

Compliance with Patients Included Conference Charter

IPPOSI Annual Conference

October 7th, 2019

Charter Requirements	IPPOSI Perspective
Including experienced patients in designing and planning the event	<p>The conference was conceived of and designed in partnership with the IPPOSI Board. The Board of IPPOSI includes experienced, senior patient advocates with experience of designing and planning their own patient-focused events. The Board of IPPOSI is always weighted in favour of patients (8 members; versus 6 each for Science & Industry members). Furthermore, the Chairperson and Vice-Chairperson of IPPOSI is always a representative of a patient organisation.</p> <p>A draft agenda was first proposed at the April 2019 Board meeting, and a final version was signed off on at the June 2019 meeting.</p> <p>The agenda was also informed by discussions that take place at the quarterly meetings of the patient-led EUPATI National Platform in Ireland.</p>
Experienced patients participate in conference and appear in audience	<p>Patient speakers/chairpersons/panellists at the conference include:</p> <p>Sarah McLoughlin (Retina International); Declan Noone (European Haemophilia Consortium); Jacqui Browne (Irish Thalidomide survivors); Caroline Murphy (Epilepsy Patient Advocate), Sheila Fitzgerald (unaffiliated patient advocate)</p>
Pays travel expenses for participating patients or carers	<p>IPPOSI offer a bursary to cover travel and other expenses for patient panellists and presenters.</p>
Offers scholarships for patients and carers who are affected by conference topic (either through website or email address where scholarship can be accessed)	<p>There is no delegate fee for the conference, so patients can register without cost.</p>

Accommodates disabilities of attending patients	The conference venue is on the ground floor of the Hilton Hotel, Charlemont Place, Dublin 2 which is fully accessible.
All programme elements open to patient delegates	Confirmed
Access provided for virtual participants	Conference speakers and panellists are video-recorded and their presentations are subsequently uploaded to the IPPOSI Vimeo page. Notice of same is then circulated widely via IPPOSI channels.
Free streaming provided online	Free streaming is anticipated for the event, but will be subject to the availability of a high-speed LAN connection at the venue.
Must be able to prove Patients Included status to public	This document outlines how the 2019 IPPOSI conference is compliant with the Patients Included Charter Clauses.
Can display Patient's Included logo on website, promo materials, and programme (can include link to PI website)	Compliant

Patients Included™ conference charter clauses:

1. *Patients or caregivers with experience relevant to the conference's central theme actively participate in the design and planning of the event, including the selection of themes, topics and speakers.*
 2. *Patients or caregivers with experience of the issues addressed by the event participate [2] in its delivery, and appear in its physical audience.*
 3. *Travel and accommodation expenses for patients or carers participating in the advertised programme are paid in full, in advance. Scholarships [3] are provided by the conference organisers to allow patients or carers affected by the relevant issues to attend as delegates.*
 4. *The disability requirements of participants are accommodated [4]. All applicable sessions, breakouts, ancillary meetings, and other programme elements are open to patient delegates.*
 5. *Access for virtual participants is facilitated, [5] with free streaming video provided online wherever possible.*
- *A conference fulfilling all five of the charter's clauses may display the trademarked Patients Included™ logo[6] on its website, promotional materials, and programme featuring a link to the conference charter's home page. Conferences should be able to provide evidence in support of their Patients Included™ status to the public [7].*
 - *Then, write a step-by-step account of how your event meets each of these requirements, and publish it on your event's website in order that it may be scrutinised by members of the public*
 - *Trademarked logo unprotected on website*
 - *Not monitored, but process is based off of meeting the standards, honesty/integrity*

All references numbered above can be found on the Patients Included website here:

<https://patientsincluded.org/conferences/>