

IPOPI'S 3RD VIETNAMESE NATIONAL PID DOCTORS AND PATIENTS MEETING



23-24 November 2019
Ho Chi Minh City, Vietnam



Meeting report

IPOPI has been continuing its PID awareness raising activities in South East Asia, most recently with the 3rd Vietnamese National PID Doctors and Patients meeting, following the 1st and 2nd meetings in 2015 and 2017. This two-day meeting took place on 23-24 November 2019 at the Hotel Nikko Saigon, Ho Chi Minh (HCMC), and was organised in close collaboration with the HCMC Children's Hospital 1. It was a well-attended and successful meeting, hosting 100 doctors during the Clinical Care Workshop on the first day as well as 50 PID patients and family members from all over Vietnam on the second day. IPOPI was pleased to return to Vietnam for the third time and see the progress made in the country since 2015. We trust to see continued progress for the years to come.

PIDs in Vietnam in a nutshell

Population: 96,5 million

Diagnosed: Close to 400 PID patients

Diagnostics: Blood cell tests and some genetic tests in collaboration with centres in Rotterdam and Hong Kong

National PID network/center: Yes

Specialized care: Adult care and transition care are being put in place in some hospitals

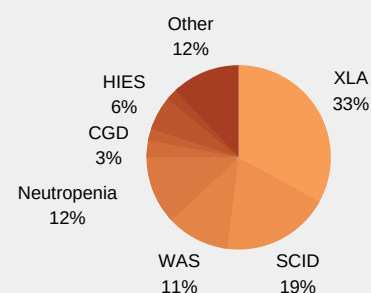
Treatment: IVIG is marketed, SCIG available on a irregular basis

Reimbursement for IG therapies: 100% of cost up to 6 years of age, 80% after 6 years of age

NMO: VietPIPs, established in 2015, 50 members

Main working areas: Public awareness, medical awareness and advocacy

Main concerns in Vietnam is poor access to diagnosis and treatment, reimbursement issues, lack of resources and low medical awareness



PID classifications in Vietnam
Source: National Children's Hospital, Hanoi



Speakers, staff and part of participants, doctors meeting 23 November

23 NOVEMBER 2019

Educational sessions - Doctors day

- Welcoming remarks, **Prof Nguyen Thanh Hung**, Children's Hospital 1, Vietnam
- Welcoming remarks, **Mrs Martine Pergent**, IPOPI President, France
- Keynote presentation: The A to Z of PIDs, **Dr Nizar Mahlaoui**, Chair IPOPI MAP, France
- Diagnosis of PIDs - molecular diagnosis & flow cytometry, **Dr Narissara Suratannon**, Thailand
- The role of IG therapy in treating PIDs, **Prof Martin van Hagen**, Vice Chair IPOPI MAP, The Netherlands
- The role of transplantation in treating PIDs (BMT focus), **Dr Nizar Mahlaoui**, France
- Vaccination and PIDs, **Dr Amir Hamzah Abdul Latiff**, Malaysia
- Severe neutropenia management, **Prof Martin van Hagen**, The Netherlands

The Clinical Care Workshop on day one provided an educational scientific programme about PIDs for Vietnamese healthcare professionals and medical students. The meeting was opened by **Prof Nguyen Thanh Hung**, Director of Children's Hospital 1, and by **Mrs Martine Pergent**, IPOPI President, who both gave welcoming remarks. The first two sessions were devoted to diagnosis and management of PIDs and provided the participants with a good overview of the A to Z of PIDs. This was followed by a session of national updates from **Dr Nguyen Minh Tuan** and **Prof Le Thi Minh Huong** as well as regional updates from the South East Asia Primary Immunodeficiencies Network (SEAPID) by **Dr Narissara Suratannon** and from the Asia Pacific Society for Primary Immunodeficiencies by **Dr Amir Hamzah Abdul Latiff**. This session emphasized the value of cooperation on national, regional and international level to ensure best possible diagnosis and care for PID patients worldwide.



Welcoming remarks by Mrs Martine Pergent

Bridging the national and the international

- CVID intro and case study – **Prof Martin van Hagen & Dr Phan Nguyen Lien Anh**
- SCID intro and case study – **Dr Nizar Mahlaoui & Dr Nguyen Thi Van Anh**
- Hyper IgM syndrome intro and case study – **Dr Narissara Suratannon & Dr Nguyen Thuy Duong**
- Hyper IgE syndrome intro and case study – **Dr Nizar Mahlaoui & Dr Cao Tran Thu Cuc**

The 4th and final session was an interactive session where international experts introduced the audience to CVID, SCID, Hyper IgM and Hyper IgE syndrome, an introduction that was followed by an invitation to local doctors to share patient cases that they have been working on. This was an appreciated section allowing for bridge building between the international and local doctors and providing meeting participants with a very good opportunity to exchange experiences and expertise.

24 NOVEMBER 2019

Educational sessions - Patients day

- Welcoming remarks, **Mrs Martine Pergent**, IPOPI President
- Welcoming remarks, **Prof Nguyen Thanh Hung**, Vietnam
- What are PIDs, **Dr Nizar Mahlaoui**, France
- How do we treat PIDs – comparison of IVIG and SCIG, **Prof Martin van Hagen**, The Netherlands
- Overview of PIDs in Vietnam, **Dr Nguyen Minh Tuan**, Vietnam

The second day was devoted to patient education and welcomed approximately 50 patients and parents from both South and North Vietnam, among them active members from IPOPI's Vietnamese national member organisation VietPIPs. The day kickstarted with educational sessions on PID diagnosis, a comparison of IVIG and SCIG as well as a very popular Question & Answer session with IPOPI MAP Chair **Dr Nizar Mahlaoui** and Vice-Chair **Prof Martin van Hagen**. During this session the patient representatives seized the opportunity to ask the experts various important questions on symptoms and diagnosis as well as on recommended treatment.



Question & Answer session



IPOPI delegation, speakers and patient representatives, PID patients meeting 24 November

Experiences from Asia Pacific

- Experience from VietPIPS, **Mrs Bui Huong Giang**, Vietnam
- Experience from MyPOPI, **Mr Bruce Lim**, Malaysia
- How can we involve more patients in our NMOs, IDFA experience, **Mrs Christine Jeffery**, Australia
- Organising an awareness campaign in Vietnam, **Mr Johan Prevot**, IPOPI Executive Director

This fruitful meeting day also featured national updates from Vietnam, Malaysia and Australia, demonstrating a wide array of both progress and challenges in these three national settings. The presentation by **Mrs Bui Huong Giang**, President of patient organisation VietPIPS, provided a good overview of the positive developments made in the organisation since it was founded in 2015 and announced their work plan for the upcoming year. In 2020 VietPIPS will mainly focus on strengthening their internal communication, proactively join in IPOPI's activities as well as contribute to increasing the awareness of PIDs in Vietnam. To further give them a chance to brain storm on activities for next year the meeting day closed with a workshop on the 10th anniversary of World PI Week, taking place 22-29 April 2020. The patient representatives were divided into two groups with a mix of participants from both north and south Vietnam and together they presented many excellent ideas for upcoming national activities.

Suggestions for World PI Week 2020

Ideas presented by group rapporteurs

Nguyen Tien Dat and Pham Thi Kim Oanh

- Strive to raise public awareness on early diagnosis and advocate for insurance coverage
- Invite patients from the whole country
- Invite rare disease group or PID specialist
- Invite media and tell patient stories
- Sell souvenirs and drawings made by patients
- Organise a picnic and an awareness walk



Reporting results from the workshop

Conclusion

The 3rd Vietnamese National PID Doctors and Patients meeting was a successful event focusing on education and exchange of experiences. It brought together approximately 100 doctors and 50 patients and parents from both north and south Vietnam and invited them to learn about the latest on PID diagnosis and treatment. We would like to acknowledge the excellent cooperation with the physicians from Children's Hospital 1 in HCMC as well as praise the commitment of the regional physicians in raising awareness. IPOPI is grateful to have had the chance to return to Vietnam for the third time and to see the progress that has been made since the first meeting. With close to 400 patients diagnosed, a number that continues to grow, we trust that the devoted doctors, nurses and patients will keep on improving the situation for PID patients in Vietnam and remain determined to continue to support them in this mission.

This meeting was sponsored by

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B I O P H A R M A



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