs</th>
<th>Total £</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capacity building</td>
<td>116,107</td>
<td>116,107</td>
</tr>
<tr>
<td>Advocacy</td>
<td>116,107</td>
<td>116,107</td>
</tr>
<tr>
<td>Collaboration</td>
<td>116,107</td>
<td>116,107</td>
</tr>
<tr>
<td>Global Patients Congress</td>
<td>130,533</td>
<td>130,533</td>
</tr>
<tr>
<td>Special projects</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

478,854 - 478,854
4 Analysis of support costs
All support costs are allocated directly to charitable activities and as such there are no support costs. Auditors’ remuneration amounted to £3,800 (2015: £3,725).

5 Trustees and staff remuneration
The trustees received no remuneration but received reimbursements of £3,583 (2015: £3,340) for expenses incurred on behalf of the charity.

### Staff remuneration and numbers

<table>
<thead>
<tr>
<th></th>
<th>Total 2016</th>
<th>Total 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>Wages and salaries</td>
<td>175,205</td>
<td>188,526</td>
</tr>
<tr>
<td>Social Security costs</td>
<td>19,464</td>
<td>39,528</td>
</tr>
<tr>
<td>Pension costs</td>
<td>5,657</td>
<td>4,414</td>
</tr>
<tr>
<td>Other personnel related costs:</td>
<td>13,410</td>
<td>66,776</td>
</tr>
<tr>
<td><em>(recruitment, training, temporary staff)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>213,736</td>
<td>299,244</td>
</tr>
</tbody>
</table>

The average number of full and part-time employees during the year was between 7 and 8.
One employee received emoluments in the band £60,000 to £70,000 (2015: Nil).
Key management personnel costs amounted to £63,190.
6 Fixed Assets

<table>
<thead>
<tr>
<th></th>
<th>Computer equipment £</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cost</strong></td>
<td></td>
</tr>
<tr>
<td>Brought forward</td>
<td>4,169</td>
</tr>
<tr>
<td>Additions</td>
<td>-</td>
</tr>
<tr>
<td><strong>Carried forward</strong></td>
<td>4,169</td>
</tr>
<tr>
<td><strong>Depreciation</strong></td>
<td></td>
</tr>
<tr>
<td>Brought forward</td>
<td>2,682</td>
</tr>
<tr>
<td>Charge for the year</td>
<td>495</td>
</tr>
<tr>
<td><strong>Carried forward</strong></td>
<td>3,177</td>
</tr>
<tr>
<td><strong>Net book value</strong></td>
<td></td>
</tr>
<tr>
<td>At 31 December 2016</td>
<td>992</td>
</tr>
<tr>
<td>At 31 December 2015</td>
<td>1,487</td>
</tr>
</tbody>
</table>

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 £1,093 was charged in the accounts for the previous period.

7. Debtors

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>Debtors</td>
<td>-</td>
<td>1,240</td>
</tr>
<tr>
<td>Prepayments</td>
<td>13,314</td>
<td>63,960</td>
</tr>
<tr>
<td>Accrued income</td>
<td>-</td>
<td>62,740</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>13,314</td>
<td>127,940</td>
</tr>
</tbody>
</table>

8. Creditors: amount falling due within one year

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>Creditors</td>
<td>-</td>
<td>133</td>
</tr>
<tr>
<td>Deferred income</td>
<td>40,000</td>
<td>4,456</td>
</tr>
<tr>
<td>Accruals</td>
<td>-</td>
<td>19,067</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>40,000</td>
<td>23,655</td>
</tr>
</tbody>
</table>
9. Analysis of net assets between funds

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted Fund £</th>
<th>Restricted Funds £</th>
<th>Total Funds £</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tangible fixed assets</td>
<td>991</td>
<td></td>
<td>991</td>
</tr>
<tr>
<td>Current assets</td>
<td>189,534</td>
<td>19,433</td>
<td>208,967</td>
</tr>
<tr>
<td>Current liabilities</td>
<td>(40,000)</td>
<td></td>
<td>(40,000)</td>
</tr>
<tr>
<td><strong>Net assets at 31 December 2016</strong></td>
<td><strong>150,525</strong></td>
<td><strong>19,433</strong></td>
<td><strong>169,958</strong></td>
</tr>
</tbody>
</table>

10. Movements in funds

<table>
<thead>
<tr>
<th></th>
<th>At 31 December 2015 £</th>
<th>Incoming Resources £</th>
<th>Resources Expended £</th>
<th>Transfers £</th>
<th>At 31 December 2016 £</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted fund</td>
<td>127,684</td>
<td>356,636</td>
<td>348,321</td>
<td>14,526</td>
<td>150,525</td>
</tr>
</tbody>
</table>

**Restricted funds:**

Global Patients Congress (1,457) 137,136 130,533 (5,279) (133)

PROTECT (5,945) - - 5,945 -

GetReal 34,758 - - (15,192) 19,566

Latin America 2015 - - - -

155,040 493,772 478,854 - 169,958

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. Surplus funds will be spent on future Congress’. The deficit will be balanced by future income.

PROTECT
The goal of PROTECT is 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.

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.

During the year staff costs incurred directly on the GetReal project amounting to £15,192 were paid out of central core funds. These costs were recharged to the project at the end of the year and a transfer has been made from the GetReal fund to reflect this cost. Staff time has been allocated on the basis of hourly timesheets during the year multiplying by an hourly staff cost rate (without markup).

Latin America 2015
Activities in Latin America are driven by the 2015 Action Plan which was developed at the regional meeting in 2013. This action plan aims to increase the capacity of patients' organizations and strengthen networks in Latin America. Surplus funds were ringfenced to be spent specifically Latin America related activities.

11. Related parties
There were no transactions between related parties during the year or prior year.
## INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS

### NOTES TO THE FINANCIAL STATEMENTS

**FOR THE YEAR ENDED 31 DECEMBER 2016**


<table>
<thead>
<tr>
<th>Notes</th>
<th>Unrestricted £</th>
<th>Restricted £</th>
<th>Total 2015 (year) £</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Income from charitable activities:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Membership</td>
<td>17,826</td>
<td>-</td>
<td>17,826</td>
</tr>
<tr>
<td>Healthcare Industry Partners</td>
<td>215,319</td>
<td>-</td>
<td>215,319</td>
</tr>
<tr>
<td>Global Patients Congress</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Special Projects</td>
<td>-</td>
<td>69,140</td>
<td>69,140</td>
</tr>
<tr>
<td>Other charitable activities</td>
<td>3,221</td>
<td>-</td>
<td>3,221</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>236,366</strong></td>
<td><strong>69,140</strong></td>
<td><strong>305,506</strong></td>
</tr>
</tbody>
</table>

**Expenditure on charitable Activities:**

<table>
<thead>
<tr>
<th>Charitable activities:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Capacity building</td>
<td>141,091</td>
<td>-</td>
</tr>
<tr>
<td>Advocacy</td>
<td>73,817</td>
<td>-</td>
</tr>
<tr>
<td>Collaboration</td>
<td>155,625</td>
<td>-</td>
</tr>
<tr>
<td>Global Patients Congress</td>
<td>-</td>
<td>14,125</td>
</tr>
<tr>
<td>Special projects</td>
<td>-</td>
<td>189,417</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>370,533</strong></td>
<td><strong>203,542</strong></td>
</tr>
</tbody>
</table>

**Net income/(expenditure)**

(134,167) (134,402) (268,569)

**Transfers**

(81,648) 81,648 -

**Net movement in funds**

(215,815) (52,754) (268,569)

**Reconciliation of funds:**

Funds brought forward

343,499 80,110 423,609

**Total funds carried forward**

127,684 27,356 155,040