

Final report and outcomes

Introduction

The 2016 IPF Workshop took place on the 18th and 19th of November in Brussels. This year the workshop was hosted by the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF), the umbrella organisation of European IPF patients' organisations founded in 2016. It was attended by 24 participants representing EU-IPFF members and other organizations from Europe, the US, Canada, and Brazil. Key sessions at this year's workshop included;

- Improving GP understanding of a rare condition
- Strengthening the capabilities of patients' organizations via membership growth and fundraising
- Working together and planning common activities

The workshop also included practical training exercises on political advocacy, social media platforms, and interview techniques.

Key outcomes

- GP understanding of IPF is the key concern shared by all patients' organisations. Activities in 2017 should focus on this problem
- The EU-IPFF and organisations from the US, Canada and Brazil should collaborate more frequently, both in terms of campaigning but also in terms of sharing resources
- A toolkit for patients' organisations on how to engage with and educate GPs should be developed for use by patients' organisations who do not have such resources available
- Two organisations approached the EU-IPFF to discuss membership

Next steps

- EU-IPFF to establish a working group for coordinating activities leading up to Pulmonary Fibrosis Awareness Month and IPF World Week
- EU-IPFF to reach out to organisations to identify which materials could contribute to a toolkit to help improve GP understanding of IPF
- PFF to identify a means of screening or streaming the Pulmonary Fibrosis Foundation (PFF) Summit for audiences in Europe and possibly beyond

Please find below summaries of each session as well as additional outcomes and recommendations

Session 1 summary

Session 1 focused on the crucial issue of how to improve GP understanding of a rare condition in order to increase rates of diagnosis. This is a crucial issue for IPF patients' organisations as in many countries a GP referral is needed before a consultation with a specialist. As is the case with many other rare conditions, GPs may struggle to identify the specific symptoms of IPF, leading to late diagnoses and much deteriorated chances of survival for IPF patients. The session aimed to provide participants with a better understanding of the barriers established by health systems and tactics to help improve GP understanding of IPF.

2016 IPF Workshop – hosted by the EU-IPFF



18-19 November 2016, Brussels

Anamaria Corca from Burson-Marsteller gave an opening presentation on general barriers to diagnosis created by health systems, reflecting on her previous work for the Standing Committee of European Doctors (CPME). Barriers included the need for GP referral, the culture of doctor-patient interaction, and the use of continuing professional development.

Claudia Crocione, a patient advocate working for the HHT Europe Network and [HHT Onlus](#) of Italy, gave a presentation on the experience of Hereditary Hemorrhagic Telangiectasia (HHT) patients' organisations dealing with the same issue. She provided participants with practical advice on building relationships with GPs, capacity-building, and establishing professional communications output to ensure that an organisation is taken seriously.

Catalina Panaitescu, a family doctor and representative of the [International Primary Care Respiratory Group](#) gave a presentation on how primary care physicians negotiate the issue of rare disease diagnosis. She identified factors such as lack of expertise, lack of time to focus on one patient, and the episodic contact a family doctor can have with patients.

Outcomes and Recommendations:

1. Awareness raising to address GP understanding remains key for IPF patients' organisations
2. Patients' organisations can begin to address the problem through discussion with GPs and GP groups, though training and good communication materials are needed to increase the likelihood that they will be listened to
3. A toolkit, including various materials to improve patients' organisations' skills in this area would be very useful
4. Collaboration with GP organisations is encouraged, at medical congresses and through collaborative projects. Projects suggested include developing training modules together or volunteering to talk to junior doctors to familiarise them with the condition
5. The International Primary Care Respiratory Group has local chapters in most countries, and should be approached as an organisation which is more receptive to the ideas and concerns of patients' organisations

Session 2 summary

Session 2 focused on the issues of membership growth and fundraising for rare disease patients' organisations. During the discussion, it was identified that most organisations do not have regular sources of funding outside of grants received from industry. Some organisations receive large charitable donations, though this is not the case for most organisations.

Sam Kynman from Burson-Marsteller provided an introduction to issues around collaboration with industry. He highlighted the importance of independence, transparency, and integrity; characteristics required to ensure that the patients' voice is credible in healthcare policy.

Claudia Crocione gave a presentation on how HHT Onlus in Italy increased their funding through organisational improvements and specific practical steps. These included training a small network of people in professional fund-raising skills and undertaking small local fundraising activities based around specific plans for how the money would be spent.

Outcomes and Recommendations:

2016 IPF Workshop – hosted by the EU-IPFF



18-19 November 2016, Brussels

1. Collaboration with industry is necessary for all organisations. Transparency and independence principles should be followed by both patients' organisation and their sponsors
2. Training and 'people-raising' is a necessary first step towards fund-raising
3. A small amount of professional assistance can go a long way
4. Be as specific as possible in how you intend to spend money and people are more likely to donate

Session 3 summary

Session 3 involved participants dividing into three groups to undertake practical training exercises.

Advocacy essentials

The session on advocacy essentials aimed to explain the importance of advocacy for IPF care, tips on how to develop an advocacy strategy, and best practices and basic principles of successful advocacy.

Outcomes and Recommendations:

1. Government and politics affects many aspects of IPF care and therefore every organisation should be aware of how to influence decision makers
2. In order to develop a successful lobbying strategy, it is crucial to identify your objectives, set tangible goals, understand your political environment, and use the right tools and tactics

Twitter academy

The 'Twitter Academy' session provided participants with an understanding of the functionality of the Twitter platform, how it can be best used, and how it can help them connect with each other and achieve their advocacy goals.

Interview training

The interview training session simulated a real 'on camera' interview. Participants were given advice on how to talk and behave in front of the camera, how to communicate with a journalist and how to prepare for the questions of journalists in order to communicate their message in the best way possible.

Session 4 summary

Session 4 focused on how patients' organisations working in the field of IPF could collaborate and share resources. Some organisations have developed very sophisticated resources that could also be used by others.

Patti Tuomey from the US Pulmonary Fibrosis Foundation (PFF) gave a presentation on the resources her organisation has developed, many of which can be used by other organisations. She also highlighted how her organisation, like HHT Onlus, evolved from more basic grass-roots activities. She underlined that creativity and thinking-outside-of-the-box have helped her organisation to grow and become stronger.

Participants pointed to resources that they have developed which can be used by other organisations. Participants were asked to speak to potential sponsors about translation or editing requirements to localise resources for their country.

PFF materials can be found [here](#).

2016 IPF Workshop – hosted by the EU-IPFF

18-19 November 2016, Brussels



The CPFF patient guide can be found [here](#). The CPFF exercise guide can be found [here](#).

The video produced by Focus Patient can be found [here](#).

Collaboration idea proposed by the EU IPFF:

1. The EU-IPFF should lead on assembling a toolkit for patients on approaching GPs to help them understand IPF, building on the resources currently available. It should be constructed in such a way that it can be localised for organisations internationally

Session 5 summary

Session 5 was an opportunity to discuss collaboration around events and campaigns. The EU-IPFF and other participants outlined some of the key dates for them in 2017 and invited others to collaborate with them. Small practical steps to help facilitate collaboration were proposed.

Collaboration ideas proposed by the PFF and EU-IPFF:

1. The EU-IPFF and PFF websites should be linked up, along with other equivalents where possible
2. All organisations should have their own social media accounts to help share each other's content
3. The PFF magazine could include a feature on the EU-IPFF, and national organisations' newsletters should do their best to feature other organisations
4. All organisations should be subscribed to each other's newsletters
5. The PFF and EU-IPFF should have joint or adjacent booths, or plan joint educational programs at medical congresses and patient education meetings
6. The PFF 'Patient Communication Centre' could be connected to other organisations internationally to field inquiries from outside of the US
7. A small working group should be created to coordinate activities ahead of IPF World Week in September 2017. The EU-IPFF will invite other organisations to be part of the working group. The following organisations already expressed an interest
 - a. Irish Lung Fibrosis Association (ILFA)
 - b. PFF
 - c. Canadian Pulmonary Fibrosis Foundation (CPFF)
 - d. Instituto Vidas Raras (APMPS)
8. All participants should circulate their calendar of activities for 2017 to all other participants to facilitate collaboration
9. Collaboration around the ILFA three Cs campaign (cough, crackles, and clubbing)
10. The PFF Summit organisers and the EU-IPFF should discuss the idea of screening or streaming a session from the 2017 Summit. Webcasts of the sessions could be posted for those unable to attend the conference.