

Annual General Meeting

29 March 2014
Ascot, UK



Minutes

Voting members present:

69 voting members were present at the AGM: 56 Full Members and 13 Associate Members. A full list can be found in the Appendix on page 7. 71 ballots were received in total including those votes received by post, email, or by proxy.

1. Welcome and procedures

Kin-ping Tsang, IAPO Chair, welcomed all members to the 2014 Annual General Meeting (AGM). The following relevant procedures were explained:

IAPO Representatives and the General Assembly: Every member organization has an "IAPO Representative". Most people at the AGM were the IAPO Representative for their organization, or attended in the place of that person. The IAPO Representatives of our members constitute the General Assembly. Only one person per member organization can vote.

- Statutes & By-Laws: IAPO members are provided with a paper copy of the Statutes and By-Laws when they join IAPO. They are also available to view online at:
www.patientsorganizations.org/statutes and www.patientsorganizations.org/bylaws.
- Matters subject to the approval of the Annual Meeting of the General Assembly are:
 - (a) Election of the Governing Board in accordance with Article IV
 - (b) Annual accounts for the previous financial year
 - (c) Appointment of the Auditor
 - (d) Any other such business as may properly come before the meeting

In 2014, there was an election to select two Governing Board Members. There was also a vote for approval of the annual accounts for last year, 2013, and the appointment of an independent examiner for the coming year's accounts, 2014. The Governing Board also presented a report on IAPO's activities and achievements in 2013 and plans for 2014 (By-Laws, Article III, Section 2).

Voting

Jolanta Bilinska, IAPO Chair Elect, outlined the voting procedures. In line with IAPO's Statutes & By-Laws, member representatives have the right to vote at the AGM in person or by proxy. In addition, IAPO set up procedures for remote ballots by post, fax and email to enable those members that are not able to attend the AGM in person to vote on the issues subject for approval of the General Assembly.

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2. Approval of the minutes of 2013 AGM

Robert Johnstone, National Voices (seconded by Myrl Weinberg, National Health Council) proposed the approval of the minutes of the 2013 AGM. The 2013 minutes were approved unanimously.

3. Election of Board Members

An election was held to select two Governing Board Members in 2014 as two Governing Board Members' terms end this year (Regina Namata Kamoga and Kin-ping Tsang). The three year terms for these Governing Board positions will start on 1 August 2014. 15 candidates were nominated by IAPO's Full and Associate Members and two Governing Board Members were elected by the General Assembly. At the AGM, the votes, including the remote ballots, were counted by one member of IAPO staff, Lizette Jensen, and one IAPO Governing Board Member, Hussain Jafri. The count was observed by an IAPO Governing Board Member, Robert Johnstone, and an IAPO Member, Kathleen Gallant (International Federation of Psoriasis Associations).

Mr Kin-ping Tsang (Hong Kong Alliance of Patients' Organizations) and Mr Joshua Wamboga (The AIDS Support Organization, Uganda) were elected to the IAPO Governing Board, both to serve from August 2014 to August 2017. A message of thanks from Joshua Wamboga was read out later in the meeting.

IAPO Governing Board Members who will be serving from 1 August 2014:

- Ms Carol Bennett, Consumers Health Forum of Australia
- Ms Jolanta Bilińska, Patients Safety Foundation (Poland)
- Mr Marc Boutin, IAPO Treasurer and National Health Council (USA)
- Mr Hussain Jafri, Alzheimer's Pakistan
- Mr Robert Andrew Johnstone, National Voices (UK)
- Ms Eva Maria Ruiz de Castilla, IAPO Secretary and Esperantra (Peru)
- Mr Kin-Ping Tsang, IAPO Chair and Hong Kong Alliance of Patients' Organizations
- Mr Joshua Wamboga, The AIDS Support Organization (Uganda)
- Dr Durhane Wong-Rieger, IAPO Immediate Past Chair and Consumer Advocare Network (Canada)

4. Accounts for 2013 and Proposal for Auditor for 2014 Accounts

Marc Boutin, IAPO Treasurer, presented the financial accounts for the year 2013. These accounts have been audited and passed by Knox Cropper. The IAPO Annual Financial Report 2013 is available on IAPO's website at www.patientsorganizations.org/finances.

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The accounts were presented in UK pounds sterling for the first time as is good practice for a UK based organisation. The 2013 financial year covers a thirteen month period from 1 January 2013 to 31 January 2014, as the accounting date was changed on this occasion to align with the UK charity registration date. The accounts show income of £572,428 and expenditure of 658,307, with a deficit in this year of £85,879. Total reserves (unrestricted and designated) are £384,847. Unrestricted reserves cover six months core costs which could be used in the event of IAPO winding down, and can be used against future funding gaps. The size of the reserve was questioned, and Marc Boutin responded that having three to nine months of reserves is best practice in many countries including the UK, and this has always been the practice for IAPO. These reserves need to be maintained and therefore cannot be used for activities such as funding more members to attend events such as the Congress. However, this year, IAPO has supported more members to attend the Congress than in previous years.

The 2013 Accounts were approved by a majority vote.

Marc Boutin then introduced a proposal from IAPO's Governing Board to use the company Knox Cropper to carry out an audit of IAPO's accounts for the 2014 financial year (1 February-31 December 2014). He confirmed that the cost of the audit is around £4,000.

Knox Cropper were approved as auditors for 2014 by a majority vote.

5. Progress Report 2013 and Plans 2014

IAPO Governing Board Members, Eva Maria Ruiz de Castilla and Durhane Wong Rieger, presented IAPO's progress in 2013 and plans for 2014. Information about IAPO's progress in 2013 and plans for 2014 can be found at [IAPO Reports and Plans](#).

The three top priorities for 2014 are:

1. Registration as a UK Charity: registration and development of new systems and procedures
2. Policy and Advocacy: Development of and advocacy for patient-centred principles for universal health coverage (including development at the Global Patients Congress)
3. Strategic Plan: impact assessment of the 2010-2014 Strategic Plan and development of the 2015-2017 Strategic Plan

Linda Craig, IAPO's Operations Director, outlined the timeline for the strategic planning process. The plan will be for three years to set a framework with clear targets for IAPO to achieve but to also allow some flexibility. Members will be invited to participate through an online survey and through telephone interviews conducted with a range of members to give diversity such as in terms of geography, disease area, and size of organisation.

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6: Questions (Q) and answers (A) and AOB

6.1 Questions sent in from members not at the AGM

Q: I observed in the Philippines that most of the patient organizations don't get support from the public and the government because there's no allocation funds for these kinds of NCD's, also the scarcity of medical information available to lay people, the lack of awareness of disease area and the lack of understanding about the Universal Health Care. In situations like this, achieving patient-centred healthcare is difficult and challenging, what advice can IAPO give to the patient organizations facing this kind of challenge?

A: This situation is not unique. In many countries and across disease there are common issues regarding scarcity of information, lack of awareness etc. IAPO's role is to define and promote a patient-centred approach and provide tools to member organisations to promote this in country.

Q: What are the steps being taken to ensure that developing countries like Philippines will achieve better healthcare in the next 5 years?

A: There are a number of international mechanisms including the Non-communicable disease action plans, the development of sustainable development goals and the drive for universal health coverage. It is important that the patient voice is represented at the international through IAPO's official relations and partnerships with the World Health Organization. In addition it is important for patients' organizations in country to advocate for better healthcare.

Q: How many times in a year all the IAPO members meet?

A: We have an AGM once a year. In a Congress year such as this often over 50% of members attend. In a non Congress year, the numbers attending is less. Recognising that not everyone can attend along with increasing our support for members to attend IAPO meetings through bursary schemes every year, we instigated remote voting and are increasing our electronic communications including webinars. At this Congress we have supported more members than before to attend through the bursary scheme and provided free registration for one person from each member organization.

Q: Can a member organisation take the lead to organize an International Conference in India on "Access to Quality Healthcare: A Right of Patients?"

A: There are different mechanisms whereby members can engage with IAPO on meetings. One is the regional meetings whereby IAPO and member organizations work together to hold the meetings. There is also a mechanism whereby members can request IAPO provide its auspices to their events. Other possibilities would need to be discussed on an individual basis.

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Q: If Yes, what kind of support can IAPO provide to the Member Organisation?

A: The details of the nature of the partnership and engagement would need to be discussed. Any support IAPO could offer would be depending on raising funding.

Q: My question is that the AGM the TOP governing body of any institution or organization and I am just wondering how can policies be passed when some member are not facilitated to attend the AGM?

A: The governance of IAPO means that policies are passed by the Governing Board as elected representatives of the General Assembly comprising all member organizations. The items subject for approval at the AGM are the election of board members, the approval of the annual financial accounts and the appointment of the auditor. To ensure that all members can vote on this IAPO instigated remote voting by post and email a number of years ago. As for most organizations (including the WHO), member organizations facilitate themselves to attend the AGM. It is not possible for IAPO to facilitate all members (of which there are 225) to attend the AGM but, as previously described, there are ways that we do support members such as through the bursary which is open to all members to apply to for support to attend the Congress and thereby the AGM.

Q: Why are there no representatives on IAPO Board for rare genetic diseases?

Question also posed from the floor: Could the representation of the Board be changed to reflect the whole spectrum of disease area or geography, especially representation of rare disease areas?

A: IAPO's Board is comprised of representatives of IAPO member organizations who are elected by the membership in a democratic process. Within the nine board members many diseases are represented including rare diseases. One of IAPO's current board members works with rare disease groups.

Q: What can the member organisation do in order to influence the local authority to carry out an intensive inspection on genuine medicine been offloaded in Zambian market?

A: Counterfeit medicines are a threat to patients worldwide. IAPO's Patient Safety Toolkit provides information and advocacy tools to advocate to combat counterfeit medicines. There are also multi-stakeholder initiatives we would recommend, and can put you in touch with, such as health professionals and other stakeholders that are working on this issue in Zambia.

Q: How do you identify and tell that this is a biological or biosimilar medicine on our Zambian market?

A: Biological medicines and biosimilar medicines that have gone through a regulatory process are safe. Patients should ask their health professional what medicine they are being prescribed. They should be aware of the reaction they have to a medicine in case they have an adverse reaction for any reason including that the medicine may be a fake or substandard.

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Q: How do you help Africa to start applying the genuine medicine to reduce certain ailments which some usually appear after applying counterfeit medicine?

A: As mentioned, IAPO has some resources, as do other stakeholders including WHO, health professionals and the pharmaceutical industry which can be used to advocate to combat fake medicines and to raise awareness with the public and patients as to the risks and what action to take. See the policy section of IAPO's website for further details.

6.2 Questions and answers from the floor

Q: What are the legal and financial implications of moving from the Netherlands to UK in relation to trustee liability especially? Is there insurance to cover this?

A: IAPO is developing guidelines and handbook for the trustees in the coming months working in compliance with laws and regulations in the UK – these will be published when ready. There is insurance to cover trustees in the rare possibility of their liability.

Q: IDF represents 160 countries. We are very thankful to Durhane Wong-Rieger – she helped us three years ago to move away from speaking about patients' voice and rights towards a charter of the rights and responsibilities of patients. Could all nominees to the Board be encouraged to say which disease they are associated with or living with? This may not be possible because of privacy but at IDF, we always say how long people have diabetes, how long they've been living with it. Many organisations are speaking for patients without patient involvement.

A: This will be taken to the IAPO Nominations Committee to study the criteria for the nomination forms for the next election. Thank you for this constructive suggestion.

AOB

Ofra Balaban (CHEN - Patient Fertility Association) presented Jo Groves, IAPO CEO with a token which represents all the patients' organisations at the AGM. Jo thanked everyone present.

Kin-ping Tsang thanked Regina Namata Kamoga for her nine years' service on the IAPO Governing Board. She was unable to attend this Congress and AGM, and a message from her was shared with the members.

Close of AGM

List of IAPO Full and Associate Members in attendance at the AGM

- Ale Asociacion, Private Assistance Institution (Mexico)
- All-Ukrainian Public Organization Stop Hepatitis
- Alpha-1 Foundation (US)
- Alzheimer's Disease International (UK)
- Alzheimer's Pakistan
- American Chronic Pain Association
- Argentine Cystic Fibrosis Association
- Association of Community Pharmacists of India
- Association PAVEL (Romania)
- BackCare (UK)
- Best Medicines Coalition (Canada)
- Canadian Organization for Rare Disorders
- Center for Regional Policy Research & Cooperation 'Studiorum' (Macedonia)
- CHEN Patient Fertility Association (Israel)
- Cochrane Consumer Network (UK)
- Conceive (Argentina)
- Consumer Advocare Network (Canada)
- Consumer Online Foundation (India)
- Consumers Health Forum of Australia
- Council of Representatives of Patient's Organizations of Lithuania
- Council of the Chronically Ill and the Handicapped in the Netherlands
- Croatian Association for Patients' Rights
- Dakshayani and Amaravati Health and Education (India)
- Epilepsy HERE (Help Education & Research for Epilepsy) (UK)
- Esperantra (Peru)
- European AIDS Treatment Group
- European Lung Foundation
- Fundación Red De Apoyo Social de Antioquia (Colombia)
- German Pain League
- Global Alliance of Mental Illness Advocacy Networks – Europe
- Global Colon Cancer Alliance
- Hamza Foundation Welfare Hospital (Pakistan)
- Health Care Consumers' Association of the ACT (Australia)
- Health Consumers Alliance of South Australia

Appendix



- Health, Rights and Justice (Mexico)
- Heart to Heart Foundation (Thailand)
- Hong Kong Alliance of Patients' Organizations
- Hungarian Osteoporosis Patient Association
- INPUT Patient Advocacy (UK)
- International Diabetes Federation
- International Federation of Psoriasis Associations
- International Genetic Alliance
- International Painful Bladder Foundation
- Italian Endometriosis Association
- Jahandad Society for Community Development (Pakistan)
- Korean Alliance of Patients Organization
- Life Saving Organization for Afghanistan
- LIVESTRONG (US)
- LUPUS EUROPE (UK)
- Moroccan Federation Supporting People with Kidney Insufficiency and Organ Transplantation
- Multiple Sclerosis International Federation
- National Alliance for Caregiving (US)
- National Health Council (US)
- National Multiple Sclerosis Society (US)
- National Voices (UK)
- Patient Health Alliance of NGO's (South Africa)
- Patients Safety Foundation (Poland)
- Pelvic Pain Support Network (UK)
- Peruvian Patient Network
- PLAN Health Advocacy and Development Foundation (Nigeria)
- Platform Health in Dialogue (Portugal)
- Polish Diabetes Association
- Psoriasis Action (Spain)
- Retina Hong Kong
- Salvadoran Association for Cancer Prevention
- Thalassaemia Society of Pakistan
- Uganda National Health Consumers/Users' Organisation
- Venezuelan Federation of Associations of People with Learning Disabilities and their families
- World Federation of Incontinent Patients