



IPOPI NMO ADVOCACY & MEDIA TRAINING
WORKSHOP
BELGRADE, SERBIA

14 & 15 SEPTEMBER 2012

REPORT



Introduction

IPOPI held an Advocacy Workshop in Belgrade Serbia on September 14-15 2012. This workshop was attended by representatives from six countries – Turkey, Hungary, Romania, Russia, Serbia and Poland. IPOPI was represented by Jose Drabwell (Chair); Johan Prevot (Executive Director) and David Watters (Strategic Consultant). Dr Beata Rzazewska participated on behalf of CSL Behring. All costs associated with attendance at the Workshop were met by IPOPI through generous sponsorship from Grifols and CSL Behring.

Workshop Day 1 Summary

After a welcome lunch and a short introductory session, where the delegates introduced each other, the Training Workshop got down to work. Johan Prevot gave an introductory presentation on the purpose of the training event and how it fitted into the IPOPI strategic objectives. This was followed by a presentation from David Watters on the how, what, who and why of advocacy – identifying and defining problems and concerns, bringing people together and getting a consensus view.



The meeting then split into two groups (for one hour) to discuss and identify the key issues affecting each NMO. Thereafter the rapporteurs reported back to a plenary session – the issues affecting each NMO being the same as the IPOPI strategic aims – a reassuring sign that the IPOPI Board are in tune with the issues affecting NMOs!

After a short refreshment break – with delicious biscuits! – the meeting re-assembled to be given an update on the tools available from IPOPI to help NMOs with advocacy and other areas of concern. This underlined for all NMOs the usefulness of the IPOPI website, which warrants regular – daily! – checking for new material.

The final session of the day outlined a practical exercise to work on for the second half of the programme on Saturday. This involved reacting to a letter received from the Minister of Health, in a mythical country, as follows:



Dear National Patient Organisation,

I am writing to let you know that with immediate effect we will no longer be able to supply the treatment for adults with primary immunodeficiencies in our country.

There are two reasons for this decision:

(1) The cost to the health budget: we have to consider the broad spectrum of medical conditions and priorities. PIDs are rare disorders and as such do not occupy a priority rating.

(2) The cost-effectiveness of Ig therapy has not been proved beyond doubt in our country. Antibiotic therapy is available.

If you want to discuss this further one of the staff will be happy to meet you – we would suggest Mr Prevot.

Jose Drabwell, Minister of Health

There would again be two groups – one to prepare for a meeting with the Minister of Health and the other to prepare a press conference, both to present in role play on Saturday afternoon.

Day one ended with dinner in a local Serbian restaurant!

Workshop Day 2 Summary

On Saturday morning the group enjoyed three presentations on advocacy in action – Johan outlining the advocacy involved in restoring immunoglobulins to the WHO Essential Medicines List; Jose outlining advocacy campaigns during World PI Week and the LATAM call to action and David talking about his experiences in obtaining compensation for people with haemophilia in the UK following infection with HIV through contaminated plasma products.. This was followed by a presentation from Johan of the European Parliament Expert recommendations and the work of the Plasma Users Platform – all geared to help with the main task of the day in the work groups.

After some basic material about preparing their case, the importance of data, and other key considerations, the groups then spent some three and a half hours working on the assigned task. After a welcome break for refreshment– and more delicious biscuits – the final action-packed



session of role play which saw a meeting with a particularly uninterested Health Minister (Jose) and an apparently helpful civil servant (Johan) aided and abetted by a Clerk (David). The meeting heightened the problem of retaining the attention of the Minister – who clearly had other things on her



mind – while maintaining dignity. The NMO created a minor problem by taking too many people to the meeting without letting the Ministry know, the Clerk created a fuss about this but the NMO delegates retained their dignity – so a good session!!

This was followed by the Press Conference. A minor hiatus had been caused a few moments before the meeting when David asked the Group how they had invited the Press to attend as he, playing the role of Bill Bragg from the Daily Rag had not been invited – a rushed Press Release appeared!! It is important to issue that Release some time in advance to inform the media. The Press Conference itself was designed to be difficult – Billy Bragg was especially unpleasant and difficult – but the others were not far behind! Then the conference was gate crashed by two reporters (Dragana and Adrian) who had not been invited However, the NMO learned much about ‘keeping their cool’ and not being side-tracked by the likes of Billy Bragg!

Conclusions

The workshop was also an excellent opportunity to identify specific issues in the region and among others the lack of proper adult care and treatment was considered to be a common priority. The role play sessions were fine-tuned during the meeting on the basis of the discussions, to add relevance to the exercise.

The role play sessions were then followed by a conclusions session which featured an interactive discussion during which the pro’s and con’s of each groups’ campaigns were thoroughly analysed. The main points were collated into a short Powerpoint presentation and some key principles and guidelines were identified for each participant to keep in mind and apply this to their own local circumstances.

All presentations made at the meeting are featured on the IPOPI website under the key events page and the advocacy and media training campaign toolkit are featured under the [Resources](#) page.

Since the meeting much valuable feedback has been received from participants telling IPOPI how much they learned from this intensive course. IPOPI is committed to continue to support NMOs in their respective advocacy campaigns to build on the outcomes of the workshop. Several IPOPI programmes are in place to ensure this continuing support.