



IPOPI-AAIAT First Thai PID Patients National Meeting Novotel Ploenchit Hotel Bangkok, Thailand 29 September 2013

Report

I. Introduction

On Sunday 29 September 2013, the First Thai National PID Patients Meeting was co-organised by the International Patient Organisation for Primary Immunodeficiencies (IPOPI) and the Thai Allergy, Asthma and Immunology Association of Thailand (AAIAT) at the Novotel Ploenchit Hotel and as part of the programme of the 15th Congress of the Asia Pacific Association of Paediatric Allergy, Respiriology and Immunology 2013 (APAPARI 2013). IPOPI wishes to express its sincere thanks to AAIAT and the APAPARI Congress organizing committee for their precious assistance with the organisation of the meeting. Special thanks were given to Dr Narissara Suratannon who devoted so much time to ensure the meeting would be successfully prepared.

The meeting brought together around 50 participants including patient representatives, doctors, nurses and other stakeholders from Thailand. The meeting was formally opened by Mrs Jose Drabwell, Chair of the IPOPI Board, Professor Suwat Benjaponpitak, APAPARI Congress President and Professor Ruxrungtham, AAIAT President. Mrs Drabwell highlighted that this was the first meeting organized by IPOPI in South-East Asia. She thanked Mr Bob LeBien, IPOPI's Honorary Life President who generously supported and initiated IPOPI's activities in the region as well as Octapharma for their support to this specific meeting.

The purpose of the meeting was to bring for the first time in Thailand patients, doctors and PID stakeholders to discuss the current PID environment, provide background PID medical information to the patients attending, identify key issues and determine the next steps in order to launch an IPOPI National Member Organisation in Thailand.

The meeting's programme featured several presentations covering the following subjects and was followed by an interactive and productive discussion:

- Educational lecture and overview of Primary Immunodeficiencies
- Overview of IPOPI's available support programmes and tools to strengthen existing and promote new patient organisations in the region
- Physician perspective on the national challenges and opportunities facing the PID community in Thailand

- Patient perspectives on the PID environment in Thailand
- Overview of other patient group experiences in Thailand

II. Presentations

1. The immune system and primary immunodeficiencies – Prof. M. Van Hagen
2. Overview of IPOPI activities and NMO Support Programmes – Johan Prévot
3. The PID environment in Thailand, Physician Perspective – Dr. V. Luangwedchakarn
4. The PID environment in Thailand, Patient Perspective – All patient representatives
5. The Thai Haemophilia Society's Experience – Mr. Ekawat Suwantaroj

1. Presentation of the Immune System and Primary Immunodeficiencies

Professor Martin Van Hagen, Rotterdam Erasmus University Hospital, provided an educational and comprehensive lecture on the components of the immune system and its role. The presentation described in simple and easily understandable terms the various parts of the immune system and the role of antibodies. It also featured a 3D video presentation on the new diagnostic tools used in Erasmus Hospital to advance research on Primary Immunodeficiency Diseases and Autoinflammatory Disease by clearly showing areas of inflammation in a patient.



2. Overview of IPOPI's activities and NMO support programmes

Johan Prévot provided an overview of IPOPI's activities and support programmes available to help NMOs with their national campaigns and actions. The presentation provided a brief historical overview of IPOPI's development, structure and key strategic objectives. Several key IPOPI achievements including awareness and advocacy programmes but also national campaigns were reviewed to provide examples of what empowered patient organisations can achieve. IPOPI's communications tools and various toolkits available to NMOs to increase awareness of primary immunodeficiencies were also explored. The presentation provided a summary of the key outcomes of IPOPI's latest patient survey which looked at Patient Needs and Outlooks. The importance of collaborating with key stakeholders including other patient organisations such as the haemophilia and rare diseases patient groups was also highlighted. Lastly the presentation stressed the need to launch a Thai National Patient Organisation and outline the benefits this would ultimately have for the Thai PID community.

3. The PID Environment in Thailand – Physician Perspective



Dr. Voravic Luangwedchakarn, Bangkok Siriraj Hospital, followed with an excellent overview of the PID environment in Thailand, from the physician's perspective. Dr Voravic first stated that the meeting provided a "significant and historical event for the PID community in Thailand". He then went on to describe the diagnostic evolution in Thailand in the last ten years, providing figures from a 2003 study as well as one from 2009. He explained that in terms of PID types frequency antibody

deficiencies are the most frequent (48,1% of patients), combined immunodeficiencies then follow (26%) and phagocytic deficiencies represent 12.5% of a total of 208 known diagnosed patients in Thailand. He also pointed out that the median duration prior to diagnosis is 2.1 years. He then went over issues pertaining to access to treatment. Treatment for the majority (64,9%) of the 208 patients was covered by the national healthcare system, followed by civil servant insurance (20,2%), private insurance plans (3,8%) and social security. He also noted that 8,2% of the patients did not have any insurance. Importantly it was highlighted that whilst access to IG therapy is covered by the national health system, bone marrow transplantation for severe PIDs is not reimbursed. He stressed the need for early diagnosis and rapid access to appropriate treatment to allow PID patients to study and lead active and productive lives.

4. The PID environment in Thailand – Patients' Perspectives

This session was an opportunity for all participating patients and parents to provide their personal testimonies and experiences. Whilst many important issues were highlighted including again the fact that bone marrow transplantation is not reimbursed by the Thai national health system and the tragic impact this has on patients and their families, inspirational stories were also shared.

One young man was very inspirational telling his story and how he struggled during his childhood fighting recurring illness and as young adult as well, but describing the positive impact of diagnosis and access to IG replacement therapy which has enabled him to work fulltime and open his own business.



5. Running a Patient Group in Thailand



Ekawat Suwantaraj (Thai Hemophilia Society) gave an engaging talk about how the Hemophilia Society established in Thailand and what they do for patients. One of his key messages was the importance of having good data and an accurate picture of the number of PID patients in Thailand. He went over the various educational and advocacy activities of the association and provided useful insights into the procedures need to formally launch a new patient group. He also highlighted the

importance of being member of the international patient organisation such as IPOPI. His advice was to first start the PID group in Bangkok and then spread to other regions.

III. Discussion, Facts and Key Priorities

The presentations were then followed by an interactive discussion during which the following key facts and priorities were identified:

- Number of know patients is 208
- 12 Paediatric Allergy and Immunology Clinics in Thailand
- 2 Adult Allergy and Immunology Clinics in Thailand
- Focus on pediatric PIDs and lack of adult care
- Adult patients are classified as 15+ years old
- Poor awareness of PID among adults' doctors
- 48.6% of identified patients are 5-15 years old
- 1/3 patients have a family history of PID
- 40 infant deaths since 2009
- In 2008, the Thai Government funded immunoglobulin replacement
- Bone Marrow Transplantation cost not covered by the government
- Availability of different immunoglobulin therapies is limited
- Only Basic Research is funded by the government
- The benefits of working with other active patient and advocacy groups
- The need for more patients support
- The need for advocacy campaigns targeting the health authorities for better coverage of PID treatment
- The need for a nationally coordinated patient registry

III. Conclusions

The meeting provided for the first time an opportunity to bring patients, doctors and stakeholders from different regions of the country together to discuss the importance of giving a voice to Thai PID patients.

In view of the issues described above, the patients and immunologists unanimously voted to start a national patient organisation and apply for IPOPI membership in the near future. It was agreed that they will meet again in 3 months' time.

In the meantime and with the help of Dr Suratannon who will liaise with Mr Suwantaraj from the Thai Haemophilia Society, information on the bureaucratic requirements necessary to register the patient organisation will be gathered. Several patients raised their hands to volunteer to actively take part in the new organisation. The Thai AAIAT also committed their support to help with the launch and activities of the new patient organisation. In the words of Professor Suwat Benjaponpitak the meeting marked "a cornerstone in the history of the PID community in Thailand" and served as a platform to launch a new organisation dedicated to improving the quality of lives for PID patients in the country.

The turnout and commitment of both patients and immunologists was most impressive and IPOPI looks forward to further supporting the Thai PID patients community.

*The meeting was organised with the invaluable support of:
Bob LeBien IPOPI Asian Development Programme
Octapharma*





From left to right: Christine Jeffery (IDFA/IPOPI), Johan Prevot (IPOPI), Jose Drabwell (IPOPI), Prof Martin Van Hagen (Erasmus Hospital Rotterdam), Ningh Van Hagen and Dr Narissara Suratannon (Paediatric Immunologist Chulalongkorn Hospital Bangkok).