



**IPOPI**  
**First Singapore PID Patients National Meeting**  
**Held at the 3rd Singapore Paediatric & Prenatal Annual**  
**Congress**  
**Grand Copthorne Waterfront Hotel, Singapore**  
**14.00-18.00hrs**  
**13<sup>th</sup> September 2014**



## Report

### **1. Introduction**

The first IPOPI Singapore PID National Patients meeting was held on Saturday 13<sup>th</sup> September 2014, at the Grand Copthorne Waterfront Hotel. The meeting was organised as an integral session at the 3<sup>rd</sup> Singapore Annual Paediatric and Prenatal annual congress in collaboration with the Singapore Paediatric Society. In the morning, the congress keynote lecturer was Professor Martin Van Hagen (Rotterdam Erasmus University Hospital) who provided an excellent lecture on “Primary Immunodeficiencies: The Past, the Present and the Future”.

The meeting which had been preceded the day before by a visit to the National University Hospital (NUH) where Prof. Van Hagen delivered a most intriguing talk on “Does your brain control your immune system?” to the PhD students.

The IPOPI meeting brought together 70 participants including patients, family members and doctors from Singapore, Thailand, Malaysia and Vietnam.

The meeting was opened by Dr Woei Kang Liew and Mrs Jose Drabwell. Special thanks were given to the Singapore Paediatrics Society, to Professor Lee Bee Wah, and last but not least Dr Woei Kang Liew and Dr Christian Harkensee without whose help the meeting would not have been organised. Professor Van Hagen was thanked for his invaluable input in both the congress scientific programme and the IPOPI meeting.

## 2. Opening Scientific Session

The IPOPI meeting started with a short scientific session and an opening address by Professor Lee Bee Wah, the pioneer of paediatric allergy and immunology in Singapore. In her address, she highlighted the importance of this first ever national patients PID meeting, expressing her hope that a direct outcome from the meeting will be the launch of a patient organisation in the country.



Dr Woei Kang then followed with a presentation reviewing the progress made in his hospital (KKH) with Hematopoietic stem cell transplantation (HSCT) and described eleven cases (nine of whom survived) mostly patients with SCID, CGD and Hyper IgM syndrome. He stressed the importance of detecting PIDs as early as possible and described one of the main challenges to be the need and the time spent in stabilising the patients before such a procedure which often takes several months.

## 3. Patients workshop: Presentations

The opening scientific session was followed by the patients' workshop and formally opened by Dr Christian Harkensee and Mrs Drabwell. Dr Harkensee highlighted the tremendous progress and growth of IPOPI in recent years and the historical day this was for Singapore. Prof Van Hagen kicked off the programme with a presentation on "The immune system and PIDs" designed to provide an overview to the patients and families in attendance. The presentation



described in simple and easily understandable terms the various parts of the immune system and the role of antibodies. Johan Prévot provided an overview of IPOPI's activities and support programmes available to help NMOs with their national campaigns and actions. He stressed the great milestones recently achieved in South East Asia with the launch of new NMOs in Malaysia and Thailand, and more recently Hong Kong. The SEASIDE

(South East Asian Society for Immunodeficiencies Experts) initiative which IPOPI has encouraged was also highlighted as a positive recent development in the region. Dr Christian Harkensee then went on to provide the physician perspective on diagnosing and treating PIDs. Based on international prevalence figures he estimated that there could be as many as 2,500 people affected by a PID in Singapore, and up to 200,000 patients in the Australasian region. He also stressed the role of patient organisations in increasing PID awareness. Mr Daniel Oon then spoke about his family's journey with HSCT and described in a very moving testimony the story of their son, Stephen, who underwent bone marrow transplantation (BMT). He described the family's journey, the isolation of Stephen in the conditioned room, the impact these months of hospitalization had on the whole family and the successful outcomes after difficult times due to the recurring infections,

lack of contact with their son, depression and chemotherapy. He described BMT as a three-phase process: pre-transplantation, transplantation and post-transplantation. Most importantly he highlighted the benefit of the treatment which cured Stephen who now leads a happy and healthy life. Mr Daniel Ng Wai Lit spoke about "coping with chronic illness and loss" from a social worker's perspective and described different aspects from medical, emotional and social perspectives. His talk was followed by a presentation



by Dr Adli Ali (Malaysia) who provided an excellent overview of the journey so far in Malaysia, where MyPOPI (IPOPI's NMO in the country) was recently created. He outlined the amazing achievements of the group in their first months of existence which include awareness raising activities during World PI Week, media campaigns including interviews on the national television channels, roadshows organized by patients and doctors to medical conferences. His presentation was perfect to set the scene for the discussion between participants about the next steps for Singapore.

#### 4. Discussion, Facts and Key Priorities

The presentations were then followed by a discussion when several facts and issues were highlighted:

- There are 5.4 million inhabitants in Singapore
- There are 95 known PID Patients in Singapore
- Prevalence based on international figures is likely to be 2,500 patients
- The most prevalent types of PIDs in Singapore are:
  - Predominantly T-Cell deficiencies (28,30%)
  - Predominantly antibody deficiencies (25,26%)
  - Phagocytic Deficiencies (17,18%)
  - Complement deficiencies (8%)
- 16 BMTs have been performed to date
- Singapore's overall expertise in PIDs is very good
- IVIG is not reimbursed by the national healthcare system.
- Patients usually have to pay for the treatment themselves or through private insurance plans
- One brand of immunoglobulin is available

- ❑ SCIG is not available yet
- ❑ PID patients and doctors would like to see IVIG covered through the national healthcare system to alleviate the financial burden this brings on patients and their families
- ❑ There is no national PID registry yet
- ❑ Transition care: only a few patients have been referred to adult services for IVIG therapy, most are regularly being followed-up by the paediatricians. Like in many other countries in the region, expertise in PID tends to concentrate in paediatrics.
- ❑ The Need for adult PID specialists was highlighted
- ❑ The importance of increasing PID awareness among doctors was highlighted
- ❑ The need for patients support was also identified

## 5. Conclusions

The meeting was an excellent opportunity to meet together with the patients and doctors to discuss the importance of starting a patient organisation in Singapore. The main outcome of the discussion was a unanimous agreement between the patients and the doctors that a national patient organisation should be launched as soon as possible.

The process to apply for IPOPI membership in the near future was reviewed. It was agreed that IPOPI would stay in close contact to guide this process and ensure that a Singaporean NMO is launched in the near future. IPOPI looks forward to further supporting this objective, which will benefit the whole PID community in the country.



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