

IPOPI
1st Philippine PID Patients-Doctors National Meeting
Held at the Microtel Hotel, Manila, Philippines
5th and 6th November 2016



Report

Introduction

The first IPOPI Philippine Patients-Doctors national meeting was held at the Microtel Hotel in Manila, the Philippines. The meeting took place from 5th to 6th November 2016 and was organized in collaboration with the Philippine Society of Allergy Asthma and Immunology (PSAAI). The two-day event included a scientific meeting with international lecturers from Spain, the Netherlands, Indonesia and Thailand as well as an interactive workshop with participants varying from PID patients and family members to local doctors and the Philippine Haemophilia Center representatives.

The first day scientific meeting was aimed at local doctors and PhD students and included international speakers lecturing on new insights and diagnosis of PIDs, promoting awareness of key medical priorities and discussing South East Asian regional PID care priorities. The second day workshop featured educational lectures for PID patients and families, experience from already active patient organisations in South-East Asia, such as the Malaysian PID organisation and the Filipino Haemophilia Center, and an interactive discussion between participants. The meeting was organised with a view of launching a national patient organisation in the country in the near future.

Day 1 – Scientific session

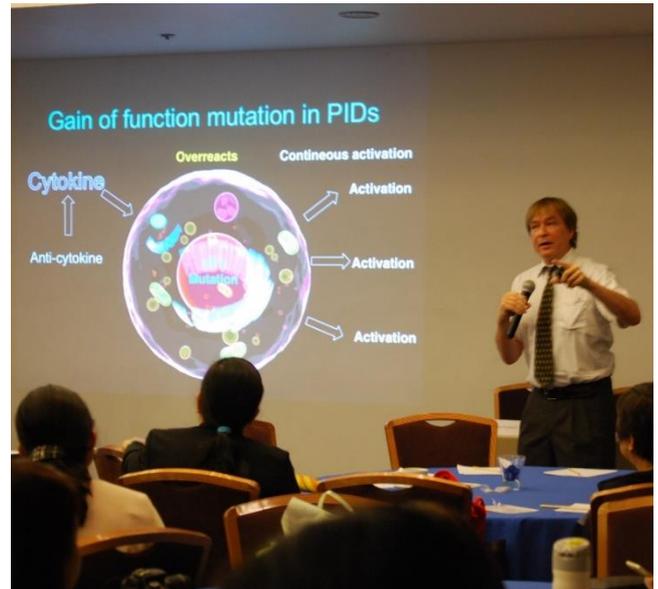
The first day scientific meeting gathered around 70 attending physicians and PHD students from the Philippines. The event was opened with the Philippine National Anthem and the PSAAI anthem. The opening remarks were given by **Dr Maria Carmela A. Kasala** (PSAAI President), **Dr Fatima Johanna Santos-Ocampo** (Immunologic Disease Council, PSAAI) and **Mrs Jose Drabwell** (IPOPI President). Dr Kasala welcomed the speakers and participating doctors. Dr Santos-Ocampo shared her contentment regarding the high numbers of participants from various parts of the country. She expressed her certitude

that the participants would have an invaluable learning experience about PIDs and her wish for the Philippine medical community to increase PID diagnosis rates in the country. Mrs Drabwell extended her thanks to Dr Santos-Ocampo and her team for their help and dedication in organising the event. She also thanked Kedrion for their support of the meeting.



The first scientific presentation was given by **Dr Teresa Español** (Honorary Vice-President of IPOPI MAP, Spain) on suspecting and diagnosing PIDs with inexpensive testing. The presentation was designed for doctors and medical students to help them identify primary immunodeficiencies in their patients. In her presentation, she emphasised the importance of early diagnosis and the main warning signs to detect an immune deficiency. She explored the characteristics of different types of PIDs and the different types of complications related to the conditions such as recurrent infections and autoimmunity problems. Finally, Dr. Teresa emphasised the importance of studying and recognising different types of PIDs in order to treat all patients.

Prof Martin Van Hagen (IPOPI MAP Member, the Netherlands and Thailand) took the stage to provide an informative presentation on novel insights on Primary Immunodeficiencies and genetic defects. Prof Van Hagen focused in particular on immunophenotyping of PIDs, classical drug therapies for PIDs, immunogenetics and its role in diagnosis and therapy of PIDs. Specific concrete examples were reviewed to illustrate new genetic defects such as gain of function mutations, as well as an overview of lessons learnt with the use of whole genome or exome sequencing. Last but not least he stressed the excellent work of the South East Asian Network of doctors for Primary Immunodeficiencies (SEAPID) and the promising outlooks of their work.



Dr Teresa Español further explored her previous topic by giving several case study examples on which steps have led to a PID diagnosis and appropriate therapy from her own experience in Spain, ranging from 'easy' cases to diagnose to more complicated cases including defects of the innate system. She highlighted the importance of family history in diagnosing PID. She also highlighted important guidelines on the careful use of different types of vaccines in PID. Dr. Espanol briefly went over the increasing use of Gene Therapy to treat PIDs and explained the main difficulties that most countries face failing to treat PID patients which cause great divergences in care between countries.



Dr Dina Muktiarti (SEAPID representative, Cipto Mangunkusumo Hospital Jakarta, Indonesia) focused her presentation on the management of primary immunodeficiencies in Asia. During her talk, she went through the common challenges facing patients, in particular undiagnosis with an estimated less than 10 percent of PID patients diagnosed in South East Asia. However, she expressed her hopefulness by introducing the recent positive PID awareness raising developments in Asia. These included the launch of the SEAPID Network and the growing number of patient groups in SE Asia. She pointed out the importance of the PID Principles of Care and the need to implement them in the region, which is confronted to profound problems when it comes to access to diagnosis and care. She concluded her presentation stating that more awareness campaigns are needed, networking between specialists and patients must continue to increase, there is a need for enhanced diagnosis capabilities and that advocacy efforts targeting policy-makers should be instigated. Finally, she thanked Dr. Narissara Surantannon (Thailand) and Dr. Adli Ali (Indonesia) for their collaboration.

Dr Florecita R. Padua (National kidney and transplant Institute, Fe del Mundo Medical Center, Manila the Philippines) followed with a presentation about PID management in the Philippines. Firstly, she expressed her contentment about the meeting which was “a dream come true” for her. She stated that during her 25 years of practise she has seen only one or two cases of the most common PIDs in the Philippines. She went through some of the specific cases and the diagnosis and treatments used. She indicated the frustration of doctors and patients because of the lack of financing, lack of tools for definitive diagnosis, lack of modalities of specific treatments and lack of skills to detect the condition. The Philippines have the technology to test and to treat PIDs but it cannot be applied because of its cost and non-viability due to its low application. However, a national health insurance has recently been launched in the country and efforts should be made to include PIDs in the reimbursement coverage. Finally, she stated that awareness among physicians,



practice guidelines tailored to the local setting and purposive advocacy by patients, families and doctors are key to ensure a better future for the PID community in the Philippines.



The final presentation of the day was a double-act by **Prof Aart Jan van der Lely and Prof Martin Van Hagen** (Erasmus University, the Netherlands) with a joint presentation about obesity, the immune system and auto-inflammation. The hazards of fructose, especially the high fructose corn syrup (HFCS), were specifically discussed. High usage of fructose leads to increased production of uric acid which shows up as fat in the body and might be disastrous to some tissues such as the liver. Increasing fructose intake is the main cause of morbid obesity. Obesity in turn leads to a range of health issues including obesity associated diseases, many of which seem to stem from inflammation and compromise immunity as well as the efficacy of vaccines. In conclusion, the importance of reducing our fast sugar intake was highlighted and having a healthy diet to stay well and avoid health problems such as heart diseases, diabetes, obesity, liver failure, and cancer.



Day 2 – Patient session

The second day opening remarks were given by **Mrs Jose Drabwell** and **Mr Johan Prevot** (Executive Director, IPOPI). Mrs Drabwell firstly thanked everyone for participating, she expressed how pleased she was to see so many patients attending from different islands of the Philippines. She also gave her thanks to the organising committee without whom the event would not have been possible and to Kedrion for their support. Mr Prevot then provided his welcoming words emphasising how important it was to bring together all stakeholders related to PIDs and to work hand in hand in order to improve the conditions and quality of life of PID patients in the country and the region.

Prof Martin Van Hagen kicked off the programme opening with an informative presentation about primary immunodeficiencies and the immune system. The presentation provided an overview of PIDs to the patients and families. The basic function of the innate immune system and the adaptive immune system were explained. Prof Van Hagen explained that all patients have an individual “repertoire” of antibodies. Some people lack these antibodies and that is when the patient should be diagnosed with PID. He introduced the roles of T-cells, B-cells and cytokines. He explained how the human cells, hormones and nervous system are all linked which makes the immune system a very complex one. A Q&A session followed his presentation. The audience was interested in stem cell therapy, immunoglobulins and the experimental immune system stimulation.



The second presentation of the day was by **Mr Bruce Lim** (President of MyPOPI, board member of IPOPI) about the experience of running a patient organisation in Malaysia. In his inspiring presentation Mr Lim talked about his personal experience with the issues and challenges he faced with his son, who lives with a PID in Malaysia regarding misdiagnosis and therefore mistreatment. He went over the reasons that led him to start a patient organisation after having a local patient meeting with IPOPI in Malaysia. He explained the challenges in the beginning of formalising the group and the following success MyPOPI had regarding awareness building, fundraising and advocacy in the country. He went through various awareness campaigns MyPOPI implemented in the media (radio, newspapers), shopping malls etc. He also introduced MyTAPIR, the MyPOPI mascot. He highlighted the importance of thinking creatively in terms of visibility but also when it comes to

manpower and advocacy. Malaysia and the Philippines share similar features and therefore similar challenges. That is why it is important for the patient groups to learn from one another and work hand in hand, he concluded.

The third presentation of the day was held by **Dr Narissara Suratannon** (Chulalongkorn University Hospital, Thailand) talking about the experience in launching a patient group in Thailand and the importance of collaboration between patients and doctors. She reviewed the progress ThaiPOPI has had since their launch and listed the main objectives of the group. ThaiPOPI has had various awareness raising activities such as visiting lectures at universities in the country. She emphasised the importance of patients getting involved in their own advocacy stating that usually it is their voice that is heard among the decision makers instead of the doctors’.



Dr Fatima Johanna Santos-Ocampo (Immunologic Disease Council, PSAAI, Philippines) then presented her views on the PID environment in the Philippines from a Physician’s perspective. She discussed the reasons behind the low awareness of PIDs in the country. In her words this is due to lack of initiative, lack of funds, lack of incentives and lack of training and exposure. She also went through important issues such as maldistribution of devoted immunologists, poor availability of tests and lack of

governmental support. She recalled how she started to be involved in PID with IPOPI through the regional meetings in SEA and proceeded to present the PSAAI objectives regarding PIDs which include awareness building among physicians and medical students, PID in CME courses, creating modules and red flags, reaching out to the key subspecialists, facilitating referrals through PSAAI website, dispelling myths and beliefs still prevalent in the rural areas and establishing a PID registry. She also mentioned the desire to help in establishing advocacy groups and patient support groups as one of their main objectives. Finally, Dr. Santos-Ocampo stated that future goals are to train medical staff, to identify PID center(s) in the Philippines, to get PIDs listed under the Rare Disease Act 2016 and other lobbying initiatives.

Mr Johan Prevot (Executive Director, IPOPI) followed with presentation about the role of IPOPI as an international umbrella organisation. He provided an overview of IPOPI's activities and support programmes available to help NMOs with their national campaigns. He talked about the recent activities IPOPI has carried out in South East Asia through the IPOPI Bob Le Bien Asian programme. With the support of the programme and its corporate partners, IPOPI has launched new patient groups in other countries in the region such as Malaysia, Thailand, Vietnam, Hong Kong and Indonesia. The creation of SEAPID also took place in Thailand in 2015 which led to the Call for Action in South East Asia being released. Finally, he went through the ideal next steps for the Philippines in launching a patient group to start advocating and improving diagnosis and treatment for the PID community in the country.



Dr Jeannie Ong (Mindanao Haemophilia Center, Philippines) presented her experiences with the Haemophilia Society in the Philippines from a physician point of view. The objectives of the presentation were to give an overview of haemophilia as a rare disease and to share the experiences on how the association was established and sustained. She talked about the importance of the role played by the patient group in securing positive outcomes regarding haemophilia care in the country. She went through the basic statistics of haemophilia in the Philippines. The challenges are similar to the ones facing PID community: most of the cases are not diagnosed leaving patients without proper treatment. There is also a lack of plasma derived products in the Philippines which means that the most severe cases must be prioritised in care. The center has been successful in giving factor concentrates for patients for free with WFH's support. She introduced the various awareness campaigns, workshops and technical trainings the center has implemented. She also introduced the stages of development the haemophilia center went through with an outreach programme, a free testing for patients suspected to have the condition and creation of a registry for patients. She also emphasised the importance of peer support and gave some helpful advice to the Philippine PID patients group under formalisation.

Arch Jaime Gonzaga (Founding president, Haemophilia association of Davao, Philippines) then talked about his experiences from a patient's perspective of the Haemophilia association, which now has around 216 members and growing. He introduced some of the practical challenges they faced with funding, spending and reaching members when they first started the group. He also went through the supporting organisations they reached out for help in the beginning and brought out some ways for patients to receive discounts on their medication such as the national disability card. Finally, he



concluded that running an organisation takes willing leaders, motivated volunteers, cooperation and effective communication.

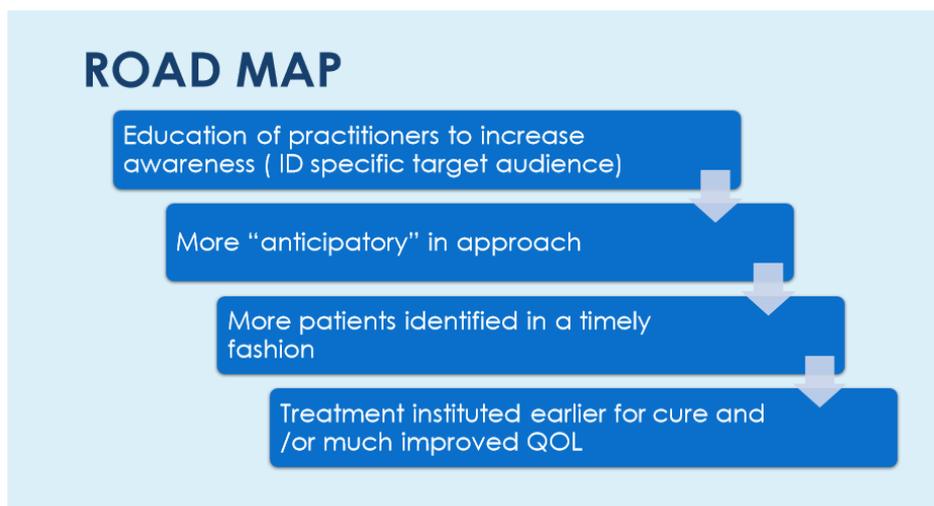
Discussion and priorities

The two-day meeting was effective in identifying some key facts and next steps for the Philippine PID community:

- 101 million habitants in the ~7 640 islands of the Philippines
- 3 treating hospitals with 150 diagnosed patients
- Prevalence based on international figures it is likely that there are 84 000 patients in the country
- IG treatment not covered by the public health insurance
- The Philippine Charity Sweepstakes Office PCSO offers funding for immunoglobulin but the waiting lists are long
- There is a possibility to apply for a national disability card to get 20% discount on medicines
- Only IVIG available currently, SCIG not available
- BMT available but not for PID, families go abroad for transplants
- Lack of diagnostic facilities, funding and expertise are the key issues
- No PID registry and no accurate number of diagnosed cases

Next steps:

- Facilitate opportunities for further training
- Identify a PID center/s for referral and management by experts formally trained for PID
- Lobbying to get PIDs listed on the Rare disease act 2016
 - Priority funding/support for awareness campaigns
 - Greater accessibility to diagnostic tests per major region
 - Refund of expenses for diagnostic tests and treatment of PID from government
 - Health Insurance
 - Implementing guidelines to vaccination policies on a nationwide scale
 - Start discussion / groundwork for new born screening
- The following Road Map was provided by Dr Santos-Ocampo:



Conclusion

The national PID meeting was the first of its kind in the Philippines bringing together patients, family members, medical students and doctors from different regions of the country. It provided an opportunity to discuss and exchange concerns in care for PIDs and concluded to a unanimous agreement that there is a need to launch a national patient organisation.

The meeting was successful in bringing out patients and families that were willing and motivated to take part in the formalisation of the Philippine NMO. On the second day after the presentations active parents with some of the PSAAI physicians sat down around a table and began discussing a name and the roles for the group. Mrs Katrina Villareal, Mrs Evelyn and Mr Andy Sanchez, Mrs Editha T. Lim, Mrs Esther Asistido and Mr and Mrs Bartolome (Onyx & Jing) were only some of the many willing parents that expressed their interest in taking part and contributing to the organisation. Some of the doctors including Dr Santos-Ocampo indicated their willingness to help and support in the next steps.

IPOPI stressed that even before registering the group in the country it is relevant to apply for associate membership to have support from the beginning. The process to apply for membership was reviewed and contact details exchanged. It was agreed that close contact between IPOPI, the new patient representatives and the supporting doctors would be kept and guidance provided to launch the patient organisation in the near future. IPOPI looks forward to supporting this objective and has great confidence that the future group will be of great benefit to the PID community in the country.



Picture: The new patient organisation in the making