

IAPO AGM Minutes

8th April 2016, London



Voting members present:

See attendee list at Appendix 1

1. Welcome and procedures

Jolanta Bilinska, Chair, welcomed all members to the 2016 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.
- 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

The minutes of the 2015 AGM were presented for agreement, and were approved unanimously.

In 2016, there was an election to select five Governing Board Members. There was also a vote for approval of the annual accounts for last year, 2015, and the appointment of an independent examiner for the coming year's accounts, 2017. The Governing Board also presented a report on IAPO's activities and achievements in 2015 and plans for 2016 (By-Laws, Article III, Section 2).

Voting

Jolanta Bilinska, IAPO Chair, 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 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.

2. Annual Financial report 2015 & Proposal for auditor for 2016 accounts

2.1 Charity Law in the UK has changed, and new regulations on presenting budgets have come into effect.

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Items on the IAPO budget have been changed, in order to clarify where we have restricted and unrestricted funds: Unrestricted – we have choice over how to use funds; Restricted – need to be used for a specific purpose. Most of our funds are unrestricted funds.

- 2.2 Auditors have inspected the accounts.
- 2.3 A significant amount of funds available in 2014 were used up in 2015, and IAPO now has fewer reserves than in the past. Income was down in 2015 partly due to factors limiting our capacity to fundraise, and was half as much as in 2014. This reduction is also partly expected because there was no Global Patients Congress in 2015.
- 2.4 The expenses are explained in the report figures. All accounting is now in GBP. Expenditure was far higher than income, meaning there is a deficit of £134K restricted + £134K unrestricted, . i.e. an overspend of £268K.
- 2.5 In summary, the picture is not as dark as figures suggest, because IAPO had large reserves (equivalent to $\frac{3}{4}$ year's expenses). There is an overlap from some of the 2014-5 figures, and some of the activities in Latin America should be seen as an investment by IAPO in the region.
- 2.6 IAPO came out of 2014 with £423K reserves, and in 2015 with £150K in reserves (£127K unrestricted, £27K restricted). This is a little lower than the level set by Board as ideal, but we will survive 2016 as a healthy organization nonetheless. The treasurer is confident that this is not a negative, but a positive report.
- 2.7 Thanks to Gavin Williams for his help, and the auditors Knox Cropper. The treasurer proposes that IAPO adopts Knox Cropper as auditors for the 2016 finances. They have answered all questions and given valuable advice on how to improve for the future.

Questions & Answers on the Financial Report

Q – Are we required to keep a specific level of reserves under legislation?

A - No, we are recommended to keep 6 months, but a risk register is a better way of regulating this whilst allowing the organization to take a risk where needed. The recommended 6 months relates to employment and other contracts that the organization is committed to. The treasurer is very comfortable with these provisions.

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Q – is 6 months enough? Wouldn't it be better to have 12 months? Especially in relation to staffing liabilities.

A – It is good to have reserves to cover Board liabilities, but also difficult in the current environment where many organizations struggle for money, we cannot justify holding large reserves. We are sitting on a stool, rather than on a comfortable cushion. We don't want to be seen as sitting on funds. We have taken account of our liabilities on contracts, and redundancy liabilities, in the calculation of reserves needed.

Q – where in the accounts is the allocation of funds for staff?

A – Staffing costs were separated between staff and projects in previous financial statements, but regulatory changes mean that now expenditure has to be split between the different activities, including staffing and other support costs. The Treasurer is happy to discuss this in more detail, but it is not presented as part of the budget.

Q – what matrix does IAPO use to apportion costs to particular activities? What do the different categories mean?

A – The Board works with more detailed figures, but that is not how the financial report is formatted. This report is presented in a standard format that is not necessarily helpful in terms of understanding the finances in detail.

Q – suggestion/recommendation that beyond the official statements, some more understandable figures could be presented.

A - We can consider that for the next AGM.

The Treasurer (Matthias Wienold) proposed that IAPO continues to work with Knox Cropper, and that they be appointed as IAPO auditors for the 2016 finances. Carried unanimously.

3. Progress report 2015 and Plans 2016

Jolanta Bilinska detailed the objectives of the strategic plan, and the activities that are undertaken to support these. She thanked previous and outgoing Board members for their hard work and support.

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Objective 1 was met through attendance at WHO regional meetings, World Health Assembly, and the Executive Board.

Objective 2 was met by increased participation in Patient Solidarity Day, which also achieved a much greater reach through greater use of social media.

Objective 3 was met through delivering a Latin American regional meeting in Panama. This region has had a 100% increase in membership, helped by IAPO Board member Eva Maria Ruiz de Castilla. With good representation in Europe (more than 100), we now need to focus on members in EMRO, Africa and North America.

Kawaldip Sehmi welcomed members, and emphasized that the strategic plan is focused on members activities, since without our members, nothing would happen. He highlighted in particular the member from PAPO who travelled from the Philippines to Guam in order to represent IAPO at the WHO regional committee meeting.

Our planned activities have been categorized into outward-facing and inward-facing tasks.

Q – could you talk a little about the collaborative work with the WHO?

A - IAPO has 3-year agreement with Patients For Patient Safety. Tomorrow Nittita Prasopa-Plaizier will be talking about the patient engagement framework at Congress.

Q – the problem with WHO is that they are not collaborating at country level (from Rosalie in Romania). WHO have so much experience, it's disappointing that they do not collaborate. Please ask WHO to be more representative at country level and involve patients' organizations.

Q – the advocacy toolkit has to be an advocacy and engagement toolkit – it's an incremental process. Sometimes we get feedback that patients are not experienced when they are participating, and they need to be effective. Other resources are needed in addition to training.

4. Governing Board Member elections

Election will be overseen by IAPO staff member, Board member, counted by Board member and members.

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An election was held to select five Governing Board Members in 2016, with two Governing Board Members' terms ending this year – Durhane Wong-Rieger and Robert Johnstone. The terms for these Governing Board positions will start on 1 August 2016. 9 candidates were nominated by IAPO's Full and Associate Members and five 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, Ziede Mesonyte, one IAPO Governing Board Member, Matthias Wienold. The count was observed by an IAPO Member, and IAPO Governing Board Member, Penney Cowan. A total of 76 ballots were cast, 36 by email prior to the AGM, and 40 on the day.

Andrew Spiegel, Global Colon Cancer Association (USA), Migdalia Denis, Sociedad Latina de Hipertension Pulmonar (Venezuela), Bejon Misra, Consumer Online Foundation (India) and Hussain Jafri, Alzheimer's Pakistan (Pakistan), were elected as new Board members.

IAPO Governing Board Members who will be serving from 1 August 2016:

- Ms Jolanta Bilińska, IAPO Chair, and President of Patients Safety Foundation (Poland)
- Mr Joshua Wamboga, IAPO Chair Elect, Executive Director, Uganda Alliance of Patients' Organizations (Uganda)
- Mr Matthias Wienold, Representative, European Aids Treatment Group (Belgium)
- Ms Penney Cowan, IAPO Secretary, Executive Director, American Chronic Pain Association (USA)
- Mr Bejon Misra, Representative, Consumer Online Foundation (India)
- Ms Migdalia Denis, President, Sociedad Latina de Hipertension Pulmonar (Venezuela)
- Mr Andrew Spiegel, Executive Director, Global Colon Cancer Association (USA)
- Mr Hussain Jafri, Representative, Alzheimer's Pakistan (Pakistan)

5. Questions and Answers and Any Other Business

There were no further items of business or questions.

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Appendix 1

Attendee list

Name	Organization
Marco Espildora	Fundacion CancerVida
Luciana Escate Penaloza	Federacion Argentina de Enfermedades Poco Freuntas (FADEPOF)
Jolanta Bilinska	Patient Safety Foundation
Tomas de Olazabal	Hypertension Pulmonar Argentina
Klara Zalatnai	Hungarian Osteoporosis Patient Association
Christina Janus	International Alliance of Dermatology Patient Organizations
Lars Ettarp	International Federation of Psoriasis Associations (IFPA)
Rubby Chawla	Indian Patients Society for Primary Immunodeficiency (IPSPI)
Gijong An	Korea Alliance of Patients Organizations (KAPO)
Anne Charlet	Lupus Europe
Gertude Buttigieg	Malta Health Network
Mira Armour	Myeloma Croatia – MijelomCRO
Robert Johnstone	National Voices
Karla Ruiz de Castilla	Esperantra
Karen Villanueva	Philippine Alliance of Patients Organizations
Giuseppe Paparella	Picker Institute Europe
Anna Sliwinska	Polish Diabetes Association
Muhamedali Kodra	Patients' Rights Association of Kosovo
David Trigger	Accion Psoriasis
Wang Ya Hsin	Psoriasis Association Taiwan
Eszter Martinovits	Psoriasis Non-Profit Association of Szeged
Jana Hlavacova	Civic Association SMS
Olesya Mishina	Society of Patients with Psoriasis
Joshua Wamboga	Uganda Network of AIDS Service Organisations (UNASO)
Rose Lule Nalukwago	Uganda Platform for Diabetics
Lynne van Poelgeest-Pomfret	World Federation of Incontinent Patients (WFIP)
Luiz Kitamura	ADJ Diabetes Brasil
Hussain Jafri	Alzheimer's Pakistan
Rozalina Lapadatu	Asociatia Pacientilor cu Afectiuni Autoimune (APAA)
Durhane Wong-Rieger	Consumer Advocare Network
Bejon Misra	Consumer Online Foundation
Vida Augustiniene	Council of Representatives of Patients Organizations of Lithuania
Kathryn Andrews-Clay	Canadian Skin Patient Alliance
Matthias Wienold	European Aids Treatment Group
Kerstin Morrison	European Lung Foundation (ELF)
Monica Kendall	Epilepsy HERE
Guillermo Guttierrez	FUNDAPSO
Penney Cowan	American Chronic Pain Association
Migdalia Denis	Sociedad Latina de Hipertension Pulmonar