

ONLINE

IPOPI **ASIAN ADVOCACY** WORKSHOP

17-18 APRIL 2021

WORKSHOP REPORT



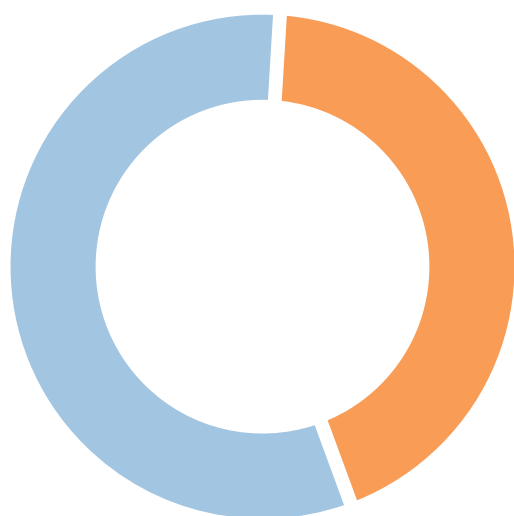
an IPOPI event

INTRODUCTION

IPOPI held a virtual Asian Advocacy Workshop on April 17-18, 2021. The workshop was very well attended, with representatives from the following 9 countries: Australia, Bangladesh, China, India, Indonesia, Iran, Malaysia, Thailand, Vietnam. The objective of the workshop was to build patient representatives' capacity in advocacy, planning and communications, so that they could use them in their activities at national level. The meeting was organised over two days and both a combination of presentations and groups discussions were organised to favour interaction amongst participants.

PARTICIPANTS' KNOWLEDGE BEFORE AND AFTER THE WORKSHOP

BEFORE



VERY GOOD (2 OF 5)

GOOD (0 OF 5)

POOR (3 OF 5)

AFTER



VERY GOOD (3 OF 5)

GOOD (2 OF 5)

POOR (0)

QUOTE:

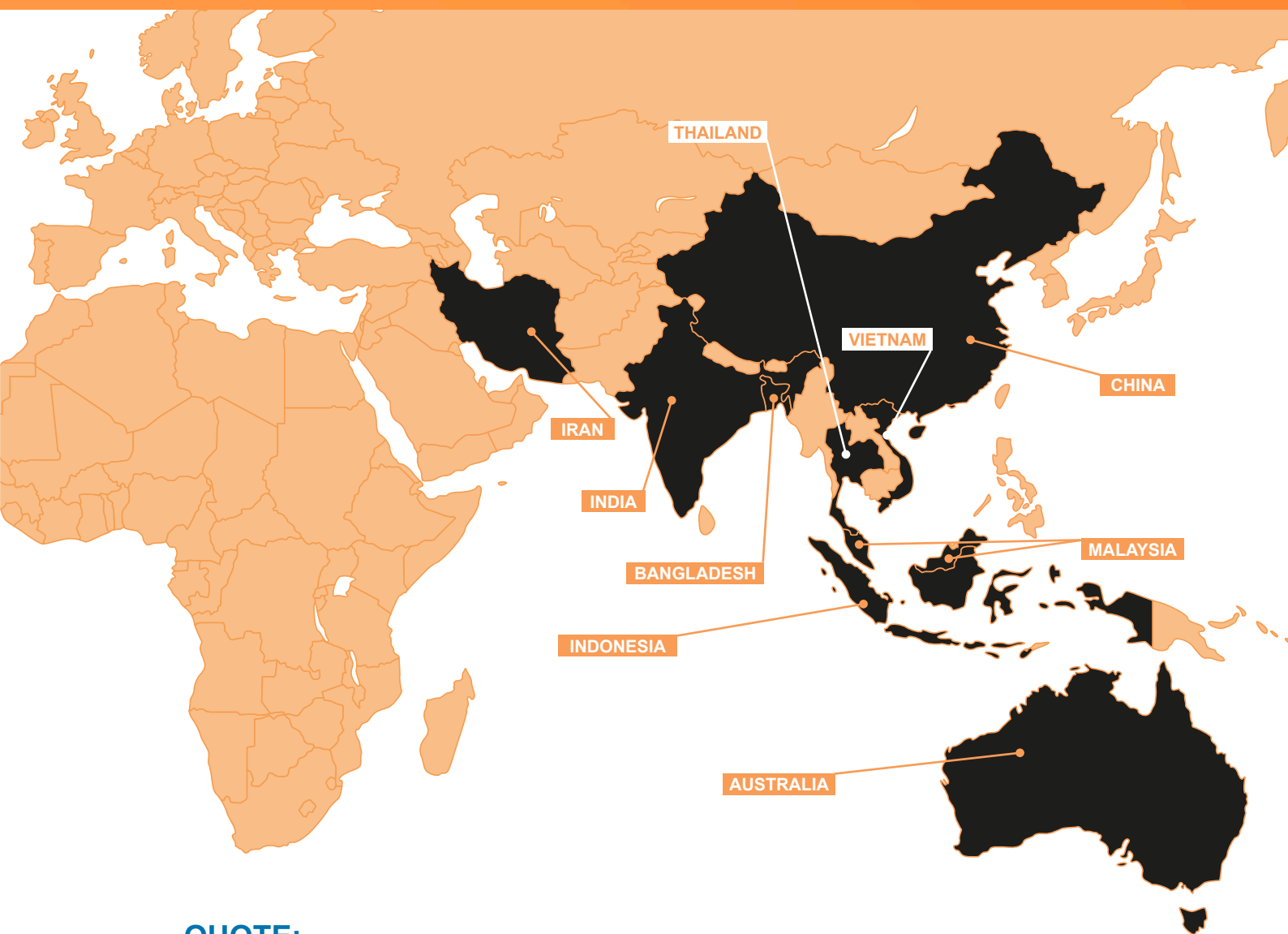
“Great workshop, kudos to all IPOPI team for setting this up super properly (It will be very challenging to do a remote workshop, but you guys nailed it!)”

PARTICIPATION OVERVIEW

TOTAL PARTICIPANTS: 24

COUNTRIES REPRESENTED: 9 (Australia, Bangladesh, China, India, Indonesia, Iran, Malaysia, Thailand, Vietnam).

To favour interaction and participation, the meeting offered the possibility of having automatic translation through Wordly (artificial intelligence translation) as well as on-demand live interpretation in Thai and Farsi. These options were well appreciated by participants and facilitated fluid and continued interactions by all. The workshop also provided an e-book through the platform Qiqo. This was used during breakout room discussions to facilitate data collection and ease of sharing in the main room.

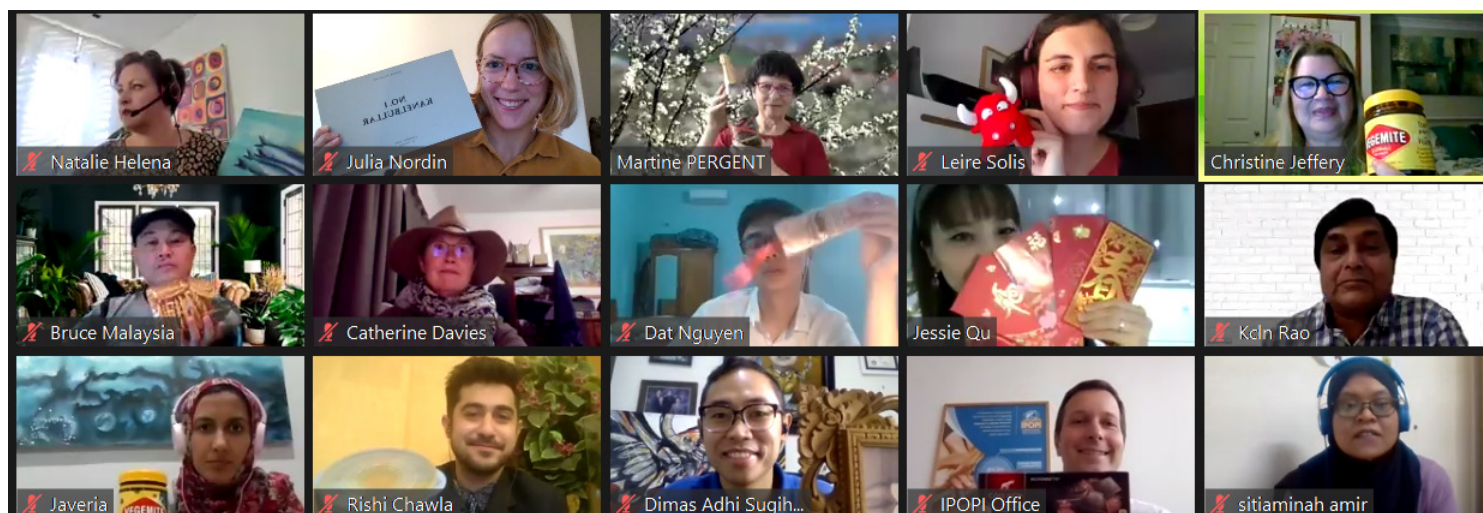


QUOTE:

“This is a great refresher for me personally on advocacy, the new perspective that I get is that advocacy can be simple and easy to start as long as we planned ahead”.

SESSION 1: WHAT'S YOUR PLAN? PREPARE FOR A MARATHON

- Introduction and welcome – Martine Pergent, IPOPI President
- Welcome – Jason Donohue, Global Community Engagement Senior Manager, SOBI
- The importance of strategy for successful advocacy: preparing for a marathon – Christine Jeffery, IPOPI Vice-President
- Practical exercise: establishing priorities – Johan Prevot, IPOPI Executive Director, Leire Solís, IPOPI Health Policy & Advocacy Senior Manager
- Report from group discussions – Johan Prevot and Leire Solís
- Conclusions – Christine Jeffery



The workshop was opened by Ms Martine Pergent, IPOPI President, by warmly welcoming participants to the two-day workshop. Mr Jason Donohue, in representation of SOBI, also said a few welcoming words to participants. After an interactive ice-breaking session to warm up the participants, Ms Christine Jeffery, IPOPI Vice-President, introduced participants to the importance of strategy and detailed the advocacy plan components that NMO representatives need to consider when consider their group's activities. Following this introduction, the skills of the participants were immediately tested in group discussions led by Mr Johan Prevot, IPOPI Executive Director, and Ms Leire Solís, IPOPI Health Policy and Advocacy Senior Manager, who invited the groups to organise the priorities and come up with actionable items of the imaginary country of Karistia. Each of the groups' rapporteurs presented their plans and showed the different ways of interpreting a challenging situation and the many different ways of acting upon the same challenges.

SESSION 2: ASPECTS OF A MARATHON – COMMUNICATIONS

- Supporting advocacy with communications – Bruce Lim, IPOPI Treasurer
- Inspiring communication examples from the region – Jessie Qu, PID Care China, KCLN Rao, IPSPi India
- Practical exercise: Communications – the value of preparing – Martine Pergent and Julia Nordin, NMO Programmes Manager
- Report from group discussions – Martine Pergent and Julia Nordin
- End of day concluding remarks – Bruce Lim

The screenshot shows a Zoom meeting interface. On the left, a presentation slide titled "Communication: WHAT" is displayed. The slide has an orange background with a pattern of small circles. It lists the following points under "What was communicated?":

- The purpose of advocacy campaign
- The needs & challenges & how to overcome those challenges
- Timeline of the advocacy project
- The cost & needs of fund raising
- The tools used to accomplish the white paper

Below the list, there are social media icons for IPOPI, including a globe, Instagram, Twitter, and Facebook, along with the IPOPI logo. To the right of the slide, there are two small images of a man speaking at a podium during an "IPOPI ADVOCACY MEETING". On the far right, there is a vertical stack of four video feeds of participants:

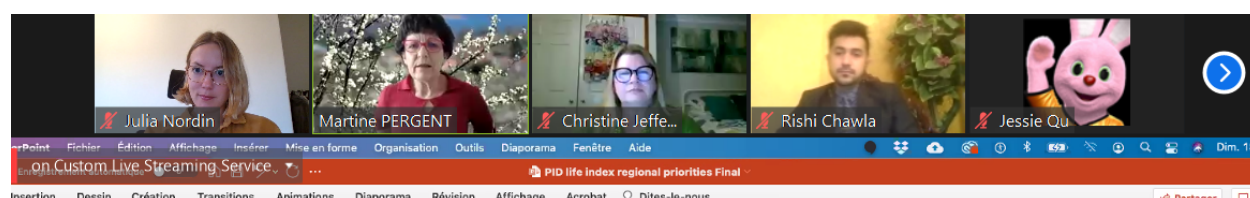
- Christine Jeffery A...
- Martine PERGENT - F...
- Javeria
- Jessie Qu

Mr Bruce Lim, IPOPI Treasurer, kickstarted the second session of the workshop by providing a very concrete and clear presentation on how communications can support and be a means for patient advocacy. It was followed by some inspiring communication examples from IPOPI members, with Mr KCNL Rao, in representation of IPSPi India, and Ms Jessie QU, on behalf of PID Care China, giving real life examples of internal and external communications at national level. The first day ended with a practical exercise, where the two groups returned to the imaginary country of Karistia to prepare either a social media strategy or a media outreach strategy for a fictional running race. After representatives of the two groups presented their work, a discussion was held during which participants agreed on the need to focus on free communication as a gold standard. The main take away was that planning and preparing communication efforts is key to optimise the efforts and resources invested.

SESSION 3: DRAFTING AN ADVOCACY PLAN

- PID priorities in the Asian region – Martine Pergent
- Practical exercise: drafting an advocacy plan – Bruce Lim and Leire Solis
Contributions from Dimas Sugiharto, Hendy Budijanto, Lenny Susanti (Indonesia) and Mohammad Iqbal Hossain (Bangladesh)
- Reports from Group discussions and conclusions – Bruce Lim and Leire Solis

The second day started in a fun manner, when participants showed an object symbolising their country. It was interesting seeing two representatives from countries as distant as Iran and Australia showing the same object! Martine then took the floor and introduced participants to the PID Life Index and addressed the many different challenges faced by the region in terms of diagnosis, care and infrastructures for PIDs. In the group discussion that followed participants were asked to work upon a challenge that had been selected by 2 different NMOs ahead of the meeting. The rest of the participants acted as advisors to the 2 NMOs and tried to provide solutions to the challenges described. One rapporteur per group presented the group's findings, showing a pragmatic and proactive approach to challenges! Both groups highlighted the lack of awareness of PIDs amongst physicians as a main challenge and several solutions were suggested, such as the inclusion of dedicated sessions on PIDs in the medical curriculum, development of leaflets, etc.



The screenshot shows a video conference interface with five participants in a row: Julia Nordin, Martine PERGENT, Christine Jeffe..., Rishi Chawla, and Jessie Qu. Below the participants is a presentation slide titled "6 key principles of care for PIDs". The slide contains a bulleted point about IPOPI's work with an international team of physicians, followed by a sub-point about defining what is important for PID patients at the national level. To the right of the text are six colored boxes, each containing one of the six key principles.

6 key principles of care for PIDs

- IPOPI has worked with an international team of physicians specialised in PIDs and patients leaders from the 5 continents
>To define what is important for PID patient at national level.

- PID diagnosis
- Treatment
- Universal coverage
- Specialised centres
- National Patient Organisations
- National registries

SESSION 4: CROSSING THE FINISH LINE

- How to implement an advocacy campaign – Christine Jeffery
- Practical exercise: Getting ready to meet the policy makers! & Role plays – Johan Prevot, Bruce Lim, Martine Pergent, Christine Jeffery
- Concluding remarks – Martine Pergent



The last session started with Christine providing a very crisp and interesting presentation on how to implement an advocacy campaign, with the objective of providing participants with the resources and knowledge to be able to identify the political hooks/barriers, potential supporters/barriers, etc. It was the perfect introduction to the following exercise where participants, organised in 2 groups, were asked to prepare an online meeting with a policy maker. Hats off to the two groups' representatives who had to face very interesting and special policy makers. Congratulations as well to our policy makers, incarnated by Johan, Bruce, Martine and Christine, who made of the role play session a fun and interesting exercise! When debriefing afterwards a series of best practice high-lights for meetings with policy makers and decision makers were identified.

DO'S AND DON'TS IN A MEETING WITH POLICY MAKERS

BEFORE THE MEETING:

- Prepare and structure well your objective(s) for the meeting, your main messages and the supportive arguments to be used.
- Prepare well the challenges but also some concrete solutions for them.
- Have a detailed script including detailed roles and messages of each of the participants. Have a plan B for each participant in case of problems on the day of the meeting.
- Consider whether bringing a document with figures and key data is needed /pertinent.
- Do some research on the main interest of the policy maker, see how your objective(s) can be linked to his/her interest.
- Make sure you know who you are meeting and the number of participants in the meeting.
- Prepare for the unexpected.

AT THE MEETING:

- Round of introduction, short and crisp.
- Need to be / stay focussed, no matter how off-topic the policy maker is. Stick to your main objective(s) and messages.
- Active listening, to connect with the main interests of the policy maker.
- Assess who is the person that can be most helpful and that you can remain in contact with.
- Try not to lose balance or be derailed. Be composed and have a positive attitude.
- Do not leave without agreeing on a follow-up meeting/call and without discussing the next steps.

AFTER THE MEETING:

- A thank you email to the participants outlining the positive outcomes of the meeting and listing the agreed next steps.
- Ensure to follow-up the thank you email, so the policy maker does not forget the meeting.

CONCLUSION

The Asian advocacy workshop was a very successful event. It stressed the importance of planning, of taking the time to carefully study challenges and identify ways to tackle them. Participants appreciated the interaction facilitated throughout the two days, as a way of learning from other participants, hearing about their experiences and getting ideas for their advocacy work in their countries. It was particularly rewarding to see the interest reached by so many different countries in the region, and the willingness of participants to stay in touch to continue discussing advocacy projects and developments in the coming months.

FEEDBACK RECEIVED

"I am really more focussed on the organisation or roadmap of a campaign."

"Really great insight into what goes on from the organisation side - I've only ever seen from the patient's side. Thanks for all the hard work."

"Always happy to see all the vibrant faces. Wish to be able to see each other in person soon. As always, insightful event and highly enriching in knowledge."

This meeting was supported by an unrestricted grant from



