

## WORLD PI WEEK EVENT IPOPI ASIAN REGIONAL PATIENT MEETING 27 & 28 APRIL 2016, HONG KONG



**The IPOPI Asian Regional Patient Meeting** was held at Le Méridien CybertPort Hotel Hong Kong on the 27 and 28 April 2016. There were 32 attendees, representing patients, parents, NMO leaders, paediatricians and nurses from Malaysia, Singapore, Hong Kong, Laos, Indonesia, Vietnam, India, Japan, Thailand and the Philippines. Representatives from Biotest Germany and Asia who sponsored the meeting also attended.

**The Welcome and Medical lectures** were given by Jose Drabwell, Geoffrey Yu, Professor Martin Van Hagen, Professor Yu Lung Lau, Dr Nizar Mahlaoui, Dr Narissara Suratannon, Dr Adli Ali and Nursing Practitioner Carla Duff, the key points being:

Asia is diverse and complex, however:

- each country has similar issues in diagnosis, treatment and care of PID patients.
- each country needs more training of doctors in the field of immunology and recognition of immunological symptoms.
- nurses play an important part as advocates and educators of PID patients.

The IPOPI PID Principles of Care are totally relevant nationally and regionally especially:

- Principle 6: Managing PID Diagnosis and Care

- Principle 2: The importance of registries. The SEAPID registry has 801 patients however, if ESID statistical data was applied of 7:100,000 people with PID, there should be 43,260 PID patients in the SEAPID registry.

**Workshop 1 discussed NMOs key successes and challenges.** These included Mr Ghazali from Malaysia, “Dew” Nushsiri from Thailand, Nurse Pingping Wang from Singapore, Dr Dina Muktiarti from Indonesia, Rubby Chawla from India, Dr Kohsuke Imai from Japan, Dr Huyen Thuc from Vietnam, Fatima Johanna Santos-Ocampo from the Philippines and an online presentation from Taiwan prepared by Dr Wen I Lee. Despite challenges, key successes included the establishment and growth of patient organisations. Patient organisations include paediatric immunologists and nurses who educate the medical profession. Some have translated IPOPI booklets, made their own pamphlets, T-shirts, key chains of the warning signs and have walks where they educate the general public. Japan have now completed 150 SCID transplants, all in a registry. 19-year-old Kureha Takenaka from Japan told her story as a SCID survivor.

Challenges common to all regions included:

- the basic PID training of medical students and further education of healthcare professionals
- increase diagnosis
- increase patient numbers
- establish patient groups
- access to treatment
- lack of choice of product
- lack of adult immunologists
- no transition care
- lack of adult diagnosis and care
- affordable treatment
- no genetic diagnostics
- lack of diagnostic equipment
- no BMT facilities and, in some countries, no BMT either.

**Workshop 2 Principles of Care workshop** Bruce Lim and Christine Jeffery encouraged attendees to discuss the current situation in their country, identifying the National perspectives and regional priorities. The majority of regions identified similar priorities. These were:

- Create statement paper for PID care – free IVIg and access to SCIG as Ig is essential treatment
- PID patients not prioritized as most important for IVIG
- IVIg supply inadequate
- Registries are important but few countries actually have one
- Government should fund PID treatment
- Need for transitional care
- Lack of adult immunologists
- must recruit more patients to patient organizations



- Join with other patient groups to increase awareness of PID
- Attend other congresses to educate about PID.

**Strategic Session:** Action: A call to action letter was written as follows:

SEAPID, IPOPI

Primary Immune Deficiencies - a mostly unrecognised disease.

The South East Asia Primary Immunodeficiencies Network (SEAPID) countries announce a call to the Ministers of Health to ensure that immunoglobulin replacement treatment must be available and funded to all diagnosed Primary Immunodeficiency patients of all ages with immediate effect according to the World Health Organisation (WHO) list of Essential Medicines.

Endorsed by: SINGAPORE, THAILAND, MALAYSIA, INDONESIA, VIETNAM, PHILIPPINES, INDIA, JAPAN, HONG KONG, LAOS, INGRID

**Next Steps:** It is hoped APSID will endorse the letter and each country can use the letter for presentation to government to make immunoglobulin replacement therapy available and preferable free to all diagnosed PID patients.