



IPOPI-MSAI
First National Malaysian PID Patients Workshop
NACLIS6
International Conference on Primary Immunodeficiencies
Intercontinental Hotel, Kuala Lumpur, Malaysia
27 October 2013

Report

1) Introduction

On Sunday 27 October 2013, the First National Malaysian PID Patients Workshop was co-organised by the International Patient Organisation for Primary Immunodeficiencies (IPOPI) and the Malaysian Society of Allergy and Immunology (MSAI) at the Intercontinental Hotel. The workshop was fully integrated in the main scientific programme of the 6th National Clinical Immunology Symposium (NACLIS) International Conference on Primary Immunodeficiencies, which was formerly opened by the Malaysian Minister for Health Datuk Seri Dr. S. Subramaniam.

IPOPI warmly thanks the MSAI and the NACLIS Congress organizing committee for their precious assistance with the organisation of the meeting. Special thanks were given to Professor Lokman Noh, Dr Amir LA Latiff and Dr Adli Ali who devoted so much time to ensure the meeting would be successfully prepared.

The workshop brought together around 20 participants including patient representatives, doctors, and other stakeholders from Malaysia and beyond. The meeting was formally opened by Mr Johan Prevot, IPOPI Executive Director, and Dr Adli Ali, coordinator of the workshop on behalf of MSAI.

Mr Prevot pointed out this was the second meeting organized by IPOPI in South-East Asia.

The purpose of the meeting was to bring for the first time in Malaysia 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 Malaysia.

The meeting's programme featured several presentations covering the following subjects:

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

2) Presentations

1. The immune system and primary immunodeficiencies – Dr. E. De Vries
2. Overview of IPOPI activities and NMO Support Programmes – Mr. Johan Prévot
3. The PID environment in Malaysia, Physician Perspective – Prof. L. Noh
4. Experience from Thalassemia Patient Group, Malaysia – Ms. Zarina Abdul Latiff, MyThal Club
5. The PID environment in Malaysia, Patient Perspective – All patient representatives

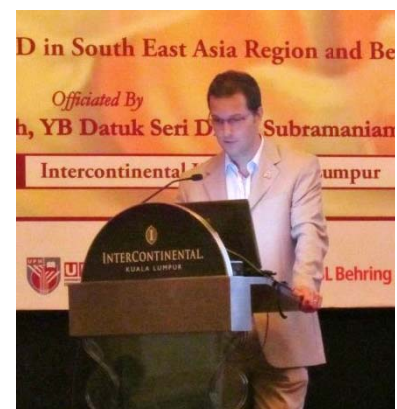
a) Presentation of the Immune System and Primary Immunodeficiencies

Dr Esther De Vries, Den Bosch (Netherlands), 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. Dr De Vries also emphasised the benefits from early diagnosis and the role of all different stakeholders (parents, patients, care providers, physicians, etc).

b) Overview of IPOPI's activities and NMO support programmes

In his presentation, Johan Prévot provided an overview of IPOPI's activities and support programmes available to help NMOs with their various campaigns and actions. A brief historical overview of IPOPI's development, structure and key strategic objectives was also given. 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. In particular, the outcomes of the excellent IPOPI National Workshop held in Bangkok, Thailand, the previous month were also highlighted.

It was pointed out that under the IPOPI Bob Le Bien programme IPOPI was seeking to fasten the launch and implementation of PID national organisations in the Asian region. 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 Malaysian National Patient Organisation and outline the benefits this would ultimately have for the PID community in Malaysia.

c) The PID Environment in Malaysia – Physician Perspective

Prof Lokman Mohd Noh, UKM Medical Centre, Kuala Lumpur, provided an overview of the Malaysian PID environment from the physician's perspective. He indicated that a patient registry was started in the 1970s but was only truly developed as of 2006. During that year the newly created Malaysian Primary Immunodeficiencies Network *MyPIN* referred 250 possible PID cases.

He then went on to describe the main concerns for the PID community in Malaysia such as mis- and underdiagnosis, the absence of coverage for IG replacement therapy in adults, the lack of coverage for advanced diagnostic tests, the need for the introduction of subcutaneous immunoglobulin therapies, for Bone Marrow Transplant facilities and the differences in treatment coverage between University Hospitals and State Hospitals which all impact access to care. He also pointed out that Malaysia is currently lacking laboratory facilities and medical specialists capable of dealing with PIDs.

d) Running a Patient Group in Malaysia

Prof Zarina Abdull Lafiff, UKM Medical Centre, Kuala Lumpur, is head of the Thalassaemia Centre at UKMMC and gave an interesting presentation on how to run a patient group in Malaysia. Thalassaemia is one of the most common inherited diseases in Malaysia affecting 150 to 300 births each year. As such it poses a significant health burden



nationwide. After several concerted efforts from the Ministry of Health, clinicians and from the Federation of Malaysian Thalassaemia Societies (FMTS) a comprehensive prevention and control programme was made available for all patients. MyThal Club one of the members of FMTS was created in 2009 but quickly received acknowledgement from other societies for its medical education meetings, patient support activities, consistently gaining support from pharmaceutical companies and for its good governance methods. It comprises over one hundred members among them patients (both adults and children), doctors and nurses. Their annual meetings elect an adequate number of representatives to take part in the executive council to facilitate decision making. This council meets every 4 months to carefully plan MyThal Club activities.

III. Patients' Perspectives and discussion

The presentations were then followed by an interactive discussion. Prof Noh invited patients in attendance and their families to share their personal experiences and views. Several testimonies were provided during which patients described the steps they and their family had to do through before diagnosis. One family shared their struggle losing their child who had a severe form of PID. . Another mother explained how her son was diagnosed after several life-threatening infections and hospitalisations in a neighbouring country. She emphasised the importance of establishing a patient group in Malaysia as mean to raise awareness of PIDs not only in the general public but also within the medical community therefore stimulating medical education on PIDs.

Prof Noh and Mr Prevot invited participants to meet in person soon after this meeting with additional patient representatives, in order to establish a local PID group. All Workshop participants enthusiastically agreed to launch an NMO to help improve the living conditions of PID patients in Malaysia.



IV. Facts and key Priorities

Prof Noh identified the following facts and key priorities impairing the care for PID patients:

- MyPIN referred 250 possible patients with PID, of which 153 were confirmed with complete diagnosis records between 1986-2012
- In 2006, the most common PID type in Malaysia was predominantly antibody deficiency (40.4%), followed by phagocytic defect (17.3%), combined immunodeficiency (11.5%) and other cellular immunodeficiencies (11.5%)
- Some novel PIDs have now also been diagnosed including DOCK 8 deficiencies, CD19 negative B cell deficiency and IL12 R B1 deficiencies
- The most frequent clinical presentations were recurrent pneumonias, followed by abscesses, gastroenterological problems, sepsis, candidiasis and otitis.
- Late diagnosis and misdiagnosis is a key issue in Malaysia:
 - Average diagnosis delay in Malaysia is 3.87 years based on 52 patients reported by 4 hospitals



- Longest recorded diagnosis delay was 13.67 years (CVID)
- The financial burden of undiagnosed PID cases is another important burden
- Lack of awareness: not only the population in general but also in the medical class.
- Limitation and poor availability of laboratory facilities and the scarcity of PID medical specialists is another important issue to tackle. Prof Noh specified the need to develop human capital, stimulating young doctors to specialize in clinical immunology
- Taken as a whole PIDs are not rare and represent a significant health concern

V. Conclusions

The workshop was an excellent opportunity to bring together for the first time patients, doctors and stakeholders from different regions in Malaysia and discuss the importance of having a strong PID patient organisation in the country. The turnout and commitment of both patients and doctors was most impressive.

The feedback received by the patients, families and doctors in attendance was extremely positive. Several patients raised their hands to volunteer to actively take part in the new organisation. It was agreed that a Malaysian National PID patient organisation should be launched as soon as possible and should apply for IPOPI associate membership in the near future. It was agreed that the patients in attendance will shortly meet again with the doctors, with the help of Dr Adli who will coordinate the process.

The Thalassaemia Society indicated they would be pleased to share information on the bureaucratic requirements necessary to register the patient organisation.

Dr Amir LA Latiff in his final remarks indicated he was extremely pleased and proud that this first patients meeting had taken place and endorsed full-heartedly the decision to launch a national patient group.

IPOPI looks forward to further supporting the Malaysian PID patient community.





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

