

IPOPI National Strategic Meeting Manila, Philippines 29 September 2018



IPOPI and PhilIPOPI organised a small-scale meeting in Manila on 29th of September 2018, to help the associate Philippine National Member Organisation (NMO) to activate and find strategies and concrete action points for the future. The NMO, since its launch, had faced organisational issues and IPOPI proposed its help to support them re-organise. Prior to the meeting, PhilIPOPI had chosen a new Board of Directors and started the registration process to become a formal organisation in the country. The board members were actively seeking to get new members and volunteers among the attending families.

The meeting started at 10am with welcoming remarks from **Dr Fatima Johanna Santos Ocampo (Dr Jonie) and by Mrs Dahlia Manzano, the President of PhilIPOPI**. She welcomed participants and expressed her gratitude towards IPOPI's and Kedrion's support in order to make the meeting happen. She also extended a warm welcome to all families that had come and thanked **Dr Eric Tayag** from the Department of Health for accepting the invitation.

Dr Eric Tayag then gave an overview of the universal health care structure in the Philippines. He showed figures on performance of the country measured in health variables compared to other countries in ASEAN. Philippines was in the lowest 4 countries in average life expectancy, maternal mortality, under 5-yrs mortality and in TB incidence rate. He also gave an overview of 'PhilHealth', explaining that the system is fragmented to private and public systems, and an overview of the F1+ health care strategy and the health delivery network in the planning by the Department of Health.



Jose Drabwell gave an introduction of the IPOPI achievements and went over the key roles of a national patient organisation giving concrete examples from IPOPI and its members. The roles are: 1) To provide support to patients & families in your country, 2) To advocate for better access to early diagnosis and treatments in an organised way, 3) To raise awareness of PID patients' needs and priorities, 4) To nurture stakeholder collaboration, 5) To disseminate information, 6) To collect data and 7) To organise key events that bring patients and the PID community together.

Bruce Lim shared his experiences with establishing and developing the Malaysian patient group MyPOPI. He stressed the fact that the organisation was only established 4 years ago and showed how quickly it had grown into a successful and powerful organisation. He gave an overview of MyPOPI's strategic road and the key objectives as well as awareness and advocacy activities. Finally, he highlighted that even with small numbers, it is possible to achieve a lot if you work together with stakeholders and stick to your plan.

Next testimony was presented by **Mr Theodore Sosoban**, Toto, an 18-year old ex-SCID patient. He is the only SCID patient that has successfully been transplanted in the Philippines in 1999, thanks to his mother's, **Mrs Emma Sosoban's** tireless lobbying together with the help of Toto's doctors. Toto gave an overview of the challenges him and his family faced after the diagnosis, related to emotional, financial, social and physical aspects. He concluded that it is of utmost importance to have a well-functioning patient group in the Philippines that PID patients and their families can reach out to.



The last presentation of the morning was given by **Dr Santos Ocampo**. She gave a testimony on the challenges PID doctors face in the Philippines. The main challenges she stressed were recognition of PIDs, lack of training of doctors and the lack of expertise, availability and affordability of diagnostic tests, the geographical challenges such as travelling in order to reach a specialist and difficulties in communication with families that live far from the referral centres, the lack of specialist treatments such as bone marrow transplantation and adjunct treatments for comorbidities and finally the lack of specialist nursing for PIDs, family guidance and transition care.

The workshop

The second half of the day was dedicated to the strategic workshop. The attendees were divided into small groups, one of patients and one of doctors. The groups were asked to identify two main challenges for them, as a patient organisation, and secondly a few action points to address them.

The challenges that were identified by both groups were:

- 1) Both patients and doctors found *financing treatment and diagnostics* to be the main challenge for PID management in the Philippines as they are not subsidised by the department of health and therefore the financial burden mostly falls on the families. The workshop attendees agreed that joint advocacy effort is the only way forward in addressing the challenge.
- 2) *Awareness* was the second challenge identified by both groups. Within awareness, the aspects highlighted were *medical awareness*, as usually patients are referred too late to immunologists because primary health carers are not aware of PIDs, as well as *public awareness* as it is very challenging to lobby for better treatment for a disease nobody has heard of.

The action points discussed to face the two main challenges were:

2) Advocacy efforts

- Organise a workshop for patients/volunteers to find more people to help out in the group
- Gather patient testimonials to be used in media (TV, newspapers)
- Join forces and lobby for inclusion of Igs in the national essential medicines list (use WHO list of essential medicines and APEC guidelines)
- Doctors to use IUIS classification to lobby for the appropriate Z-packages
- Meeting with paediatric society to get BMT accessible for PID as it is for other diseases

1) Awareness efforts

- Organise a WPIW event
- Gather patient testimonials to be used in media (TV, newspapers)
- Patients presenting their stories in various medical events and meetings, such as annual convention of medical school
- Get the Philpopi Facebook group and website up and running
- Translate and disseminate printed materials to hospitals and clinics

The PhilIPOPI Board also agreed on the following steps:

- After the formal registration process is final, set up a bank account
- Make some cost estimates for establishing the website and organising a meeting
- Reach out to companies and IPOPI for funding the first activities
- Use PhilIPOPI Facebook page to inform membership

IPOPI wishes to thank Kedrion Biopharma for its support towards this event.

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Post Meeting note: The PhilIPOPI President resigned some weeks after the meeting. Following a discussion between PSAAI doctors and the remaining PhilIPOPI board members Colly Carag was appointed as new President for the group.