

## IPOPI SOUTH EAST ASIA ADVOCACY & MEDIA TRAINING WORKSHOP

### KUALA LUMPUR, MALAYSIA

### 22 & 23 SEPTEMBER 2018

## MEETING REPORT



### Introduction

IPOPI held a South East Asia Advocacy & Media Workshop in Kuala Lumpur (Malaysia), on September 22 and 23 2018. The workshop was attended by representatives from five countries (Malaysia, Thailand, Philippines, Indonesia and Vietnam). IPOPI was represented by Jose Drabwell (Chair), Christine Jeffery (Treasurer), Bruce Lim (Board member and MyPOPI President), Saara Kiema (NMO Programme Officer) and Leire Solis (Health Policy & Advocacy Manager). The workshop was preceded by a joint NACLIS-IPOPI meeting, which was honoured by the presence of Dr Nazrila Hairizan Nasir, Deputy Director (Primary Health Care) from the Family Health Development Division, Ministry of Health, Malaysia.

Mr Zhang Shouqing attended the first day of the advocacy and media training workshop on behalf of CSL Behring. The workshop was organised with the generous support of CSL Behring.



### **Joint meeting NACLIS – IPOPI – Summary**

The 10<sup>th</sup> National Clinical Immunology Symposium (NACLIS) took place on 22 and 23 September. A joint Opening Ceremony of IPOPI, the Malaysian Society of Allergy & Immunology (MSAI) and the Malaysian Patient Organisation for Primary Immunodeficiencies (MyPOPI) took place on Saturday morning. Dr Nazrila Hairizan Nasir took the floor to express the willingness of the Ministry of Health to understand more about PIDs in Malaysia and about the challenges faced by patients with PIDs and specialists in the country. Dr Amir Hamzah Abdul Latiff and Jose Drabwell took the floor to welcome participants and encourage them to learn, work and get to know each other during the two-day meeting.

After the coffee break, the combined session continued with presentations explaining what advocacy meant and examples of advocacy campaigns, both at international and national level. Jose Drabwell explained the concerted efforts from patients, doctors and other concerned stakeholders in order to achieve settled objectives. Bruce Lim, MyPOPI President and IPOPI Board Member, gave an overview of the campaign his organisation has been leading for the past years in order to make of PIDs a priority for health authorities and address the three main challenges identified by the Malaysia PID community. Leire Solis described the potential of the PID Principles of Care and the Implementation Package for patient organisations in need for suggestions for their advocacy work.

## Workshop day 1 afternoon

After lunch, NMO representatives gathered in the room to kick-start the training. The afternoon started with a breakout session where patients and doctors were invited to identify and discuss the key issues affecting each NMO. Then the challenges lying ahead were described and discussed, so representatives would link them to the PID Principles of Care (for more information, please refer to Annex 1). After some refreshment, Saara Kiema and Leire provided an overview of the materials developed by IPOPI and available to all NMOs that could help them in their reach out to media or in the planning of an advocacy campaign.



Participants to the workshop were invited to chill out with a dinner in a typical Malay restaurant.

## Workshop day 2

The second day of the workshop was dedicated to two role plays that would allow patients to get a practical experience of a meeting with government officials and a press conference. The objective was to expose them to a semi-real situation and review their performance to improve it for future and real meetings. NMO representatives were split into two groups and prepared both role-plays for an hour. In order to facilitate the exercise, after the governmental meeting for both groups, the performances were discussed by the actors and IPOPI staff (who played the role of very busy governmental officials – Minister included!). The idea was to hear what and how patients and doctors felt during the exercise and hear their comments on how they could improve the flaws mentioned and what could be used in a real-live interview.



The second role play, the press conference, saw much more self-confident and informed patients and medical advisers. IPOPI staff played the roles of three very different journalists, so as to show the different types of persons they could find at their press conferences. In spite of a very noisy mock tabloid reporter incarnated by Christine and a somewhat deaf reporter played by Jose, both groups did an excellent job in keeping their focus and tried to stick to their objectives.

## Conclusions



[www.ipopi.org](http://www.ipopi.org)

The workshop was used to provide patient representatives both theoretical presentations on what tools are available for building a successful advocacy campaign, as well as to put them on the spot and help them learning by experiencing a mock meeting with the Government and a press conference.

All in all, patient representatives appreciated the tools showed during the presentations and exchanged on their national situations, enquiring about each other's experiences and requesting further details on activities developed by the Malaysian PID patient group, MyPOPI.

The role sessions saw improvements from the first to the second and helped patient representatives understand what would be required for when preparing for meetings with government officials and with journalists. Participants considered that a one-pager with a list of key and short sentences explaining what PIDs and immunoglobulin replacement therapies are would be very helpful for future meetings. The one-pager has been included as Annex I of this report.

Relevant information and kits that can be used by patient representatives are all available at IPOPI's website: <https://ipopi.org/nmos/nmo-toolbox/>

## ANNEX I

### About PIDs

Primary immunodeficiencies or PIDs are a growing group of more than 350 rare and chronic disorders preventing the immune system from working properly or at all.

PIDs are recognised as rare disorders but taken as a whole they represent a substantial number of patients.

If PIDs are left untreated, they can cause serious organ damage and can endanger patient's lives.

When diagnosed on time, these disorders are treatable and many severe forms are curable but if not treated, they are often chronic, serious or fatal.

PID diagnosis has a direct impact on patients' quality of life, prognosis and survival, as well as their families, and society in general.

Early diagnosis is critical; a delay in diagnosis not only has devastating consequences for the patient but is also wasteful of health care resources.

Prompt PID diagnosis results in lower healthcare costs.

Treatment for PIDs is safe and effective.

### About immunoglobulin replacement therapies

Immunoglobulin replacement therapies are biological medicines derived from human plasma.

Ig can be administered to the patient either intravenously or subcutaneously. Both administration routes are effective and safe.

Immunoglobulin (Ig) replacement therapy is absolutely essential for the treatment of the majority of patients with PIDs.

There is no alternative therapy for most PIDs, so Ig therapy should be prioritized for PID patients.

Ig therapies cannot be made by recombinant technology, as the whole range of protective antibodies is required.

Ig therapies are included in the World Health Organisation (WHO) Lists of Essential Medicines. It is highly desirable for all countries to have a broad spectrum of Ig products since they are not generic drugs.

Full and adequate implementation of WHO Model List of Essential Medicines List both for adults and children is needed.

Patients with PIDs have the same right to treatment and care as other patients with more common diseases.

## ANNEX II

### Key Issues affecting NMOs and suggested solutions

Principle of Care	Issue	Suggestions
1. The role for specialised centres	<ul style="list-style-type: none"> <li>• Lack of diagnostic facilities</li> </ul>	<ul style="list-style-type: none"> <li>• Train lab technicians in PID diagnosis</li> </ul>
	<ul style="list-style-type: none"> <li>• Establish network of reference and specialist centres</li> </ul>	<ul style="list-style-type: none"> <li>• If centres work together samples could be sent for analysis to larger centres etc</li> <li>• Train haematologists/ other specialists in PID diagnosis</li> </ul>
	<ul style="list-style-type: none"> <li>• No immunologists in public hospitals</li> </ul>	<ul style="list-style-type: none"> <li>• Lobby health authorities for inclusion of clinical immunology as essential medical specialty (also a govt issue)</li> </ul>
	<ul style="list-style-type: none"> <li>• No adult PID specialists</li> </ul>	<ul style="list-style-type: none"> <li>• Establish transition care programmes by putting paediatricians in touch with adult specialists/internal medicine specialists</li> </ul>
2. The importance of registries	<ul style="list-style-type: none"> <li>• No registry</li> </ul>	<ul style="list-style-type: none"> <li>• This is a clinician related issue</li> <li>• Develop your own member database</li> <li>• Contact regional societies who could help e.g. ESID</li> </ul>
3. The need for international collaboration for scientific research	<ul style="list-style-type: none"> <li>• This is a Clinician related issue</li> </ul>	<ul style="list-style-type: none"> <li>• Most Clinical bodies do collaborate on research</li> <li>• Explore collaboration opportunities through regional societies &amp; international networks</li> </ul>
4. The role of patient groups	<ul style="list-style-type: none"> <li>• Low membership</li> </ul>	<ul style="list-style-type: none"> <li>• Info leaflet in clinic</li> <li>• Contact card for specialists</li> <li>• Branding</li> </ul>
	<ul style="list-style-type: none"> <li>• Distance</li> </ul>	<ul style="list-style-type: none"> <li>• Hold small regional meetings</li> </ul>
	<ul style="list-style-type: none"> <li>• Communication with members</li> </ul>	<ul style="list-style-type: none"> <li>• Parent get togethers</li> <li>• Family day - lectures &amp; sharing</li> <li>• Website/social media</li> <li>• WhatsApp/Skype teleconference</li> </ul>
	<ul style="list-style-type: none"> <li>• Awareness of PIDs</li> </ul>	<ul style="list-style-type: none"> <li>• Contact lists</li> <li>• Social media</li> <li>• Tell your story to the press</li> </ul>
	<ul style="list-style-type: none"> <li>• Stigma</li> </ul>	<ul style="list-style-type: none"> <li>• Share stories</li> </ul>
	<ul style="list-style-type: none"> <li>• Funding</li> </ul>	<ul style="list-style-type: none"> <li>• Sponsorships (pharma/industry/govt)</li> <li>• Fundraising (walks, donations)</li> <li>• Strategic Plan (finances)</li> <li>• Use IPOPI guidelines</li> </ul>

	<ul style="list-style-type: none"> <li>• No government policies in place</li> </ul>	<ul style="list-style-type: none"> <li>• Work with govt</li> </ul>
5. Management and treatment options of PIDs	<ul style="list-style-type: none"> <li>• Cost of treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Govt funded – paediatrics &amp; adults</li> <li>• National Insurance cover cost of treatment</li> </ul>
	<ul style="list-style-type: none"> <li>• Travel</li> </ul>	<ul style="list-style-type: none"> <li>• Can treatment be provided in a local hospital e.g. cancer ward?</li> </ul>
	<ul style="list-style-type: none"> <li>• Doctor’s “ego”</li> </ul>	<ul style="list-style-type: none"> <li>• Be respectful but firm</li> </ul>
6. Managing PID diagnosis and care in all countries	<ul style="list-style-type: none"> <li>• Availability of diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>• Train more immunologists</li> <li>• Train other specialists in immunology</li> <li>• Train lab technicians/clinical pathologists in PID diagnosis</li> </ul>
	<ul style="list-style-type: none"> <li>• Availability of treatment</li> </ul>	<ul style="list-style-type: none"> <li>• WHO <a href="http://www.who.int/">http://www.who.int/</a></li> <li>• WHO EML <a href="http://www.who.int/medicines/publications/essentialmedicines/en/">http://www.who.int/medicines/publications/essentialmedicines/en/</a></li> <li>• APEC initiatives <a href="https://www.apec.org/">https://www.apec.org/</a></li> </ul>
	<ul style="list-style-type: none"> <li>• Healthcare professional lack of knowledge</li> </ul>	<ul style="list-style-type: none"> <li>• More training of PIDs in medical degree</li> </ul>