

Open Call for Members Participation in the 8th Global Patients Congress with Possibility of Bursaries

Terms of Reference

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Please ensure you read carefully the entire document to increase your possibility of playing a leading role at the coming 8th Global Patients Congress. For your application to be considered, it is paramount that the rules outlined below are closely followed.

The Scheme

The 2018 Global Patients Congress (2018 GPC) brings together IAPO members from around the world with other healthcare stakeholders to exchange knowledge, share best practice, and discuss developments in patient-centred healthcare. IAPO is committed to broadening the participation of patients' organizations from all world regions in the GPC.

For this purpose, IAPO has established an Open Call for Members Participation in the 8th Global Patients' Congress and combined it with the opportunity of getting Bursaries for those meeting the eligibility criteria, depending on the level of funds available (The Scheme).¹

The Scheme will be aimed at members who are interested in contributing to the Congress activities in a variety of roles: delivering a presentation, acting as a panel chair, acting as a rapporteur, or exhibiting a poster. The Scheme will provide an opportunity for identifying and supporting up-and-coming patient advocates who would benefit from participating in the Congress.

This Scheme will also be aimed at supporting a limited number of patient representatives from IAPO member organizations who would otherwise be unable to attend the event. Bursaries will be awarded to selected members and cover particular costs to assist their attendance at the Congress.

Objectives

- Increase patients' representation at the Congress.
- Enable members to attend that otherwise would not.
- Provide patient advocates with an opportunity to network and strengthen their skills, which they will be able to put in practice to support their organization's development and work.
- Diversify the Congress's global representation and assist in creating a balanced regional spread from around the world.

Instructions

- This call aims to elicit applications from IAPO Members who are interested in contributing to Congress in a variety of capacities.

¹ Assessing and allocating the bursaries is an ongoing process as we secure funding from our donors. The donors' final commitment, and our final allocation, on bursaries may go on to the end of April 2018.

- The application process will be divided in 2 sections: **Section 1.** Application for contributions to Congress (presentations, posters, rapporteurs, chairs); **Section 2.** Bursary application.
- Applicants who are able to meet the cost of their own travel and accommodation have to fill in and submit **Section 1 only.** Those who do not have sufficient funding must fill **Section 1 AND Section 2 (both sections submitted to us).** Bursaries will not be awarded to applicants who are not willing to contribute towards the congress programme content and activities.
- Being successful in the Open Call to present (Section 1) **does not mean you are automatically awarded a bursary.** Bursaries are limited and their allocation will be determined on the basis of additional selection criteria.
- Applicants with their own means, in order to maximise your possibilities of succeeding in getting the opportunity to present, should consider submitting Section 1 only (Contribution to Congress).

Eligibility criteria

Members are required to meet all the following criteria in order to apply for **contributions to Congress (Section 1):**

1. Be an IAPO Member (Full or Associate).
2. Applicant's organization has no outstanding membership fees.
3. Be registered for the Congress through the Eventbrite website.
4. Be ready to play an active role throughout GPC 2018.
5. Be able to communicate in English.

Members are required to meet all the following criteria in order to apply for a **bursary (Section 2):**

1. Be registered for the Congress through the Eventbrite website.
2. Applying member is not able in any way to support even one representative to attend the Congress. Only one application from each member organization will be considered. If the member's organization registers a second person to come to the Congress, the bursary recipient will automatically lose the bursary.
3. Applicant's organization is an IAPO Full Member. There are no bursaries available for Associate Members.
4. Applicant's organization has no outstanding membership fees.
5. Applicant's organization has not received a bursary for the last two Congresses (2014 and 2016).
6. Applicant's organisation has a gross annual income lower than US \$ 250,000 (membership fee - level 1).

Section 1: Call for applications to contribute to GPC 2018 Activities

GPC is a unique opportunity for our global community of members to come together, share the work they carry out on a daily basis and establish meaningful connections with other patient advocates and healthcare stakeholders. Members' willingness to play an active role throughout GPC 2018 is critical to the event's success and to ensure this is truly and fully patient-driven. Section 1 provides an opportunity for IAPO members to apply for contributing in 4 different ways to this year's congress:

1. Speaker
2. Chair
3. Rapporteur
4. Poster exhibitor

Applicants will be asked to express their interest in **two categories (maximum)**. Each category has specific selection criteria that must be fulfilled. It will be up to applicants to demonstrate their suitability to the categories they are applying for.

Speaker

Successful applicants in this category will appear in the Congress Programme and will have an opportunity to present to a global, multi-stakeholder audience about the advocacy work they carry out and the impact they generate. Speakers will have 10 to 15 minutes to deliver their presentations at the GPC 2018.

To apply for this category, IAPO members will be required to provide an abstract. To increase chances of success, applicants must ensure they closely follow these rules in preparing and submitting the abstract:

- Word limit: 200 words (abstracts exceeding this limit will be penalised);
- Ensure the abstract is closely aligned with the panel topic/theme;
- Do not focus on describing their organisation but place an emphasis on the impact that their work has produced;
- Clearly explain how they have engaged with relevant stakeholders;
- Place emphasis on impact and outcomes.

Below is an overview of the panels applicants may consider applying for:

PANEL 1: Patient Empowerment in Universal Health Coverage

In 25 September 2015, the General Assembly of the United Nations adopted Resolution A/RES/70/1. By officially endorsing this document, the leaders of the 193 United Nations

(UN) Member Countries agreed on a comprehensive set of goals and targets and committed themselves to work tirelessly to implement this Agenda fully by 2030. The 17 Sustainable Development Goals (SDGs) and 169 targets of Agenda 2030 identify the global priorities that will guide, inspire, and stimulate UN Member Countries' political action for the next 15 years.

Patient groups have an important role to play in this long-term journey. First, patients are well placed to ensure that governments develop and properly follow-up on feasible policies in the three dimensions of [Universal Health Coverage](#) (UHC). Depending on local and national context, the degree of urgency with which these dimensions are perceived will vary considerably across countries. Patients are called on to identify which are the most sensible and urgent priorities, around which political and policy action is needed in order to progress towards UHC for all.

Below are additional details that applicants should take in consideration when preparing the presentation's abstract:

- This will be a multi-stakeholder panel in which IAPO members will be representing the patient voice;
- The successful applicant needs to clearly demonstrate how they have generated impact in advocating for universal health coverage;
- Presentations focusing on advocacy approaches to UHC that can possibly be scaled up to other countries would be particularly welcomed.

PANEL 2: Patient Empowerment in Regulation

Empowered patients are patients who are able to meaningfully engage with [healthcare regulators](#) to ensure that the medicines and medical products that are authorised are really adequate to meet patients' needs. In 2005, the European Medicines Agency (EMA) passed a framework of interaction with patients' and consumers' organisations. Its objective is to define the approach to patients' and consumers' relations and to tackle new challenges. The framework provides an opportunity for patients to provide input and perspectives on crucial matters such as transparency, product information, pharmacovigilance and interaction with the scientific committees. Patients are today increasingly willing to cooperate with regulators, not only in Europe. This panel will provide an opportunity to discuss challenges and opportunities of patient involvement in medical products regulation.

Below are additional details that applicants should take in consideration when preparing the presentation's abstract:

- This will be a multi-stakeholder panel with representatives from various regulators and IAPO members will be representing the patient voice;

- The successful applicant needs to provide practical examples of how they have engaged with healthcare regulators (not necessarily at regional level) and to provide a clear overview of the impact they have generated;
- Applications regarding engagement with EMA, Food Drug Administration (FDA) or African Medicines Agency (AMA) are particularly welcomed.

PANEL 3: Patient Empowerment in Research

The issue of [patient empowerment in research](#) has played a pivotal role in recent policy and advocacy activities at IAPO. Patients fully recognise the benefits and value of research in identifying new and effective medicines and medical devices. At the same time, patients believe research can deliver even more meaningful results if patients are adequately involved in all stages of the research processes, from research priority setting to communication and dissemination. Research is one of the areas in which proper patient empowerment can make a strong difference. However, for that to happen, research stakeholders must see and recognise the value of “moving beyond patient participation” and working with patients as equal partners. This panel will discuss extensively the most urgent issues at stake when it comes to patient involvement in research.

Below are additional details that applicants should take in consideration when preparing the presentation’s abstract:

- This will be a multi-stakeholder panel with representatives from industry, publishers, and research institutions. IAPO members will be providing the patient perspective.
- The successful applicant needs to provide practical examples of how they have engaged with key stakeholders in research and how they have actively contributed to the development of patient-centric research programmes.
- The presenter will put an emphasis on the impact their role has had on the quality and patient centricity of the research process.

PANEL 4: Patient Empowerment in Global Advocacy

IAPO is a non-state actor in official relations with the World Health Organization (WHO). This provides us with the possibility of giving statements at the annual World Health Assembly and to enable our members to take part in WHO-led activities (e.g. research projects). Global advocacy is crucial to the role that IAPO plays, given its [mission](#), vision, and scope. This panel will explore and discuss avenues to patient empowerment at global level by shedding light on relevant examples of successful advocacy with global institutions (WHO, UN).

Below are additional details that applicants should take in consideration when preparing the presentation’s abstract:

- This will be a multi-stakeholder panel with representatives from global institutions and IAPO members will be representing the patient voice;
- The successful applicant needs to provide practical examples of how they have engaged with global institutions (e.g. WHO) and to provide a clear overview of the impact they have generated;
- Applications placing emphasis on how the process of global advocacy started and evolved step by step are particularly welcomed.

PANEL 5: Patient Empowerment in Health Delivery

One of the principles at the core of what IAPO is and does is partnership. IAPO aims to make tangible advancements towards the achievement of patient-centred care by establishing successful collaborations and partnerships with relevant [healthcare stakeholders](#). By closely working as equal partners with key healthcare stakeholders, empowered patients can create appropriate conditions to shape health policy and practice. In this regard, interaction and engagement with hospital, pharmacists, and more in general, health delivery professionals are particularly crucial.

Below are additional details that applicants should take in consideration when preparing the presentation's abstract:

- This will be a multi-stakeholder panel with representatives from various healthcare professions.
- The successful applicant needs to provide practical examples of how they have engaged with healthcare workers, such as pharmacists, or within hospitals.
- Applications placing emphasis on impact are particularly welcomed.

PANEL 6: Patient Empowerment within Pharmaceutical Industry

Industry representatives' willingness to involve patients has significantly increased over the latest years. At the same time, patients too are showing stronger openness to collaborate in industry-led activities, such as, for example, clinical Research and Development. Collaboration and partnership are two principles that stand at the core of IAPO's mission of achieving patient-centred healthcare. However it is crucial that patient-industry relations are established and thrive in compliance with the highest standards of transparency, accountability, and respect. The panel will shed light on successful examples of [industry-patient collaborations](#) and will look into solutions that can be expanded beyond the specific case and implemented more broadly in the healthcare spectrum.

Below are additional details that applicants should take in consideration when preparing the presentation's abstract:

- This will be a multi-stakeholder panel with representatives from industry and IAPO membership.

- The successful applicant needs to provide practical examples of how they have engaged with industry in compliance with the principles of accountability, transparency, and respect.
- Applications placing emphasis on impact will be particularly welcomed.

Chair

Successful applicants in this category will have an opportunity to chair one of the Congress panels. The role of the Chair is critical to the success of every panel session. The Chair introduces the session and the speakers, makes sure the discussion is lively and engaging, and wraps up the panel before closing the panel.

IAPO is looking to appoint chairs for each of the following panel sessions (refer to the description provided in the previous section):

- PANEL 1: Patient Empowerment in Universal Health Coverage
- PANEL 2: Patient Empowerment in Regulation
- PANEL 3: Patient Empowerment in Research
- PANEL 4: Patient Empowerment in Global Advocacy
- PANEL 5: Patient Empowerment in Health Delivery
- PANEL 6: Patient Empowerment within Pharmaceutical Industry

To apply for this category, IAPO members will be required to demonstrate how they meet a set of specific selection criteria. To increase the chances of success, applicants must provide clear answers to the following questions and stick to the word limit:

- Which panel they would like to chair?
- Provide details of any previous experience they have in chairing panels. If this would be the first time for them, provide details about the approach that they would follow to make the session a successful one (Word limit: 100 words. Answers exceeding this limit will be penalised).
- Demonstrate their skills as a moderator / host (Word limit: 100 words. Answers exceeding this limit will be penalised).
- Provide details about their knowledge of the topic discussed in the panel they would like to chair (Word limit: 100 words. Answers exceeding this limit will be penalised).

Rapporteur

The role of the rapporteurs is crucial throughout the entire event. The successful applicants will be allocated to the activities spanning across the GPC 2018. Their role will be to take notes from the sessions they are allocated to, identify the main highlights and key takeaways, and present these

in the plenary session at the end of Days 1 and 2. The rapporteurs' role is critical to ensuring IAPO members agree on the key messages emerging from the Congress and that they are able to convey these externally with a strong, united voice.

To increase chances of success, applicants must provide clear answers to the following questions and stick to the word limit:

- Provide details of any previous experience they had in acting as a rapporteur. If this would be the first time for them, provide details about the approach that they would follow to perform this role (Word limit: 100 words. Answers exceeding this limit will be penalised).
- Demonstrate their presentation skills and experience (Word limit: 100 words. Answers exceeding this limit will be penalised).
- Provide details about their ability to synthesise complex messages and identify most relevant points and takeaways (Word limit: 100 words. Answers exceeding this limit will be penalised).

Poster Exhibitor

IAPO will also provide members with an opportunity to present their posters in the exhibition area. If you are interested in presenting a poster about the various facets of patient empowerment, apply by submitting an abstract.

To increase chances of success, applicants must make sure that they closely follow these rules in preparing and submitting the abstract:

- Word limit: 200 words (abstracts exceeding this limit will be penalised);
- Ensure that the abstract is closely aligned with the theme of patient empowerment;
- Do not focus on describing their organisation but place an emphasis on the impact that their work has produced;
- Clearly explain how they have engaged with relevant stakeholders;
- Place emphasis on impact and outcomes.

Please note that IAPO will not be able to provide funding to assist applicants in the preparation of their poster.

Section 2: Call for bursary applications

Bursary assessment criteria

Bursaries will be awarded by taking in consideration the following criteria in addition to those related categories in Section 1:

- Motivation – Why applicant is interested in attending the Congress.
- Leadership – How applicant will benefit from attending the event and use the opportunity to establish useful networks and share learnings within their organization and local networks.
- Geographic location – Criterion to ensure regional diversity in the event, mostly from members from Low and Middle Income Countries.
- Viability – Criterion to assess the cost-benefit of having a member at the congress whose travel expenses are extremely high or who will experience difficulties in getting a travel visa (e.g. 8 countries recent travel ban to t).

Bursary recipients' commitment

- All bursary recipients are expected to write a 300-500 word report on how the conference has contributed to their professional development. To be submitted by no later than 1 month after the Congress.
- Bursary recipients (level 1) will be responsible for providing IAPO with the confirmation of their travel arrangements and visa in order to have their accommodation booked by IAPO. Deadline: 27 April 2018.
- Bursary recipients (levels 2 and 3) will be responsible for letting IAPO know the payment method they choose for receiving the grant (i.e. international bank transfer) and appropriate bank details. Deadline: 27 April 2018.
- In case of no-show at the Congress or registering a subsequent representative of the organization, members will be required to return the full amount of the bursary to IAPO.

Bursary amount

There will be **three levels** of bursaries for members to apply for, the first level being a fixed amount and the other two levels flexible amount, though capped.

Level 1 Bursaries will cover 3 days of accommodation (23 to 25 May 2018) at the Miami Marriott Dadeland Hotel, where the Congress will be held. In this case, the bursary recipient is responsible for paying for all their travel costs, including visa and insurance. IAPO will only be responsible for booking the hotel and no money will be transferred for bursary recipients. IAPO will not be held responsible for any extra hotel expenses incurred by bursary recipients during their stay.

Level 2 Bursaries will cover travel, visa and insurance expenses only. Bursary recipients will, thus, have to pay for the accommodation costs themselves. Level 2 bursary is capped at a total of US 1,200. Members must inform us how much they expect to spend for their travel, visa and insurance in their application. IAPO will transfer the money to bursary recipients for them to make their own arrangements.

Level 3 Bursaries will cover 3 days of accommodation (23 to 25 May 2018) at the Miami Marriott Dadeland Hotel in addition to travel, visa and insurance expenses of up to US 1,200. Members will be requested to inform how much they expect to spend for their travel, visa and insurance. IAPO will transfer the money to bursary recipients for them to make their own travel arrangements. With regards to accommodation, IAPO will be responsible for booking the 3 nights at the hotel. IAPO will not be held responsible for any extra hotel expenses incurred by bursary recipients during their stay.

Subject to available funding, IAPO may have to allocate applicants to lower bursary levels than the one they have applied for. To increase applicants' chances of obtaining a bursary and allow IAPO to maximise the number of bursary recipients, applicant must ensure to apply for the level that is closest to their absolute needs.

Level	Description	Total amount
1	Accommodation (3 nights – 23 to 25 May 2018)	IAPO will book accommodation directly so no money transfer will take place
2	Travel expenses (flights, visa and insurance)	Up to U\$1,200
3	Travel expenses (flights, visa and insurance) and accommodation (3 nights – 23 to 25 May 2018)	Up to U\$1,200 + accommodation directly booked by IAPO

The assessment process

1. Applicants who are interested in applying for The Scheme will be able to do so via the application form available from 26 February 2018.
2. The application forms will be evaluated and ranked by two IAPO staff members.
3. Strong but not immediately successful applicants will be placed on a waiting list. If they applied for Section 1, they might be offered a role in the Congress if one becomes

available. If they also applied for Section 2 (Bursary), they might be allocated a bursary subject to additional funds.

4. With regard to Section 1, successful applicants will be identified based on how strongly they demonstrate they meet the selection criteria. With regard to Section 2 (Bursary), the fund is limited and decisions will be made on the basis of on how strongly they demonstrate they meet the selection criteria as well as of available funding. The possibilities of participating in the Congress might be higher if applicants only apply for Section 1.
5. IAPO will hold a short induction with successful applicants to ensure that they are aware of the duties of their roles and, in case they are awarded a bursary, of bursary rules and commitments.

Scoring

1. Applicants will be given points ranging from 1 to 5 in each criterion (1 being the lowest score, and 5 the highest). Scores will be determined according to appropriateness and relevance of the answers provided. Applicants will be ranked accordingly to the total points achieved. With regard to Section 2 (Bursaries), should two or more applicants obtain the same score, decisions will be made with aim of having a balanced representation from all regions (Geographic location) and based on how the "Leadership" criterion was addressed in the application.
2. In addition, and aiming to ensure a diverse regional representation of participants, priority will be given to applicants from Low and Middle Income Country and members who have never attended the Global Patients Congress in the past.

Timeline

Activity	When
Open Call launch	Monday 26 February
Deadline for sending Open Call applications	Sunday 18 March
Open Call applications assessment	19 to 22 March
Communication of Open Call results	Friday 23 March
Deadline for receiving bank details or visa/travel confirmation from bursary recipients	Friday 27 April
Bursary payments and accommodation booking for bursary recipients	From Monday 02 April