

ONLINE

REPORT

IPOPI
DOCTORS & PID
PATIENTS MEETING
THAILAND

27-28 NOVEMBER 2021



an IPOPI event

INTRODUCTION

In November it was time for IPOPI to return to Thailand to host a doctor and patient meeting for participants interested in learning more about primary immunodeficiencies. This virtual meeting was held on November 27-28 2021, and was split in two parts with the first day focusing on medical education for physicians, and the second day offering sessions for patient representatives, patients and their relatives. Since the first IPOPI National PID meeting organised in Bangkok in 2013, IPOPI has channelled efforts into strengthening the PID community in Thailand on various occasions, and it was a pleasure having the opportunity to re-connect with the patients and doctors in this country once again.

The meeting was co-organised with The Faculty of Medicine at Chulalongkorn University in Bangkok and the Thai Patient Organisation for Primary Immunodeficiency.



BANGKOK

PARTICIPATION OVERVIEW

TOTAL REGISTRATIONS (NOV 27-28): 157

OVERALL EXPERIENCE RATING (N=13)



DOCTORS MEETING – NOV 27

The meeting began with four sessions of medical education targeting physicians, co-organised with The Faculty of Medicine at Chulalongkorn University in Bangkok, Thailand. Both national and international speakers had been invited to this meeting to present on topics such as exome sequencing in genetic diagnosis, diagnosing adult patients, immunodeficiencies and autoimmune disease, among many other topics. In addition to this, the meeting hosted two interactive expert panel discussions, focusing on two 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 ON DIAGNOSTIC METHODS
- PRESENT KEY APPROACHES FOR SUCCESSFUL PID MANAGEMENT
- IDENTIFY DIAGNOSIS AND TREATMENT OPTIONS FOR COMPLEX CASES

SESSION 1: INTRODUCTION

MODERATED BY MS MARTINE PERGENT

- Introduction and welcome – Ms Martine Pergent, IPOPI President
- Welcoming remarks – Prof Nattiya Hirankarn, Head Department of Microbiology and Immunology, Faculty of Medicine, Chulalongkorn University, Thailand
- Sponsor's welcome - Mr Noppadol Taweetungworapan, General Manager Thailand, Grifols
- Keynote presentation: Is allergy a state of immunodeficiency? - Dr Narissara Suratannon, Pediatric Allergy & Clinical Immunology Research Unit, Chulalongkorn University, Bangkok, Thailand

The first meeting day was opened by Ms Martine Pergent, IPOPI President, who warmly welcomed participants to the meeting and gave them a flavour of IPOPI. She also introduced Prof Nattiya Hirankarn from the Faculty of Medicine, Chulalongkorn University, to give welcoming words on behalf of the Department of Microbiology and Immunology. In her speech, Prof Hirankarn thanked researchers and practitioners in the field for the important work they do, as well as shared the good news that the department will continue their strong cooperation with Erasmus Medical Center in the Netherlands in the future. Following this, the audience heard welcoming words from Mr Noppadol Taweetungworapan from Grifols, the meeting sponsor. The remaining part of this session was devoted to immunodeficiencies and allergies, an interesting keynote presentation given by Dr Narissara Suratannon from Chulalongkorn University. Dr Suratannon discussed atopic dermatitis and how some patients with PID initially may present with isolated atopic disease and later develop other features of immune dysregulation and/or infection, which should be in the back of the mind of physicians working with these patients. This presentation was well appreciated and very relevant for physicians diagnosing immunodeficient patients.



Is “Allergy” a state of Immunodeficiency ?

Narissara Suratannon, MD.

Pediatric Allergy & Clinical Immunology Research Unit, Allergy and Immunology division,
Department of Pediatrics, Chulalongkorn University, Bangkok, Thailand

27 November 2021



SESSION 2: THE PID ENVIRONMENT IN THAILAND

MODERATED BY MS MARTINE PERGENT

- The current state of PID in Thailand - Dr Wasu Kamchaisatian, Secretary of AAIAT, Samitivej Children’s Hospital, Bangkok, Thailand
- COVID-19 and patients with immunodeficiency in Thailand - Prof Punchama Pacharn, Division of Allergy and Immunology, Department of Pediatrics Faculty of Medicine, Siriraj Hospital, Bangkok, Thailand

The second session of the day zoomed in on the PID environment in Thailand, with Dr Wasu Kamchaisatian from Samitivej Children’s Hospital starting by presenting its current state. He provided a comprehensive overview of the journey of primary immunodeficiencies in Thailand, starting in the 1960’s until today, travelling through the different phases with increasing manpower over the years. Amongst the challenges that remain he highlighted poor public awareness of PIDs, limited genetic testing for PIDs and specific treatments not being covered by the national health care system. In the second and final presentation of this session Prof Punchama Pacharn from Siriraj Hospital focused on patients with PID in the context of COVID-19 in Thailand. Prof Pacharn explained that

the data is limited because of the limited testing, but that they have 94 patients in their records to this date, with approximately 37% of these being asymptomatic or suffering a mild course of the disease. She also discussed the reaction to the vaccines by PID patients and mentioned that PIDs are not on the priority list for vaccinations. These two presentations were followed by an interactive question-and-answer-session where speakers from the two first sessions had the opportunity to address questions from the audience.

**Current Stage of PIDs in Thailand;
The Progressing Steps**

Wasu Kamchaisatian, M.D.
Pediatric Allergist/Immunologist
Samitivej Children's Hospital
On behalf of Thai PID Network,
The Allergy, Asthma & Immunology Association of Thailand

Samitivej Children's Hospital logo and IPOPI logo are visible at the bottom.

**COVID-19 and patients with
immunodeficiency in Thailand**

Assoc. Prof. Punchama Pacharn
Allergy & Immunology division, Department of Pediatrics,
Siriraj Hospital. Thailand

Video feed of Assoc Prof Punchama Pacharn is shown on the right.

**Challenge in PID diagnosis:
Single gene defect or else?**

Gun Phongsamart, MD
Queen Sirikit National Institute of Child Health

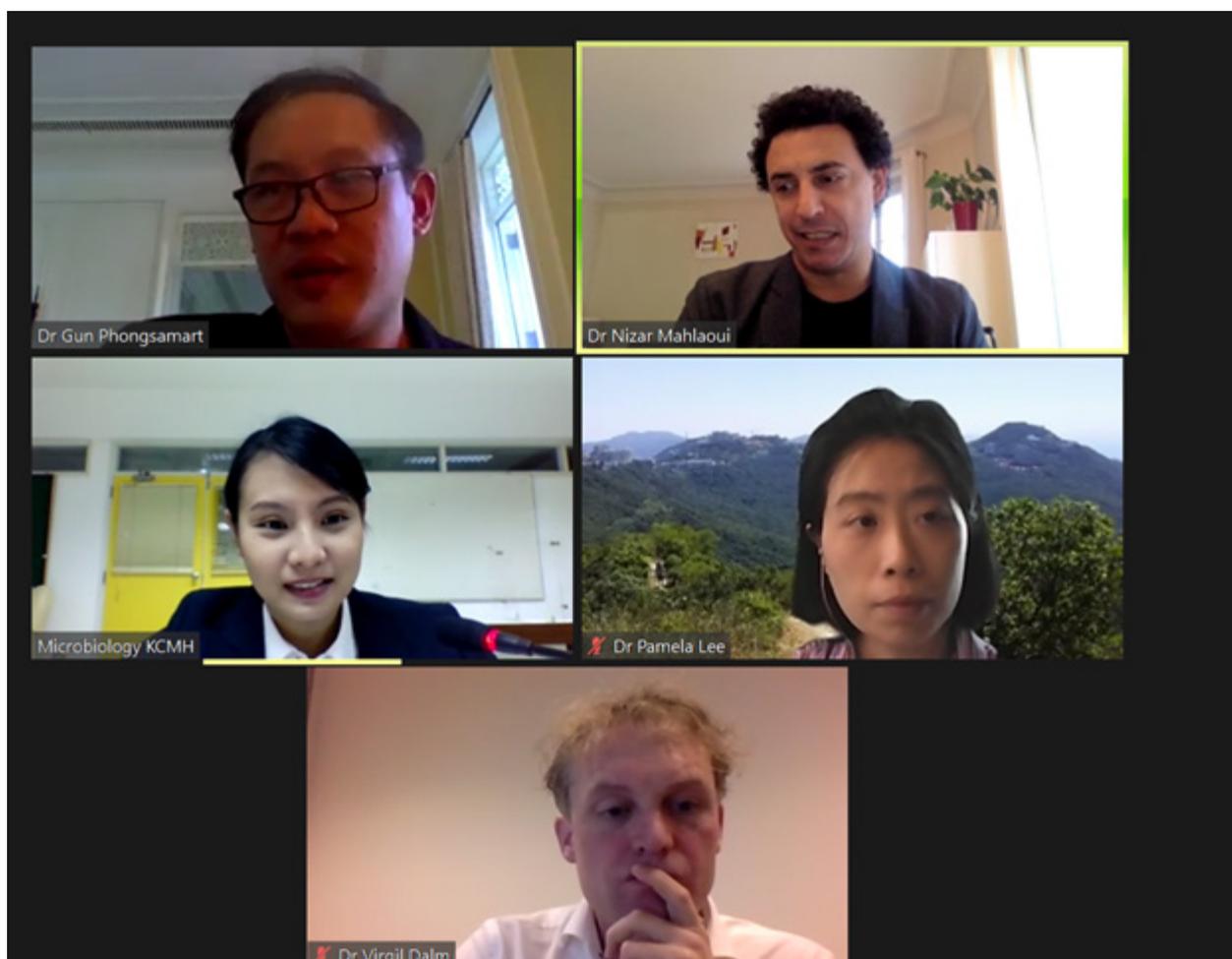
Video feed of Dr Gun Phongsamart is shown on the right.

SESSION 3: DIAGNOSIS

MODERATED BY DR KORNVALEE MEESILPAVIKAI AND DR NIZAR MAHLAOU

- The place of exome sequencing in genetic diagnosis - Dr Pamela Lee, The University of Hong Kong
- Diagnosing adult patients - Dr Virgil Dalm, Internist-Clinical Immunologist, Departments of Internal Medicine and Immunology, Erasmus University Hospital, Rotterdam, The Netherlands
- Complex case presentation on diagnosis and panel discussion - Dr Gun Phongsamart, Queen Sirikit National Institute of Child Health, Bangkok, Thailand

The third session was devoted to covering different aspects of PID diagnosis, a theme moderated by Dr Kornvalee Meesilpavikkai from Chulalongkorn University and Dr Nizar Mahlaoui from Necker Enfants-Malades Hospital in France. It started with an interesting presentation on exome sequencing in genetic diagnosis by Dr Pamela Lee from the University of Hong Kong, who presented the diagnostic approach to PIDs and discussed what is the next generation sequencing, including which gene sequencing method to use. Her presentation was followed by Dr Virgil Dalm from Erasmus University Hospital in the Netherlands, who offered the audience the adult physician perspective concerning diagnosis, including how to recognise the combination of clinical features, and not only focus on infections. The last part featured a complex case presentation on diagnosis by Dr Gun Phongsamart from the Queen Sirikit National Institute of Child Health in Thailand, which was followed by a panel discussion with experts Dr Kornvalee Meesilpavikkai, Dr Nizar Mahlaoui, Dr Virgil Dalm and Dr Pamela Lee. In his presentation, Dr Phongsamart presented a complex case with a young boy with recurrent pneumonia, among other symptoms, since age two months. Dr Phongsamart was asked about the patient's whole exome sequencing and was advised to revisit it to potentially diagnose the boy and provide him with a targeted and more exact treatment.

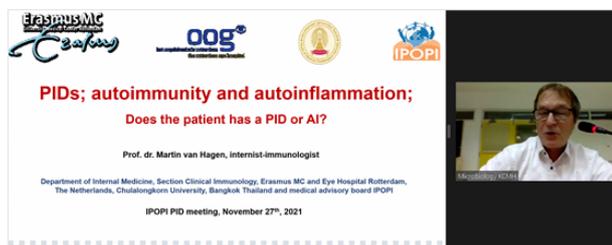


SESSION 4: PID MANAGEMENT

MODERATED BY MR JOHAN PREVOT AND DR NARISSARA SURATANNON

- Does your patient have an autoimmune disease or immunodeficiency? - Prof Martin van Hagen, Vice-Chairman IPOPI MAP, Rotterdam Erasmus University Hospital, Netherlands
- A multidisciplinary approach – the key to success for PID management – Dr Nizar Mahlaoui, Chairman IPOPI MAP, Necker Enfants-Malades Hospital, France
- Case presentation on complex management and panel discussion, Dr Parichat Khaosut, Rheumatologist, Department of Rheumatology, Chulalongkorn Hospital, Bangkok, Thailand & Dr Onnicha Chaisetsumpan, Department of Pediatrics, Faculty of Medicine Chulalongkorn University, Bangkok, Thailand

After giving the audience the opportunity to get up to speed on PID diagnosis, the final session of the day offered the same chance for PID management. Moderators Mr Johan Prevot from IPOPI and Dr Narissara Suratannon from Chulalongkorn University opened the session and introduced the first topic; a comparison between autoimmune disease and immunodeficiency presented by Prof Martin van Hagen from Erasmus University Hospital. In his talk, Prof van Hagen covered immune dysregulation as well as immunological PID comorbidities and non-immunological comorbidities and stressed that the field of PIDs and immune dysregulation needs more exploration to ensure appropriate management for these patients. Next in line was Dr Nizar Mahlaoui, who discussed how to successfully manage PIDs, through a multidisciplinary approach. This was also highlighted in Prof van Hagen's presentation, and the two thus complemented each other. The last element of the day was a case presentation on complex management by Dr Parichat Khaosut and Dr Onnicha Chaisetsumpan from Chulalongkorn University, followed by a final expert panel discussion featuring Dr Narissara Suratannon, Dr Nizar Mahlaoui, Prof Martin van Hagen and Dr Pamela Lee, who all provided their expert opinions about the best management for this patient.



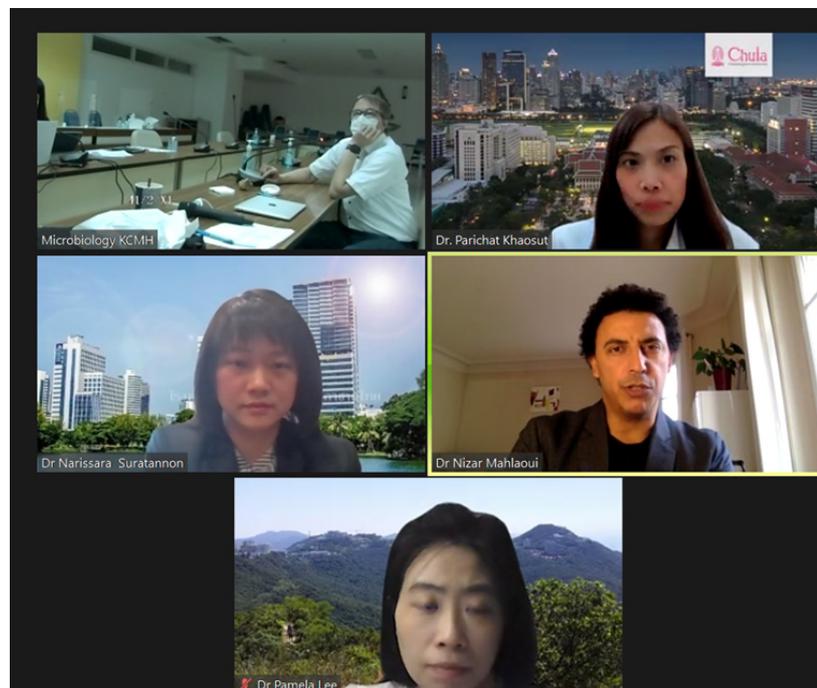
ERASMUS MC
OQS
IPOPI

PIDs; autoimmunity and autoinflammation;
Does the patient have a PID or AI?

Prof. dr. Martin van Hagen, internist-immunologist

Department of Internal Medicine, Section Clinical Immunology, Erasmus MC and Eye Hospital Rotterdam, The Netherlands, Chulalongkorn University, Bangkok Thailand and medical advisory board IPOPI

IPOPI PID meeting, November 27th, 2021



Microbiology KCMH

Dr. Parichat Khaosut

Dr Narissara Suratannon

Dr Nizar Mahlaoui

Dr Pamela Lee



IPOPI

Case presentation on complex management: Autoimmune vs PID

Dr. Onnicha Chaisetsumpan
Dr. Parichat Khaosut

Division of Allergy, Immunology and Rheumatology,
Department of Pediatrics, Faculty of Medicine, Chulalongkorn University,
King Chulalongkorn Memorial Hospital, Bangkok, Thailand

IPOPI Thai Doctors & PID Patients Meeting 27-28 November 2021



PID PATIENTS MEETING – NOV 28

The following day patient representatives, patients and their relatives were welcomed to a full programme tailored to this audience. The participants were introduced to primary immunodeficiencies and treatment options by both national and international speakers, and the programme also offered participants the opportunity to ask questions to the doctors in a dedicated session. This meeting was co-organised with the Thai Patient Organisation for Primary Immunodeficiency and offered simultaneous interpretation from English to Thai for all participants to ensure an optimal meeting experience.

MEETING OBJECTIVES

- INCREASE KNOWLEDGE ON PRIMARY IMMUNODEFICIENCIES
- DISCUSS AVAILABLE TREATMENT OPTIONS
- IMPROVE AWARENESS OF THAIPOPI AND ITS ACTIVITIES
- LOWER THE THRESHOLD FOR DOCTOR-PATIENT INTERACTION
- IDENTIFY ACTIVITIES TO TACKLE POTENTIAL LACK OF AWARENESS

SESSION 1: INTRODUCTION

MODERATED BY MS MARTINE PERGENT

- Welcoming remarks and introduction to IPOPI, Ms Martine Pergent, IPOPI President
- Welcoming remarks and status update from ThaiPOPI, Mr Ronnapee Nushiri, ThaiPOPI
- Keynote: What are PIDS? Dr Intan Juliana Abd Hamid, Primary Immunodeficiency Diseases Group, Regenerative Medicine Cluster, Institut Perubatan & Pergigian Termaju, Universiti Sains Malaysia, Pulau Pinang, Malaysia
- How do we treat PIDs – comparison of IVIG and SCIG - Prof Martin van Hagen, Vice-Chairman IPOPI MAP, Rotterdam Erasmus University Hospital, Netherlands
- Intravenous Immunoglobulin: Production and Quality Controls - Ms Pattana Mangjak, Plant Manager, The Thai Red Cross Plasma Fractionation Centre, National Blood Centre, The Thai Redcross Society, Bangkok, Thailand
- Q&A on diagnosis and treatment: ask the expert - Dr Gun Phongsamart, Queen Sirikit National Institute of Child Health, Bangkok, Thailand

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. The floor was given to Mr Ronnapee Nushiri from ThaiPOPI, who gave a status update on the organisation and its activities in the past years, including participating in medical meetings and engaging in blood donation day. This was followed by a comprehensive overview of PIDs, presented by Dr Intan Juliana Abd Hamid from the Universiti Sains Malaysia. In her presentation Dr Hamid touched upon various aspects of PIDs, including their classification, clinical manifestations, and clues to diagnose PIDs. This was a very informative presentation that allowed the participants to better understand what warning signs to look out for, and what to do when potentially identifying them.

The third speaker was Prof Martin van Hagen, who returned on the second day to look closer at intravenous and subcutaneous immunoglobulin treatments for PID patients. Prof van Hagen discussed both advantages and disadvantages associated with these treatments, both from a patient's and a doctor's perspective, stressing that it is vital to personalise care to ensure that each patient can enjoy good quality of life. His presentation was followed by an interesting overview of intravenous immunoglobulin production, presented by Ms Pattana Mangjak from the Thai Red Cross Plasma Fractionation Centre. This first session ended with a Question-and-Answer-session with Dr Gun Phongsamart, addressing questions on PID registries, medical awareness, availability on bone marrow transplants and much more.



SESSION 2: WORKSHOP: TEACH SOMEONE ABOUT PIDs

MODERATED BY MR BRUCE LIM

- Introduction to awareness workshop and examples from MyPOPI — Bruce Lim IPOPI Board Member, President Malaysia Patient Organisation of Primary Immunodeficiencies
- Practical exercise: small efforts go a long way to spread awareness — Mr Ronnapee Nushiri, ThaiPOPI
- Closing words and next steps – Ms Martine Pergent, IPOPI President of Child Health, Bangkok, Thailand

The second half of the meeting was devoted to an interactive workshop focusing on spreading awareness on PIDs in Thailand, moderated by Mr Bruce Lim from IPOPI. The session started with Bruce discussing how to approach awareness raising activities and introducing the audience to inspiring examples from MyPOPI on this theme. In his presentation Bruce presented tools to target both the general public and health care professionals, as well as discussed activities targeting their own membership, all in all a very informative and interesting presentation. This was followed by an interactive workshop led by Mr Ronnapee Nushiri from ThaiPOPI, where participants were invited to think of ideas to increase the awareness of PIDs in Thailand. The group suggested to organise a family day for patients, relatives, and for doctors, to build a strong relationship and share experiences. The closing words for this meeting were given by Ms Martine Pergent, who emphasised the power of patients joining together to ensure a better situation in their countries for patients with primary immunodeficiencies.

WHO IS YOUR TARGET AUDIENCE?

OUR TARGET ARE:

1. General Public (Including School Goers)
2. Healthcare Professionals, Medical Students, Nurses
3. Internal Members




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FORUMS & PIDS
MEETING
THAILAND
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IPOPI

การประชุมเพื่อแสดงความคิดเห็น

กิจกรรม	ผู้เข้าร่วม	ความสำเร็จที่คาดว่าจะได้รับ
ตัวอย่าง : การประชาสัมพันธ์ให้ความรู้ความเข้าใจ รวมถึงการศึกษาร่วมกับผู้ป่วย PID	ตัวอย่าง : ผู้ป่วย PID หรือ ผู้ปกครองของผู้ป่วย PID	ตัวอย่าง : สามารถเข้าถึงผู้ป่วย PID ภายในท้องถิ่น
1 งาน Family Day 2 เสนอถึงความสำคัญในการรักษาผู้ป่วยโรคกระดูก	ผู้ป่วย PID ผู้ปกครองของผู้ป่วย PID แพทย์ และกลุ่มผู้ป่วย PID ผู้บริหาร สปอภ. I	สามารถดึงสมาชิกผู้ป่วย PID เข้าร่วมชมรมได้มากขึ้น



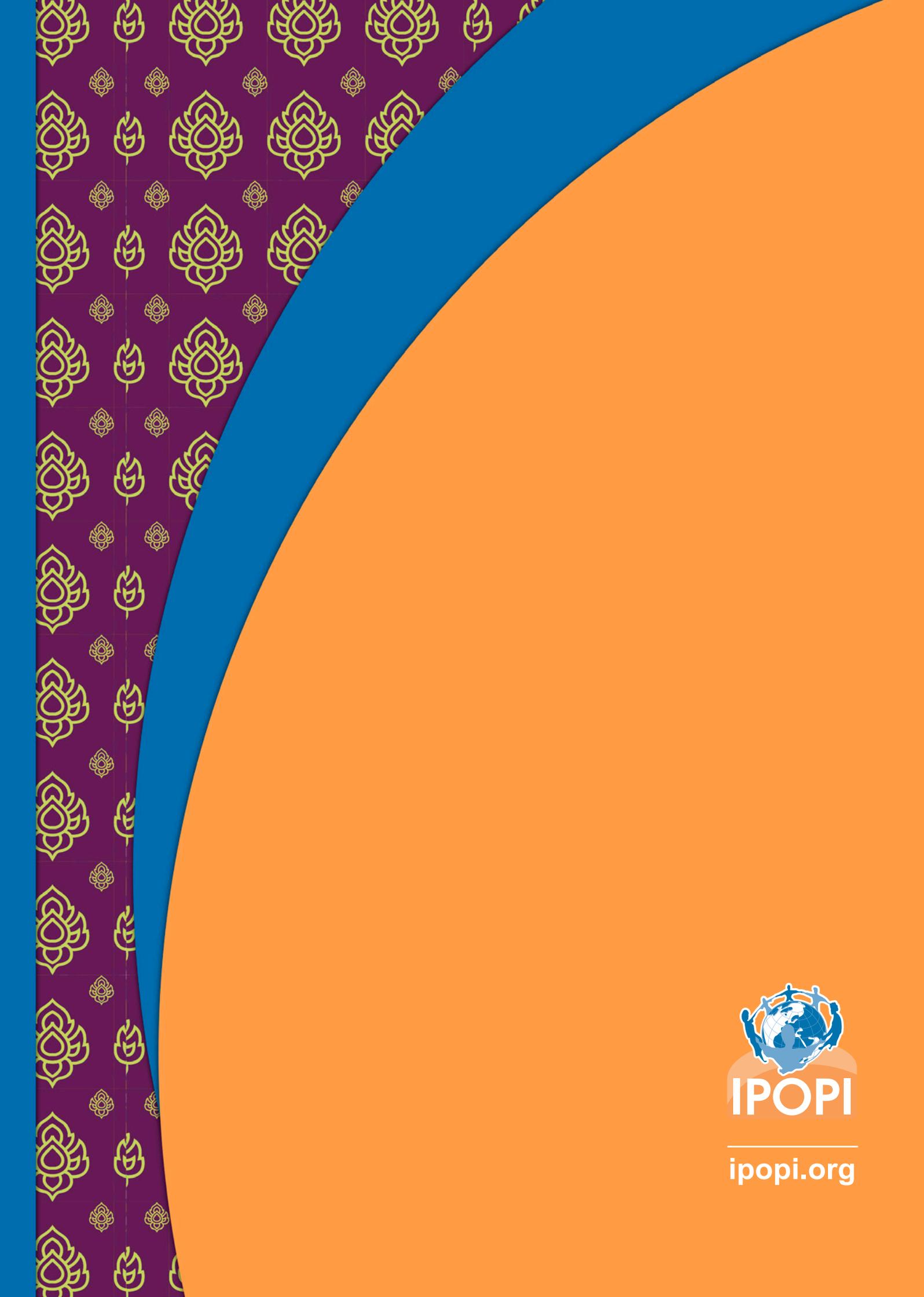
Mr. Ronnapee Nushiri

CONCLUSION

It was a pleasure to return virtually to Thailand for IPOPI's Doctors and Patients Meeting to discuss the current PID environment, the progress made and the challenges remaining in the country for the years to come. The meeting reached its objective to improve awareness of PIDs, diagnosis and management in Thailand and to stimulate discussions for the participants of both the doctors and patients meeting. IPOPI looks forward to continuing to support and collaborate with our colleagues in Thailand in the future.

GRIFOLS

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



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