

IPOPI 2nd Regional Asian PID Patients and Doctors Meeting Bangkok, Thailand 10-11 November



IPOPI organised its second Regional Patients and Doctors meeting in Asia on 10-11 November in Bangkok, Thailand, with the support of Shire. The two-day meeting was organised back to back with FIMSA (Federation of Immunological Societies of Asia-Oceania) Congress 2018. The first day of the meeting was geared towards doctors, with lectures on clinical care and latest treatment and diagnostic advances as well as a panel discussion on difficult cases submitted by the participating doctors. The second day was dedicated to patient education, with informative lectures and a workshop on awareness and World PI Week. The meeting brought together 40 participants including patients, doctors and nurses from 7 countries (China and Hong Kong, Australia, India, Malaysia, Thailand, Vietnam and Indonesia).

Doctors' day, 10 November

The day started with an introductory session. The welcoming remarks were given by **Prof Nattiya Hirankarn**, the Vice-President of AAIAT (Allergy, asthma and immunology association of Thailand), thanking IPOPI for their work in the region with raising awareness and fostering collaboration through such meetings. **Mrs Martine Pergent**, the President of IPOPI then gave a keynote presentation on status of the PID Principles of Care (PoC), highlighting the good developments in the region and giving an overview of challenges, echoing the PoC. **Prof Martin Van Hagen** presented his opening scientific lecture on the endocrine system and PID, highlighting the link between PIDs and hormonal functions. The session was concluded by Mr René Büchel from Shire, sharing insights on the developments of plasma collection and products in Asia, highlighting the need for more source plasma collection in the region to match the growing need.

The 2nd session focused on regional care and treatment priorities. The session was opened by **Dr Narissara Suratannon** from Chulalongkorn University, Thailand giving a lecture on the most common signs to suspect a PID, going over the most commonly used diagnostic tools, some speciality diagnostics, and a new genetic diagnostic tool, global screening array (GSA), suitable for resource-limited regions. **Prof Surjit Singh**, the APSID President elect, then gave an overview of APSID (Asia Pacific Society for PID) perspectives of the challenges for PID care in the region, mentioning underdiagnosis, the challenge of clinical diversity, lack of life-saving treatments and low awareness. The session was concluded with a patient testimony by **Dr Geoffrey Yu** from PID League Hong Kong, giving his story from receiving XLA diagnosis to becoming a doctor.

The 3rd session of the day included lectures on improving diagnosis rates in Asia. The 1st speaker of the session was **Dr Adli Ali** from University Hospital Oxford, with a presentation on newborn screening for SCID, giving the pros and cons of the TREC/KREC assay and the status of implementation in the region, as well as touching on the topic of the treatment availability for SCID. **Dr Wim Dik** from Erasmus Medical Centre, the Netherlands followed, giving a presentation on specific antibody testing for PID, going over some aspects of vaccination responses for PID diagnosis. Finally, **Dr Virgil Dalm** from Erasmus Medical Centre gave an overview of genetic diagnosis, stating that identifying the gene defect can also lead to better treatment outcomes.

The last session of the day was an interactive workshop on difficult PID cases, pre-submitted by the attending doctors. Three cases were discussed during the meeting by the expert panel: **Prof Martin Van Hagen, Prof Surjit Singh, Dr Virgil Dalm, Dr Wim Dik, Dr Narissara Suratannon and Dr Adli Ali**. The first case “Unprecedented severe infective colitis in a patient with primary immunodeficiency: solving the conundrum” was presented by **Dr Thong Pui Ling** from Malaysia. The panel predicted a leaky SCID and concluded that a genetic diagnosis is needed to confirm it. The second case regarding a patient with suspected Job’s syndrome was presented by **Dr Nguyen Minh Tuan** from Ho Chi Minh, Vietnam. The conclusion by the expert panel was that although HSCT is sometimes a possibility for treatment of the disease, genetic testing would be required to confirm whether to stick with supportive care or to go for HSCT. The last case was presented by **Prof Martin van Hagen**, on a patient with a DOCK8 deficiency in the need of a HSCT but unwilling to go through the treatment due to the good current state of health. The conclusion by the panellists was that as the clinical phenotype was not so severe at the time and if after all information has been provided for the patient about the possibility of severe complications in the future, the patient’s wishes should be respected.

Patients’ Day, 11 November

The 2nd day was opened by a few words from **Mrs Martine Pergent** from IPOPI, which followed by a welcome speech by **Mr Ronnapee Nushsiri** from ThaiIPOPI, expressing his excitement about the workshops laying ahead and thanking IPOPI for providing the platform to meet with other PID patient representatives in Asia. The welcome words were then followed by the 1st session of the day, containing educational lectures on the history of PID from the 1950s to this day by **Prof Martine van Hagen**; on Plasma pheresis and Immunoglobulins by **Mr Johan Prevot**, Executive Director of IPOPI; on Subcutaneous Immunoglobulins (SCIG) by **Dr Adli Ali**; and on ABC of BMT as treatment for PIDs by **Dr Virgil Dalm**.

The 2nd session of the day moved on to presentations on awareness and access to care, and the importance to work together. The presentations and testimonies included: Success stories by IPOPI and its NMOs by **Ms Saara Kiema, IPOPI**; a physician testimony on why patient organisations are important by **Dr Huyen Thuc**, National Children’s Hospital Hanoi; insights and lessons learnt by the Haemophilia Association of Thailand by **Mr Ekawat Suwantaroj**; and an NMO case study – MyPOPI examples of working together by **Mr Bruce Lim**, Malaysian Patient Organisation for PID.

The last session on the day was a workshop on awareness raising and World PI Week. After a few introductory words by **Mrs Martine Pergent, Mrs Jose Drabwell** from IPOPI first gave an overview of the available World PI Week tools and a peek to the new developments in the 2019 campaign. **Mrs Christine Jeffery** from IDFA then gave an introduction to the workshop which followed. The participants were divided into two working groups and given tasks to come up with ideas for campaigning on three topics: 1) *Public awareness*, 2) *Medical Awareness* and 3) *Political awareness*. The results were compiled in an outcome PowerPoint report that can be found on IPOPI.org as well.

Conclusions

This was the first time IPOPI had a difficult cases workshop for doctors, which was very well received by the participants. It was also the first time for IPOPI and its NMOs in the region to meet with the newest addition to IPOPI family, PID Care China as well as to collaborate with FIMSA. The meeting was very well received by the participants. Many of the attending IPOPI NMOs have also already communicated their plans for World PI Week 2019 to IPOPI, following the awareness workshop.

IPOPI wishes to thank Shire for its generous support towards the organising of the event, as well as Kedrion for the travel grants it provided.

