



IPOPI THAI PRIMARY IMMUNODEFICIENCY MEETING

22 NOVEMBER 2022 – BANGKOK, THAILAND

an **IPOPI** event

IN COLLABORATION WITH



MEETING **REPORT**



CO-ORGANISERS



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IPOPI'S DOCTORS AND PATIENTS MEETING

IPOPI was delighted to be back in-person in South East Asia to continue its PID awareness and educational activities in the region, this time with an IPOPI National doctors and patients meeting held in Bangkok, Thailand on November, 22-23, 2022. During the first day, IPOPI welcomed 200 participants to a fantastic doctor's meeting dedicated to discussing the latest developments in the primary immunodeficiency field in Thailand. On the second day, IPOPI hosted a patients' meeting with members of the Thai Patient Organisation for Primary Immunodeficiency (ThaiPOPI), its national member organisation, to work on strategies to strengthen and further develop their activities and to discuss specific priorities for the Thai patients.

The meeting was co-organised with The Faculty of Medicine, Chulalongkorn University in Bangkok, the Care-for-Rare Foundation, the Allergy Asthma and Immunology Association of Thailand, the Program Management Unit for Human Resources & Institutional Development, Research and Innovation in Bangkok (PMU-B), and the Thai Patient Organisation for Primary Immunodeficiency.

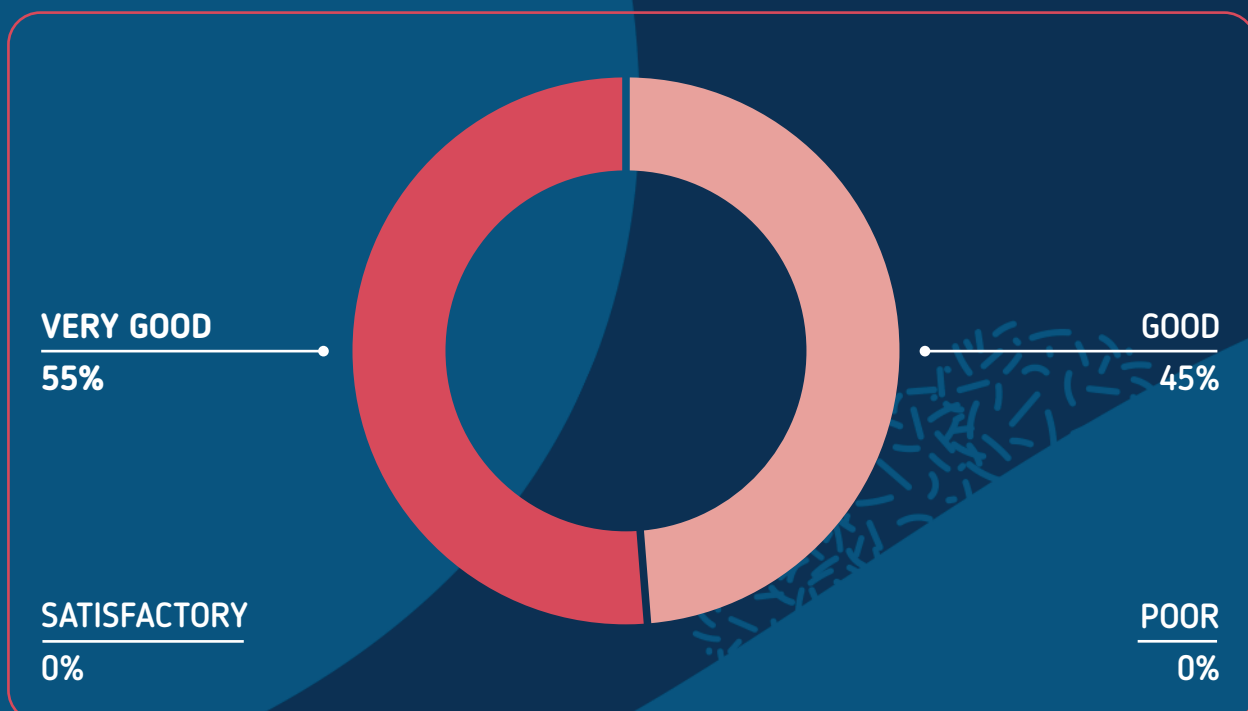


PID DOCTORS' MEETING - NOVEMBER 22

PARTICIPATION OVERVIEW

Total participants (Nov 22): 194 (onsite 76, online 118)

PROGRAMME IN GENERAL





BANGKOK





The meeting consisted of a symposium and two educational sessions targeting physicians, co-organised with The Faculty of Medicine, Chulalongkorn University in Bangkok, Thailand. The **exciting programme** featured various key national and international speakers who presented important subjects such as an introduction to the **JAK-STAT pathway**, **JAK inhibitors in PIDs and autoinflammatory diseases**, **gene sequencing in PIDs**, among others. Furthermore, the effects of **COVID-19** and vaccination against SARS-CoV-2 in PID patients were discussed and the recently characterised disease “**anti-IFN γ autoantibodies associated immunodeficiency syndrome**” was introduced. In addition to this, the meeting hosted one interactive expert panel discussion, focusing on three cases of complex diagnosis and management to encourage participants to think more broadly when diagnosing and treating patients.



MEETING OBJECTIVES

- Increase awareness of PIDs amongst physicians in Thailand
- Discuss the national PID environment
- Improve knowledge of diagnostic methods
- Present key approaches for successful PID management
- Identify diagnosis and treatment options for complex cases

MC: Pannipa Kittipongpattana, M.D. Faculty of Medicine, Chulalongkorn University, Bangkok

INTRODUCTION

- Introduction and welcome – **Prof. Vorasuk Shotelersuk**, Associate Dean of Research Affairs, Chulalongkorn University
- Welcome remarks - **Ms. Martine Pergent**, IPOPI President, **Prof. Christoph Klein**, Care-for-Rare, **Prof. Martin Van Hagen**, Erasmus University Medical Center

The meeting was opened by **Prof. Vorasuk Shotelersuk**, who welcomed the participants to the meeting and gave a few words highlighting the importance of this meeting. Prof. Shotelersuk stressed how PIDs are a big portion of the Rare Diseases group, with 5 million people living with PIDs, emphasising that with appropriate access these are treatable conditions. Following this, the Chulalongkorn University in Bangkok honoured **IPOPI** (in the person of **Ms. Martine Pergent** and **Mr. Johan Prevot**), the **Erasmus Medical Center**, in the Netherlands (in the person of **Prof. Martin van Hagen**) and **Care-for-Rare** (in the person of **Prof. Christoph Klein**) with tokens of appreciation to celebrate the strong collaboration among these organisations.

Prof. Christoph Klein was first introduced to give welcoming words on behalf of Care-for-Rare. Following this, the audience heard from **Ms. Martine Pergent** who warmly welcomed all participants both in person and online to the meeting and provided a short introduction to IPOPI. She also thanked all co-organisers, highlighting the key support of Prof. Narissara Suratannon to IPOPI and the work of Mr. Ronnapree Nushiri, president of the Thai Patient Organisation in Thailand. Lastly, **Prof. Martin van Hagen** provided some welcoming words on behalf of the Erasmus Medical Center, in the Netherlands.



CARE FOR RARE GLOBAL ALLIANCE SYMPOSIUM

Moderated by Prof. Kanya Suphapeetiporn, M.D., Ph.D.

- Precision diagnostics in rare immune-mediated diseases, **Prof. Christoph Klein**, Care-for-Rare Foundation, Munich, Germany
- From genetic testing to patient care in primary immunodeficiencies and very early onset inflammatory bowel disease, Assoc. **Prof. Voranush Chongsrisawat**, M.D., **Prof. Kanya Suphapeetiporn**, M.D., Ph.D. Assist. **Prof. Narissara Suratannon**, M.D. Faculty of Medicine, Chulalongkorn University, Bangkok, Thailand
- Q&A

This symposium was devoted to global cooperation. **Prof. Christoph Klein** opened the symposium with a presentation that emphasised the importance of precision diagnostics, with human organoids derived from bone marrow being introduced as a cutting-edge tool. Prof. Klein also highlighted the need for a doctor-patient collaboration, assuring the patient's right to have a voice in the decision-making of their treatment. **Prof. Voranush Chongsrisawat**, **Prof. Kanya Suphapeetiporn** and **Prof. Narissara Suratannon** provided three comprehensive presentations on the usefulness of gene sequencing, that exemplified through several case reports in which identification of the gene variant resulted in targeted therapy and improved patient outcome.



SESSION 1 – HOT TOPICS IN PIDS

Moderated by Prof. Nattiya Hirankarn, M.D., Ph.D. and Prof. PM van Hagen, M.D., Ph.D., Erasmus, the Netherlands

- The current landscape for primary immunodeficiencies in Thailand **Dr. Wasu Kamchaisatian**, M.D., Secretary of AAIAT, Samitivej Children's Hospital, Bangkok
- Cytokine-specific autoantibodies: phenocopies of PIDs? **Dr. Wim Dik**, Ph.D., Erasmus, the Netherlands
- The STATs, an introduction, **Prof. PM van Hagen**, M.D., Ph.D., Erasmus University Medical Center, the Netherlands
- STAT3 GOF mutation, **Dr. Kornvalee Meesilpavikkai**, Faculty of Medicine, Chulalongkorn University, Bangkok, Thailand
- STAT6 GOF mutation, Assist. **Prof. Narissara Suratannon**, M.D. Faculty of Medicine, Chulalongkorn University, Bangkok, Thailand
- Q&A

The following session of the day started with **Dr. Wasu Kamchaisatian** providing a comprehensive overview of the development of primary immunodeficiencies in Thailand, highlighting the main current challenges. **Dr. Wim Dik** followed, giving a presentation on a newly discovered disease (anti-IFN γ autoantibodies associated immunodeficiency syndrome) which is predominantly seen in the Asian population.



Next, the participants had the opportunity to hear about the exciting developments of the JAK-STAT pathway by **Prof. Martin van Hagen**, **Dr. Kornvatee Meesilpavikkai**, and **Prof. Narissara Suratannon**. **Prof. van Hagen** introduced the topic, presenting the results of the latest investigation on two homozygous variants that are currently being studied in functional assays but are hypothesized to have contributed to the extinction of the Neanderthal population due to their strong detrimental immunomodulatory effects. **Dr. Meesilpavikkai** gave a presentation on the recent findings identifying novel gain of function (GOF) variants in STAT3. The session was concluded with an exciting presentation by **Prof. Suratannon** of the first gain-of-function STAT6 variant causing a severe early-onset allergic phenotype to be reported.

MC: Preyanit Takkinsatian, M.D. Faculty of Medicine, Vajira Hospital, Navamindradhiraj University, Bangkok

SESSION 2

Moderated by Assoc. Prof. Punchama Pajarn and Dr. Virgil Dalm, Erasmus

- Infections and non-infectious manifestations in primary immunodeficiencies: What we learn from the European Society for Immunodeficiencies Registry **Dr. Nizar Mahlaoui**, Necker-Enfants Malades University Hospital, Paris, France
- Patients with primary immunodeficiencies and SARS CoV 2: Clinical spectrum and immune responses to vaccination **Dr. Virgil Dalm**, M.D., Ph.D., Erasmus University Medical Center, Rotterdam, the Netherlands
- Gene editing in primary immunodeficiencies, where are we now? Assoc. **Prof. Nipan Israsena**, M.D., Ph.D., Faculty of Medicine, Chulalongkorn University, Bangkok, Thailand
- JAK inhibitors used in PIDs and autoinflammatory diseases, Assist. **Prof. Sira Nanthapisal**, M.D., Thammasat University, Bangkok, Thailand
- Q&A

The following session started with **Dr. Nizar Mahlaoui** who joined the meeting virtually and offered the audience the ESID Registry perspective concerning the infections and non-infections manifestations in PIDs. His presentation was followed by **Dr. Virgil Dalm** who introduced the effects of COVID-19 and vaccination against SARS-CoV-2 in PID patients were discussed and the recently characterized disease “anti-IFN γ autoantibodies associated immunodeficiency syndrome”. **Prof. Nipan Israsena** gave a presentation on the development of gene therapy as a promising alternative to HSCT for patients with Wiskott-Aldrich syndrome (WAS). She presented recent results from an investigation on the impact of the current methods on the platelet number and function in these patients. Finally, **Prof. Sira Nanthapisal** provided a useful overview of the various indications in which JAK inhibitors have been applied as treatment was provided. These presentations were followed by an interactive question-and-answer-session where speakers had the opportunity to address questions from the audience.



SESSION 3 – CASE STUDIES

Moderated by Dr. Watcharoot Kanchongkittiphon, Dr. Nizar Mahlaoui, M.D., Ph.D

- Case study presentation, Fellow/ **Dr. Gun Pongsamart**, M.D., Queen Sirikit National Institute of Child Health, Bangkok, Thailand
- Discussion with a panel of experts
- Case study presentation, Fellow/ Assoc. **Prof. Punchama Pajarn**, MD, PhD, Siriraj Hospital, Bangkok, Thailand
- Discussion with a panel of experts
- Case study presentation, Fellow/ **Dr. Watcharoot Kanchongkittiphon**, M.D., Mahidol University, Bangkok, Thailand
- Discussion with a panel of experts
- Closing remarks, **Ms. Martine Pergent**, IPOPI

The final session of the day offered the audience a unique opportunity to learn from complex case presentations on PIDs, presented by **Dr. Gun Pongsamart** and his team, **Prof. Punchama Pajarn**, and **Dr. Watcharoot Kanchongkittiphon**. This was followed by a final expert panel discussion featuring **Dr. Watcharoot Kanchongkittiphon** and **Dr. Nizar Mahlaoui** who provided their expert positions on the best management of these patients.



PID PATIENTS' MEETING – NOVEMBER 23

The following day, patient representatives, patients and their relatives were welcomed to a programme tailored to Thai-POPI's key current priorities and concerns. The participants were introduced to IPOPI and ThaiPOPI, and provided a great opportunity to work closely on the development of ThaiPOPI and discuss how to tackle some key issues facing PID patients in the country. This included a discussion on proposed steps for improving the infusion service for IVIG and access to vaccination for PID patients in Thailand. This meeting was co-organised with ThaiPOPI and offered simultaneous interpretation from English to Thai for all participants to ensure an optimal meeting experience.

MEETING OBJECTIVES

- Increase knowledge of primary immunodeficiencies
- Discuss the improvement of the infusion service for IVIG
- Discuss the access to vaccination
- Strengthen ThaiPOPI
- Lower the threshold for doctor-patient interaction
- Identify key action points to tackle the key concerns

SESSION 1 – INTRODUCTION

Moderated by Ms. Martine Pergent and Mr. Bruce Lim

- Welcoming remarks and introduction to IPOPI, **Ms. Martine Pergent**, IPOPI President
- Welcoming remarks and status update from ThaiPOPI, **Mr. Ronnapee Nushiri**, ThaiPOPI President
- Patient Registration and membership, **Mr. Ronnapee Nushiri**, ThaiPOPI President

MC: Narumon Jitchanwichai and Dr. Rapisa Nantanee

The patients' meeting was opened by **Ms. Martine Pergent**, who welcomed participants to a meeting day devoted to patient representatives, patients, and families in Thailand. She started by introducing IPOPI and focused on the work of an active patient organisation, highlighting its importance for the improvement of PID patient care in Thailand, and worldwide. The floor was then given to **Mr. Ronnapee Nushiri** from ThaiPOPI, who provided an update on the organisation and its activities in the past years and the development plan for its membership. This presentation was then followed by a roundtable discussion with IPOPI representatives and **Dr. Narissara Suratannon** experienced advice on how to improve the registration and membership process.



SESSION 2 – IMPROVEMENT OF PID CARE IN THAILAND

Moderated by Mr. Bruce Lim

- Improvement of Infusion Service for IVIG: Current practice of IVIG treatment – **Dr. Gun Pongsamart**; and proposed solution by ThaiPOPI – **Ms. Narumon Jitchanwichai**
- Vaccination for PID during Covid 19: Current guideline for LAAB (Long Acting Antibody) in Thailand – **Dr. Gun Pongsamart** ; and proposed solution by ThaiPOPI – **Ms. Narumon Jitchanwichai**
- Closing words and next steps – **Ms. Martine Pergent**, IPOPI President

MC: Narumon Jitchanwichai and Dr. Rapisa Nantanee

The second half of the meeting was devoted to the discussion of solutions for the country for improving the infusion service for IVIG and access to vaccination for PID patients. The session started with **Ms. Narumon Jitchanwichai** comprehensive presentation of the IVIG infusion service package available in Thailand, focusing on important points such as access to hospitals, time and flexibility of treatment, and reimbursement. **Dr. Gun Pongsamart** followed with a presentation on vaccination conditions for patients with PIDs, highlighting a targeted guideline for LAAB in Thailand. The second part of the session focused on a roundtable discussion on the development of action plans targeting ThaiPOPI's main concerns. **Mr. Bruce Lim** provided a very interesting and motivational presentation, providing tools to target both the membership development and advocacy campaigns to improve the PID patients care in Thailand. The closing words were given by **Ms. Martine Pergent**, who once more highlighted the power of patients' and parents' voices united to ensure a better situation in Thailand for patients with primary immunodeficiencies.



CONCLUSION

It was a pleasure to be back in person in Thailand for IPOPI's Doctors and Patients Meeting to discuss the current landscape of PIDs, the latest developments, and the impending challenges to overcome in the years to come. The two meetings were very well received by the participants and their main objectives were met.

IPOPI is deeply grateful for all the support toward this meeting provided by the Care-for-Rare Foundation, Faculty of Medicine Chulalongkorn University; Allergy, Asthma and Immunology Association of Thailand (AAIAT); Erasmus University Medical Center; Program Management Unit for Human Resources & Institutional Development, Research and Innovation (PMU-B) and Thai Patient Organisation for Primary Immunodeficiencies (ThaiPOPI).



IPOPI would like to thank Grifols for their generous support towards this meeting.

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