



IPOPI
First Vietnamese PID Patients-Doctors National Meeting
Held at the Baoson Hotel,
Hanoi, Vietnam
9.00-15.00hrs
3rd December 2015



Report

1. Introduction

The first IPOPI Vietnamese PID Patients-Doctors National Meeting took place at the Baoson Hotel on Thursday 3rd December 2015. The meeting was organised in collaboration with the National Hospital of Paediatrics in Hanoi and the Vietnamese Paediatrics Association. Over 80 participants from various regions in Vietnam including patients, family members, doctors, the Vietnamese Haemophilia Society and guest lecturers from The Netherlands and Thailand were in attendance. The event received significant media attention with television interviews being conducted.

A one-day educational scientific meeting intended for doctors and PhD students at the Hanoi National Hospital of Paediatrics was held on 2nd December 2015 where Prof. Van Hagen, member of IPOPI's Medical Advisory Panel (MAP), delivered the keynote lecture on "Novel insights into primary immunodeficiencies: new genetic defects". Other doctors from Erasmus University Hospital in Rotterdam delivered lectures on primary immunodeficiency (PID) related topics

including “Congenital neutropenia and chronic granulomatous disease” (Dr Virgil Dalm), and “Diagnostics in PID: immunodeficiency vs auto-immunity” (Dr W.A. Dik).

The first IPOPI Vietnamese PID Patients-Doctors National Meeting was opened by Prof Lê Thị Minh Hương (Hanoi National Hospital of Paediatrics), Prof. Nguyen Cong Khanh (Vietnamese Paediatrics Association) and Mrs Jose Drabwell (IPOPI President). Prof Lê Thị Minh Hương extended her special thanks to the attending international experts for sharing their expertise to help diagnose and treat PID patients in Vietnam and specifically Prof Van Hagen for his help in training Vietnamese doctors. She also thanked the numerous doctors, patients and families,



coming from different regions of Vietnam. She stated “Vietnam wants to update its medical knowledge and techniques to treat disorders such as PIDs so that our patients and their families can have better lives”. Mrs Drabwell extended IPOPI’s thanks to Prof Lê Thị Minh Hương and her dedicated team without whose efforts and precious help this meeting would not have been organised so efficiently. She thanked Kedrion for their support

of the meeting. Prof. Nguyen Cong Khanh provided the formal welcome address highlighting the fact that this day was a very important one in Vietnam. This was the first ever National PID meeting and the first national assembly of patients and doctors. He emphasized the importance of collaboration with other doctors, patients, other countries, organisations and industry. He expressed his hope for better lives for children living with a PID and their families, and all PID patients in Vietnam.

2. Scientific session: presentations

The meeting started with a scientific session. **Prof Van Hagen** (IPOPI MAP Member, Netherlands and Thailand) first provided a presentation on “The immune system and PIDs” designed to provide an overview to the patients and families. The presentation described the basic function and various components of the innate immune system and the adaptive immune system, including the role of T-cells, B-cells and cytokines. The function of cytokines, the varying degree of the immune ‘repertoire’ in different people, and interestingly the links between the immune system, hormones and the nervous system were explored. Prof Van Hagen also went over the basic diagnostic tests that can be used to achieve a diagnosis of PIDs as well as of the more complex tests available. He presented several case studies highlighting the many different types of complications including auto-immunity problems and granulomatous that can arise with PIDs and provided an inventory of treatment options available to treat such complications. He also outlined several findings from



IPOPI's survey on "Patient Needs and Outlooks" and reported on the outcome of a SF36 quality of life study performed in Rotterdam.

Dr Narissara Suratannon (Dr "May", Thailand's Chulalongkorn University Hospital) then followed with a most interesting presentation reviewing the progress of the Thai patient organisation (ThaiPOPI) since their creation and the work of SEAPID, the South East Asian Network of Experts on PID launched earlier this year in Bangkok with the support of IPOPI and the Care-for-Rare Foundation. She stressed the importance of developing better knowledge and expertise of PIDs in South East Asia so that patients can live fulfilling lives. She stated "*ThaiPOPI was created at the initiative of IPOPI who you will realize after today will become your very good friends moving forward*". She listed the main objectives of ThaiPOPI: encourage better care and diagnosis, proper treatments for PID, educate doctors and nurses to recognize PIDs and support patients and their families. She went over the various awareness raising activities undertaken by ThaiPOPI (ie ThaiPOPI session during the Thai Immunology and Allergy Society meetings, awareness raising visits in universities across the country) and by SEAPID (ie promotional activities during the International Primary Immunodeficiencies Congress – IPIC2015) and the benefits this has had, with many new cases being referred to the SEA experts: "Doctors are becoming more aware about PIDs and understand we have a structure in place".



Prof Lê Thị Minh Hương then talked about the PID experience in Vietnam. The presentation went over the key challenges facing patients and doctors in Vietnam but also outlined the great progress made in the last five years. Not so long ago in 2008 only 2 confirmed cases of PID were known in Vietnam. In 2011 the Immunology department at Hanoi National Hospital of Paediatrics was



established and increased attention was given to PIDs. In 2014 genetic testing started to be available and the first HSCT treatment was performed successfully in a baby with SCID. By 2015, 73 diagnosed cases are known in Vietnam. She pointed out that based on the Vietnamese population and recent PID prevalence estimates, the number of potential cases is around 75,000 patients. She provided helpful guidance to the families in attendance on additional measures besides IG treatment such as hygiene, prevention measures and balanced nutrition. She outlined the practical difficulties facing patients in Vietnam given many patients live in the provinces and don't have easy access to the treatment and care that is needed. She expressed her wish to establish "VietPOPI" so that Vietnamese patients with PID can have the support they deserve. She also stressed the importance of medical education including PIDs into the

medical curriculum as well as the need to establish PID treatment guidelines specific to the Vietnamese situation. Discussions are being held with the Vietnamese Ministry of Health on this important topic.

3. Patients session: Presentations

The patients' session first featured a presentation by Mr Johan Prévot (IPOPI Executive Director) who 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 through the IPOPI Bob Le Bien Asian development programme with the launch of new NMOs in Malaysia, Thailand, Hong Kong, and more recently Singapore and Indonesia where new patient groups are currently being formed. The creation of SEAPID at the meeting which IPOPI co-organized with the Care-for-Rare Foundation in Bangkok in early 2015 and the South-East-Asian Call for Action was highlighted as a key development for the region. Lastly, he mentioned the upcoming IPOPI Asian regional patients meeting in April 2016 back to back with the APSID congress and organised with the collaboration of SEAPID.



Dr Nguyen Hoang Nam (Vietnamese Haemophilia Society) followed with a presentation outlining the experience of the haemophilia patient organisation in Vietnam. The society was established in 2007 and is led by a Board of Directors made up of 9 doctors and 4 patients. Currently the society has 1000 members and regional branches established in the different regions. The main activities of the group consist of educational programmes, political advocacy and campaigning. Monthly meetings are organised in the regional branches. The Vietnamese society is an NMO of the World Federation of Haemophilia and is also twinned with the Irish Haemophilia Association.



The two presentations were followed by a PID patient panel session in which parents expressed their personal struggles and hopes for the future. Ms Bui Huong Giang first spoke about her own family experience having lost one child to PID but also her hope for the future. "We want to know about the diagnosis of our children. We need to understand what can happen and what we can do to take care of them. We need to have guidelines for the treatment of PIDs in Vietnam so that patients can receive appropriate care". She highlighted the difficulties facing her family and other families living in the provinces so far away from the hospital and the fact that children who are already very vulnerable need to travel more than once a month if problems occur between treatments. She went over the discrimination against her child in school due to the fact other students and professor stigmatize his condition and the need to create better awareness so that children with PID also have a better quality of life. Lastly she indicated how worried she was knowing that once a child reaches 18 years of age the national insurance no longer covers the costs of immunoglobulin replacement therapy. Another mother from the Northern part of Vietnam spoke and endorsed the statements made by Ms Giang as a summary of the issues confronting

most Vietnamese families with a child affected by PID. Another family member expressed the fact the meeting had also brought her reassurance that children with PID in Vietnam can have a good future and a good quality of life. She indicated that knowing about the situation in other countries was very helpful and important to her. Some questions were raised about bone marrow transplantation and gene therapy and Prof Lê Thị Minh Hương provided further information on these topics.

4. Discussion, Facts and Key Priorities

The presentations and panel session were extremely useful in identifying several key facts and issues in Vietnam:

- There are 90 million inhabitants in Vietnam
- Hanoi National Hospital of Paediatrics is the main centre for PID treatment
- In 2008 there were only 2 known PID cases
- In 2015, there are 73 known PID Patients in Vietnam
- Prevalence based on international figures (1:1,200) is likely to be 75,000 patients in Vietnam
- In 2011 the Hanoi National Hospital of Paediatrics established the first Immunology department in the country
- The first HSCT treatment was successfully performed in October 2014 but funded through charitable donations as the national health insurance does not cover it:
 - 2-month old baby with SCID
 - Donor – father
 - HSCT performed at 3months of age
 - Child is now stable and doing well
- IVIG is reimbursed by the national healthcare system as follows:
 - 100% of the cost until 6 years of age
 - 80% of the cost from 6 to 18 years of age
 - Not reimbursed above 18 years of age
 - The cost of an IVIG vial is high 5 million Vietnamese dong and most families cannot afford the monthly 20% copayment which is more than their monthly earnings
- SCIG is not available yet
- BMT treatments are not funded
- Lack of diagnostic facilities and expertise are the key issues
- There is no national PID registry yet
- The Need for adult PID specialists was highlighted
- The importance of increasing PID awareness among doctors was paramount
- The need for patients support was also identified
- Opportunities for collaboration exist:
 - Leading hospitals in Japan, Netherlands, France, Hong Kong, USA already collaborate
 - IPOPI
 - This will help improve diagnosis rates in Vietnam

5. Conclusions

The meeting was the first ever National PID meeting Vietnam bringing together doctors and patients from different regions of the country. It provided a great opportunity to meet together and discuss the importance of starting a patient organisation in Vietnam.

There was a unanimous agreement between the patients and the doctors that a national patient organisation should be launched as soon as possible. Some of the patients in attendance including Mrs Bui Huong Giang indicated their willingness to take part and contribute to the patient organisation. It was agreed that a first step should be to identify patients willing to participate in the future group which will be started with the support of Prof Le Huong and her colleagues. IPOPI warmly thanked all patient and family representatives who travelled from afar to actively take part in the event.

The process to apply for IPOPI membership in the near future was briefly reviewed. It was agreed that IPOPI would stay in close contact to guide this process and ensure that a Vietnamese 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.

The meeting was organised with the invaluable support of:

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And



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