

# IAPO AGM Minutes

## 20<sup>th</sup> November 2017, London



### **Voting members present:**

See attendee list at Appendix 1

### **Opening of the Annual General Meeting (Jolanta Bilińska)**

#### **Item 1: Welcome & Procedures (including minutes of AGM 2016)**

Jolanta Bilinska, Chair, welcomed all members to the 2016 Annual General Meeting (AGM).

JB reemphasised the matters subject to the approval of the Annual Meeting of the General Assembly as:

- (a) Election of the Governing Board members
- (b) Annual financial report of the previous financial year
- (c) Progress report and strategy from 2015-2017, future plans for 2018-2020, and Congress 2018
- (d) Questions regarding any other business and information including relocation from Netherlands to UK and how this impacts activities

**The minutes of the 2016 AGM were presented for agreement; the motion was proposed by Hussain Jafri and seconded by Mira Armour. The AGM minutes for 2016 were approved unanimously.**

#### **2018 Board Elections Voting Procedure Explained**

Jolanta Bilinska, IAPO Chair, outlined the election and voting procedures. Every organization has one vote, and this is cast by one representative on behalf of that organization. Member Organizations have been given the chance to read information on all candidates in advance and to make their decision based on the profiles candidates submitted. Members were allowed to vote for three candidates, however, any more than three would result in an invalid vote.

The Governing Board Member candidates must represent all WHO regions, and it was noted that the current Board members are representing most of these regions. This is important as we need a good understanding and involvement of the regions in IAPO's activities.

Jolanta Bilinska then stated the current Governing Board Members of the General Assembly; Jolanta Bilińska (Chair), Hussain Jaffri, (Interim Treasurer), Migdalia Denis (Secretary), Penney Cowan (Chair Elect), Andrew Spiegel and Androulla Eleftheriou. Joshua Wamboga's term ended in July 2017 and one Board member, Bejon Misra, was removed from Board in October 2017 after a hearing by the Board members. In this election, there are three Governing Board Member positions to be voted upon.

# IAPO AGM Minutes

## 20<sup>th</sup> November 2017, London



Victoria Gilbert and Antonio Ciaglia was nominated as the staff representative for the election process, and Maya Zlatanova as membership representative. Those voting in person were invited to cast ballot papers; ballot papers were also accepted by post, email or by proxy.

### **Item 2: Annual Financial Report 2016 & Proposal for appointment of Auditors for 2017 Accounts (Hussain Jafri)**

- 2.1 In August, Matthias Wienold resigned therefore as Treasurer Elect, Hussain Jafri became Interim Treasurer
- 2.2 IAPO company accounts have moved from the Netherlands to the UK
- 2.3 2016 was a more successful financial year than 2015. More income was raised than during previous year, and expenditures were substantially lower despite the expense of Congress.
- 2.4 Full statement of financial activities are available on IAPO website
- 2.5 Of total unrestricted income raised from activities (£356,636); £6,245 was from membership, £345,955 was from Healthcare industry partners, and £4,436 from other charitable activities.
- 2.6 Total restricted income was £137,135 from global healthcare conference in London.
- 2.7 This gives a total income for 2016 of £493,772 (significantly higher than the year previously by £188,266).
- 2.8 Expenditure given as strategic objective, and stuck to budget, spending £116,107 for capacity building, advocacy, and collaboration. Total expenditure for unrestricted funds was £478,854.
- 2.9 Total net income for 2016 was £14,918 compared to loss in previous year.
- 2.10 Money was transferred from other account into main account resulting in £155,040 funds brought forward, and £169,958 total funds carried forward in 2016.

#### Questions regarding financial report:

Q – Was the income increase primarily due to more industry funding?

Kawaldip/Jolanta – Yes, this was due to more project funding, for example toolkits and biosimilars report. Reduced costs were also from reduced staff and office space costs. Income in 2015 fell partly due to CEO transition and industry partner uncertainty and restructuring, however after that short time, income has raised since. IAPO should also spread risk to statutory bodies.

Q - How many sources of income do we have?

Gavin/Jolanta – We have small amounts from members (£100 or so, but brings relationship), and largest amounts from healthcare industry partners, one off partners eg for congress, and small amount of funding for honorariums and consultancy fees. But the bulk is from core funders and partners. This is why income dropped with CEO changeover, because relationships with pharmaceutical companies were lost. Pfizer are willing to give IAPO more funds in 2018

# IAPO AGM Minutes

## 20<sup>th</sup> November 2017, London



Q – Regarding staff, do you have plans to take someone on for fundraising? Will they be part-time?  
Kawaldip – Yes. They would be employed on commission, not a full-time employee. We currently don't have a fulltime fundraiser; we only rely on industry partner relationships. IAPO has thought it could be beneficial to bid for funds and put proposals to UK trust funds to target for development.

Q – Why doesn't IAPO organize own fundraising to raise awareness in a campaign, since one main objective is raising awareness? Has IAPO considered doing an awareness raising event?  
Kawaldip – Yes, it is important. However we do not want to do the work national and regional organisations would carry out, so IAPO's stance is to support regional teams to help raise funding and use levy to do local projects together.

**The Annual Financial Report 2016 was presented for approval; the motion was proposed by Jolanta Bilinska and seconded by Mira Armour The Annual Financial Report 2016 were approved unanimously.**

**Hussain Jafri informed the AGM that it is a requirement by law to appoint auditors for 2017-2018. Knox Cropper is one of the leading firms of Chartered Accountants servicing the "Not for Profit" Sector. They have been IAPO's Auditors for past Years. It was proposed to appoint Knox Cropper again as auditors; the motion was proposed by Jolanta Bilinska and seconded by Maya Zlatanova. Knox Cropper appointed as IAPO auditors unanimously.**

### **Item 3: Progress Report Strategy Outturn 2015-2017; Plans for 2018-2020 and Global Patients Congress 2018**

Jolanta Bilinska reported the strategic objectives for 2015-2017, by leading the patient voice on global healthcare issues, advancing patient engagement, and empowering the global patient movement.

In 2015, there was a change of CEO. Objective 1 was met through taking part in the 2015 WHA, WHO Regional Committee Meetings, and Biosimilar Toolkit. Objective 2 was met through holding our fifth IAPO Latin American Regional Meeting and attending and presenting at the HTAi International Conference in Oslo. Objective 3 was met through Patient Solidarity Day and a formalized relationship with Alianza Latina by signing a Memorandum of Understanding.

In 2016, Objective 1 was met through the 7<sup>th</sup> Global Patients Congress in London, taking part in the WHO Executive Board and 69<sup>th</sup> WHA, the WHO Regional Committee Meetings, and high-level meetings including UN General Assembly Summit meetings. Objective 2 was met by participation in various

# IAPO AGM Minutes

## 20<sup>th</sup> November 2017, London



conferences and forums, including Prince Mahidol Award Conference in Thailand, UHC Annual Financing Forum, FIFARMA meeting in Panama, and the World Health Summit in Berlin. Objective 3 was met through Latin American country cluster workshop, Patient Solidarity Day 2016, and African consultations.

In 2017, Objective 1 was met through high representation at 70<sup>th</sup> WHA, WHO Regional Committee Meetings and IMI-GetReal and IMI-PREFER work. Objective 2 was met through participation in FIFARMA's Capacity Building Strategy, HTAi International Conference in Rome, and development of IAPO-industry collaborative projects e.g. Empowerment and Biosimilars toolkits. Objective 3 was met through African Regional Meeting in Uganda, Alianza Latina Forum, and is the organization of Patient Solidarity Day 2017 around the theme empowered patients through knowledge. Also we are looking into partnership with ISQua and Kawaldip has met with ISQua CEO to discuss how can we work towards mutually beneficial collaborative initiatives. Moreover, we are also working with WHO on patient safety. Last year IAPO renewed its official relation with WHO.

Kawaldip outlined IAPO's strategy for 2018-2020. A Member consultation was launched to provide feedback on the proposed strategic plan pathway for 2018-2020. Furthermore, there will be a strategy committee formed of the IAPO CEO, three IAPO Board Members, three IAPO Members, and one IAPO Industry Partner (Bristol-Myers Squibb). IAPO proposed strategy consists of three main strands; to empower patient communities globally to advocate effectively for PC-UHC, to drive research processes and the development of evidence base for PC-UHC and to shape law, policy and practice in PC-UHC at global, regional and national levels.

Kawaldip outlined plans for IAPO's 8<sup>th</sup> Global Patient Congress, May 2018. Reasons for holding congress in Miami were based on access; Latin American patient groups will have easier access, European groups could still afford to attend. There are fewer African organizations or low income countries that can afford to travel hence IAPO is looking at providing grants to them for their travel expenses.

The process of organising and selecting the theme of Congress was described by Kawaldip. Logistics and the programme are still in development and as we wait to establish a Committee. We want to highlight evidence base and best practice that increases the availability of quality, safe, accessible and affordable services through patient engagement and empowerment. One framework to use is the value chains approach. Values chains exist in healthcare funding, structural arrangements, processes and functions, medicines development, medicines regulation, Health Technology Assessment and health informatics.

#### **Item 4: Governing Board Member Elections**

# IAPO AGM Minutes

## 20<sup>th</sup> November 2017, London



Jolanta Bilinska explained that the changeover from the Netherlands to UK has resulted in a change in bi-laws. Lawyers have been contacted to advise on the start date for Governing Board Membership since the usual date of 1<sup>st</sup> August is long after election. Term dates will be announced shortly after a decision is made by the Board.

Esther Walker from European AIDS Treatment Group arrived late at the AGM; voting had ended and counting of votes was already in progress. She was refused voting, which she challenged formally. Jolanta Bilinska replied to this challenge by stating that the time for voting had passed, and since ballot box has been closed and ballot papers had already started being counted, the vote would not be accepted.

Maya Zlatanova announced names of new Governing Board Members: Penney Cowan, Neda Milevska-Kostova and Sita Ratna Devi.

### Questions regarding Governing Board Member Elections:

Q – Since relocation from Netherlands to UK, would you consider returning given Britain is now leaving the EU? Would IAPO stay in the UK for the foreseeable future, since another move would be very destabilizing?

Jolanta/Kawaldip – The Brexit has changed many things and the IAPO Board is looking considering all option. There are both advantages and disadvantages

Q –Do you not need to be in EU because it is a global organization? Which languages do you operate in?  
Kawaldip/Jolanta - Since the Congress held in Latin America, there has been many members from this region and it has resulted in pressures to translate content into Spanish. However, English is IAPO's operational language. IAPO welcomes organizations from all regions. However for administration their representative to IAPO must be English speaking. The representative can translate things for their boards into their own language themselves.

Q – Are we exploring European funds?

Kawaldip – Yes we are. We have taken on IMI funding, as well as European conference and congress funds. The full list of European Commission funding on the accounts.

Q – Will the next AGM be earlier in the year, since this year's was a little late?

Kawaldip – Yes, we will hold it in May, possibly in Miami Congress. Usually AGM is held during Congress.

Q – Regarding previous Board member, why was Joshua excluded from Board?

# IAPO AGM Minutes

## 20<sup>th</sup> November 2017, London



Jolanta – The term for Board members is 3 years, and since Joshua was elected in 2014 will therefore finish term this year. Joshua wanted to be re-elected but did not receive enough votes. He can stand in the next election.

Q – Why was Bejon removed from the Board?

Jolanta - I had provided more information at the beginning of the meeting about Bejon Misra's removal from the Board. This is the first time a Board member has been excluded from the Board. This decision was taken by the Board as per our status and bylaws.

### **Item 5: Questions and Answers and Any Other Business**

Jolanta Bilinska encouraged members to be active during Congress. IAPO always holds side events at the World Health Assembly. IAPO also held 3 break-out meetings at the 2016 Congress. WHO PFPS, NCD Alliance, Latin American. In 2017 at the World Health Assembly IAPO hosted side meetings on Biotherapeutics, polypharmacy and pain management, safe blood donations resolution, private health financing and world sepsis resolution. In Miami members can hold side meetings at Congress to share experiences and build relationships. There will be a Latin American meeting.

Q – Congress will be held in the US, therefore it will be difficult for many organizations from certain countries to obtain visas and gain entry into the US due to current US travel ban. How will certain organizations be able to get visas?

Jolanta – IAPO will provide a support letter to US embassy. Where certain regional members can't attend IAPO will hold a regional meeting for example in WHO EMRO region.

Hussain - Organising a conference outside Europe or in the developing world is difficult as funders not willing to support, the alternative is regional meetings that members from that region can attend.

Q - Next time, a deadline should have been given for a time voting will close.

Jolanta – During next AGM, 15 minute increments could potentially be used.

Q – Suggestion that Congress could be broadcasted via online tools, since not everyone can travel there especially those who have conditions.

Jolanta – Yes, agree. IAPO give travel grants and last year's conference was filmed as well, however, there is motivation for more technology and social media engagement.

# IAPO AGM Minutes

## 20<sup>th</sup> November 2017, London



Q – It is important to have infrastructure for patients to hear best practices from other patients, and give patients platform where they can find networks of other patients and sharing of advice and experiences.

Hussain – suggested what is practical for IAPO is to have a directory perhaps with websites.

Q – Suggestion that, as membership from different regions, IAPO could ask each organization to share two stories, with patients' challenges/recommendations. This could be written in own language, or even as a YouTube video with translation into different languages via subtitles, and potentially ask WHO to support on this.

Jolanta/Kawaldip – Yes, IAPO plans to adopt this type of activity on a larger scale. IAPO is currently working on a "Trivago-like" search engine which would highlight what is available to patients in their region and give latest evidence.

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# IAPO AGM Minutes

## 20<sup>th</sup> November 2017, London



### Appendix 1:

#### Attendee List AGM 2017:

Organization	Name
Alzheimer's Pakistan	Hussain Jafri
Patient Safety Foundation	Jolanta Bilinska
FindMeCure	Maya Zlatanova
Mijelom Croatia	Mira Armour
Association of European Coeliac Societies	Virginie Potbury
Thalassaemia Society of Pakistan	Yasmin Raashid
European AIDs Treatment Group	Esther Walker (joined mid-way)