REVIEW
OF ACTIVITIES AND ACHIEVEMENTS

A Year of Accomplishments

2025

☎ 03-5131 4122

www.mypopi.org

PERSATUAN PESAKIT IMUNODEFISIENSI PRIMER MALAYSIA (MYPOPI)

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President's Message

Dear Members, Partners, and Friends of MYPOPI,

As I look back on the journey we have shared in 2025, my heart is filled with gratitude, hope, and deep admiration for our incredible community.

Every page of this report tells a story-not simply of activities or achievements, but of courage. It is the story of children who continue to smile despite countless hospital visits, parents who never stop fighting for thier loved ones, adults living with Primary Immunodeficiency (PID) who face each day with resilience, and healthcare professionals who walk beside them with unwavering dedication.

Bruce W D Lim

Their strength is the reason MYPOPI exists, and their voices continue to inspire everything we do.

This year, we took meaningful steps together to ensure that no one living with PID feels alone. We shared real patient experiences, advocated for greater access to treatment, raised awareness of Severe Combined Immunodeficiency (SCID) and other primary immunodeficiencies through the media, collaborated with hospitals and healthcare professionals, and reached communities both in Malaysia and across the region. Each conversation started, each story shared, and each partnership formed has brought us one step closer to a future where PID is recognised ealier, undertsood better, and treated more effectively.

One of the greatest privileges of serving as President is meeting the remarkable individuals behind these stories. Time and again, I have witnessed extraordinary resilience in families who face uncertainty with hope, patients who choose to encourage others despite their own challenges, and volunteers who generously give their time so that others may receive support. These moments remind us that while PID may be a rare condition, the compassion within our community is truly extraordinary.

President's Message

Our achievements this year were only possible because so many people believed in our mission. To our Medical Advisory Panel, Executive Committee, Board Members, volunteers, healthcare professionals, sponsors, partner organisations, donors, and every advocate who stood with us—thank you. Your commitment has helped MYPOPI grow stronger and has given countless patients and families renewed confidence that they are not facing this journey alone.

We are also encouraged by the growing recognition of the patient voice in shaping healthcare. Every opportunity to engage with policymakers, medical experts, and fellow rare disease advocates brings us closer to meaningful and lasting improvements for those living with PID. Progress may sometimes seem gradual, but every step forward represents hope for another child to be diagnosed earlier, another family to receive the right support, and another patient to live a fuller and healthier life.

Although we celebrate the progress made in 2025, we know our journey continues. There are still families searching for answers, patients waiting for timely diagnoses, and individuals who need access to better care and treatment. MYPOPI remains committed to standing beside every one of them—to listen, to advocate, to educate, and to ensure that no voice goes unheard.

As we look towards the future, let us continue to walk this journey together—with compassion in our hearts, courage in our actions, and hope in everything we do. Together, we are building more than awareness; we are building a community where every person living with PID is valued, supported, and empowered to live with dignity and hope.

Thank you for being part of the MYPOPI family and for believing in our shared mission. Together, we will continue to make a meaningful difference—one patient, one family, and one life at a time.

With heartfelt gratitude,

Bruce W D Lim
President
Persatuan Pesakit Imunodefisiensi Primer Malaysia (MYPOPI)

EXECUTIVE COMMITTE AND BOARDMEMBERS

EXECUTIVE COMMITEE
Bruce Lim - President and Co-Founder
Siti Aminah Binti Amir - Vice President
Karen Koh - Secretary and Co-Founder
Latifah Binti Abdul Majid - Assistant Secretary
Saravanan Valiatham - Treasurer

BOARD MEMBERS
Rosanna Roshini Martin
Stallone Anak Anthony
Dr Tan Yu Hui
Anida Sazila Binti Salleh

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MEDICAL ADVISORY PANEL 2025

MEDICAL ADVISORY PANEL
Dr. Amir Hamzah Abdul Latiff **Chairman Medical Advisory Panel** Allergy & Immunology Centre Pantai Hospital Kuala Lumpur
Dr. Intan Juliana Abd Hamid **Vice Chairman Medical Advisory Panel** Primary Immunodeficiency Diseases Research Group Department of Clinical Medicine Institut Perubatan & Pergigian Termaju, USM
Prof. Dr. Lokman Mohd Noh **Honorary Medical Advisor** (Immunology)
Assoc. Prof. Dr. Intan Hakimah **Medical Advisor** Consultant Paediatrician and Clinical Immunologist & Allergist Head Clinical Immunology Unit Department of Paediatrics Faculty of Medicine and Health Sciences Universiti Putra Malaysia
Assoc. Prof. Dr. Adli Ali **Medical Advisor** Consultant Pediatric Immunologist and Senior Lecturer Department of Pediatrics Faculty of Medicine UKM Hospital Pakar Kanak- Kanak, UKM
Dr. Kent Woo **Medical Advisor** Consultant Physician, clinical immunologist and allergist Allergy Immunology Clinic Gleneagles Hospital Kuala Lumpur

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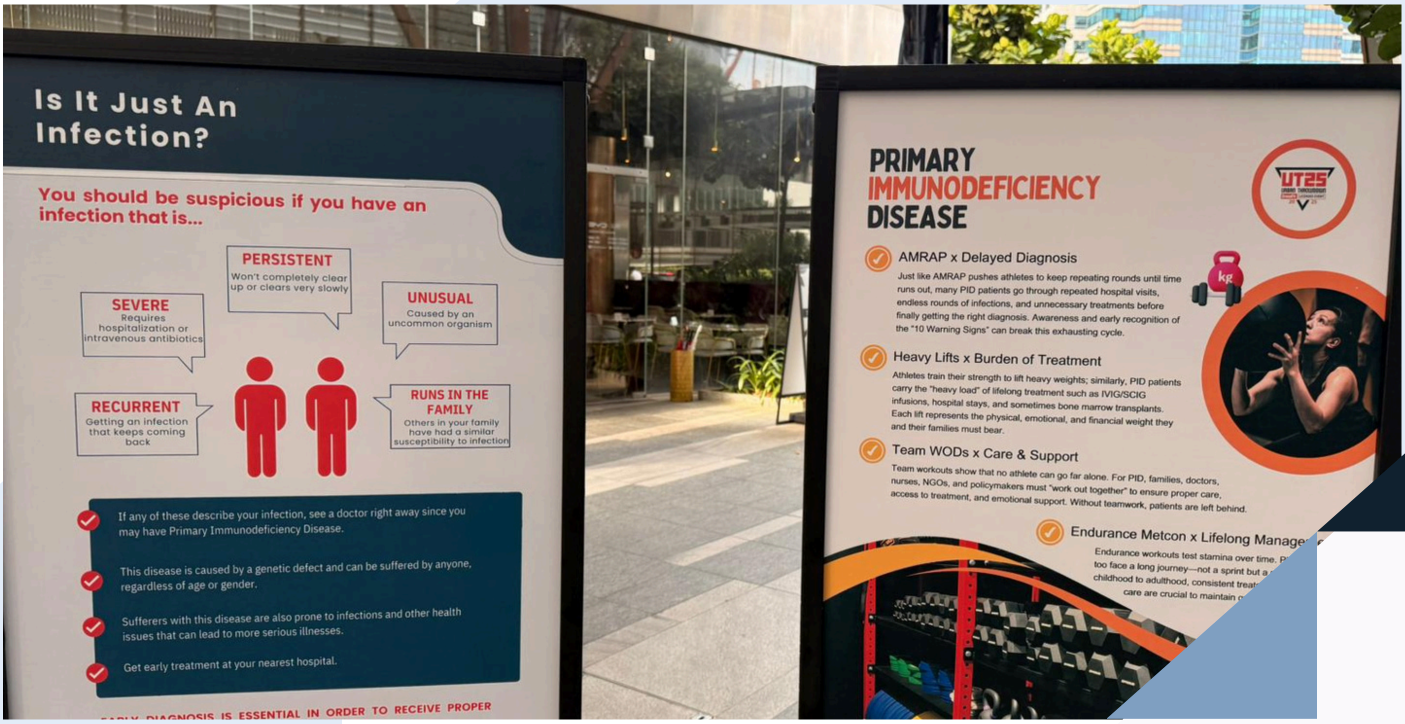
MEDICAL ADVISORY PANEL 2025

MEDICAL ADVISORY PANEL
Dr. Adiratna Mat Ripen **Medical Advisor** Immunologist and Head of Cancer Research Centre (CaRC) Institute for Medical Research (IMR) National Institutes of Health (NIH) Ministry of Health Malaysia
Dr. Mohd Azri bin Zainal Abidin **Medical Advisor** Paediatric Clinical Immunologist and Allergist Department of Paediatrics Hospital Sultan Abdul Aziz Shah, UPM
Dr. Sangeetha Siniah **Medical Advisor** Paediatric Infectious Disease and Immunologist Department of Paediatrics Hospital Tunku Azizah, Hospital Wanita dan Kanak-kanak Kuala Lumpur
Dr Marina Md Sham **Medical Advisor** Paediatric Infectious Disease and Immunologist Department of Paediatrics Hospital Tunku Azizah, Kuala Lumpur
Assoc. Prof. Dr. Asrul Bin Abdul Wahab **Medical Advisor** University Lecturer Jabatan Mikrobiologi & Imunologi Perubatan
Dr. Zarina Thasneem Zainudeen **Medical Advisor** University Lecturer Department of Clinical Medicine Institut Perubatan dan Pergigian Termaju, USM
Dr. Ilie Fadzilah Binti Hashim **Medical Advisor** Lecturer Department of Clinical Medicine Institut Perubatan dan Pergigian Termaju, USM

ABOUT MYPOPI



Is It Just An Infection?

You should be suspicious if you have an infection that is...

PERSISTENT Won't completely clear up or clears very slowly

SEVERE Requires hospitalization or intravenous antibiotics

UNUSUAL Caused by an uncommon organism

RECURRENT Getting an infection that keeps coming back

RUNS IN THE FAMILY Others in your family have had a similar susceptibility to infection

- ✓ If any of these describe your infection, see a doctor right away since you may have Primary Immunodeficiency Disease.
- ✓ This disease is caused by a genetic defect and can be suffered by anyone, regardless of age or gender.
- ✓ Sufferers with this disease are also prone to infections and other health issues that can lead to more serious illnesses.
- ✓ Get early treatment at your nearest hospital.

DIAGNOSIS IS ESSENTIAL IN ORDER TO RECEIVE PROPER

PRIMARY IMMUNODEFICIENCY DISEASE

✓ AMRAP x Delayed Diagnosis

Just like AMRAP pushes athletes to keep repeating rounds until time runs out, many PID patients go through repeated hospital visits, endless rounds of infections, and unnecessary treatments before finally getting the right diagnosis. Awareness and early recognition of the "10 Warning Signs" can break this exhausting cycle.

✓ Heavy Lifts x Burden of Treatment

Athletes train their strength to lift heavy weights; similarly, PID patients carry the "heavy load" of lifelong treatment such as IVIG/SCIG infusions, hospital stays, and sometimes bone marrow transplants. Each lift represents the physical, emotional, and financial weight they and their families must bear.

✓ Team WODs x Care & Support

Team workouts show that no athlete can go far alone. For PID, families, doctors, nurses, NGOs, and policymakers must "work out together" to ensure proper care, access to treatment, and emotional support. Without teamwork, patients are left behind.

✓ Endurance Metcon x Lifelong Manage

Endurance workouts test stamina over time.
too face a long journey—not a sprint but a
childhood to adulthood, consistent treat
care are crucial to maintain

Persatuan Pesakit Imunodefisiensi Primer Malaysia (MYPOPI) is a nonprofit organisation and registered society caring for patients and supporting families affected by Primary Immunodeficiencies (PID).

Our aims are to help ensure that those affected by a primary immunodeficiency have the knowledge needed to manage their condition effectively and to ensure that their health needs are understood and addressed by those involved in policy and delivery of healthcare

OUR MISSION

01

Support

To provide various forms of support to individuals or families affected by PID in Malaysia.

02

Reference

Become a reference center for Malaysians who need information in all aspects related to PID

03

Advocate

Spread awareness and understanding about PID in Malaysia.

04

Representative

Be a representative and intermediary for PID patients in Malaysia in fighting for their rights and needs.

05

Collaborate

Collaborate with stakeholders in conducting studies and research in all aspects related to PID

MYPOPI

2025
HIGHLIGHTS

S Sponsorship

A Achievements

E Events

MYPOPI

MYPOPI SPONSORSHIP

CSL Behring
Biotherapies for Life™

SUPPORT FOR SCIG PT TESTIMONIAL VIDEO

For many individuals living with Primary Immunodeficiency (PID), life involves a continuous and often demanding treatment journey. This journey typically begins with regular Intravenous Immunoglobulin (IVIG) therapy and, for some patients, progresses to Subcutaneous Immunoglobulin (SCIG) treatment as their medical and lifestyle needs evolve.

MYPOPI is committed to advocating for SCIG as an important alternative to IVIG, particularly for patients who face challenges with intravenous access or frequent hospital visits. By enabling home-based therapy, SCIG provides greater flexibility, reduces treatment burden, and enhances the quality of life for PID patients and their families.

In collaboration with CSL Behring, MYPOPI produced a short testimonial video that showcases the real-life experiences of PID patients and their families. The video features seven families sharing their treatment journeys, highlighting the positive changes they have experienced after transitioning from IVIG to SCIG.

We extend our sincere thanks to CSL Behring for their continued support in providing access to SCIG treatment for patients in Malaysia.

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SINGAPORE PID AWARENESS 2025

Primary Immunodeficiencies (PID), also known as inborn errors of immunity (IEI), are a group of over 500 rare, chronic diseases caused by genetic mutations that impair the immune system. These disorders can occur spontaneously or be inherited, affecting anyone regardless of age, gender, or race. While some PIDs appear in childhood, others may only develop in adulthood. Despite their differences, all PIDs share one key feature: a disrupted immune system, which leads to increased susceptibility to infections, including repeated, prolonged, or unusually severe infections.

In September, MYPOPI collaborated with the Singapore PID Committee to raise awareness about PID in Singapore. With the support of Singapore's healthcare community, as well as IPOPI and Xpodium, the event successfully reached both children and adults, helping to spread knowledge and understanding of these rare conditions.

We sincerely thank IPOPI, Xpodium, and the Singapore PID Committee for making this event meaningful and successful, and we hope for continued collaboration in the future.

MYPOPI ACHIEVEMENTS

BFM RADIO STATION

On 28th August 2025, MYPOPI was invited as a guest on BFM Radio’s “Health and Medical Issues” segment to discuss SCID (Severe Combined Immunodeficiency), also known as “bubble boy” disease. Associate Professor Dr Adli Ali and Bruce Lim, President of MYPOPI, highlighted the importance of newborn screening for early detection, giving affected children a chance at life.

We sincerely appreciate this opportunity to raise awareness about this rare disease, which is not widely known in Malaysia. Our thanks to BFM Radio for inviting us to share more about SCID and other rare disorders.

You can listen to the podcast here: https://www.bfm.my/content/podcast/how-newborn-screening-helps-scid-families-and-other-rare-disorders

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SCID PHOTOSHOOT

19 July 2025

MYPOPI

On 19 July at Taman Tugu, this initiative was successfully carried out by MRDS in collaboration with MYPOPI. The photoshoot aimed to tell the stories of SCID warriors by presenting their portraits alongside personal narratives in a photo exhibition, held in conjunction with the launch of the National Rare Disease Policy at Parliament.

Through this platform, MYPOPI represented and amplified stories from across the country, showcasing the voices and lived experiences of children from diverse communities and cultural backgrounds.

MYPOPI sincerely appreciates MRDS for the invitation to represent and share our community’s stories at the Rare Disease Parliament.

RAISING SCID AWARENESS: MYPOPI & THE STAR

On 20th July 2025, The Star newspaper published a story about baby Jaasritha Sai, who was diagnosed with SCID (Severe Combined Immunodeficiency).

Through this collaboration with The Star, we were able to raise public awareness and emphasize the key aspects of SCID, including its impact on patients and the importance of early detection.

'She had no immune system'

By REVATHI MURUGAPPAN
starhealth@thestar.com.my

AS a parent, you'd probably never guess that if your child repeatedly gets an infection, it could be due to a genetic disorder.

Even medical practitioners may not be aware of this.

Primary immunodeficiencies – now often referred to as inborn errors of immunity (IEI) – are a group of more than 500 rare, inherited conditions where a part of the immune system is missing or severely impaired.

These genetic flaws can affect anyone regardless of age, gender or race, leading to an increased susceptibility to infections, autoimmune diseases or other immune problems.

The infections may show up in the skin, sinuses, throat, ears, lungs, brain, spinal cord, or in the urinary or intestinal tracts.

IEI patients often have repeated infections, infections that won't clear up, or unusually severe infections.

They can also present with tumours, severe allergies, multiple enlarged lymph nodes or an enlarged liver.

Researchers are discovering more and more IEI, with the most common one being antibody deficiency.

Antibodies are proteins that protect you when unwanted substances such as bacteria, viruses and toxins enter your body.

"Some people may have mild IEI, but do not display any symptoms.

"Perhaps those with recurrent episodes of upper respiratory tract infection [URTI] could have it, but they don't know because they have never done a blood test to check if there is a problem with the function of antibodies," says Hospital Sultan Abdul Aziz Shah (HSAAS) consultant paediatrician and clinical immunologist and allergist Associate Professor Dr Intan Hakimah Ismail.

An emergency situation

Out of all the IEI, severe combined immunodeficiency (SCID) is the most critical one.

This condition impacts the T cells, as well as the B cells and natural killer cells – all immune cells that originate from the bone marrow and are crucial for fighting off infections.

Infants with SCID appear healthy at birth, but are highly vulnerable to severe and potentially fatal infections.

Usually, the prognosis is poor, as babies don't live past a year unless they get a bone marrow transplant.

Says Assoc Prof Intan: "We consider SCID as a paediatric emergency, so we have to go all out to get them a transplant as quickly as possible.

"With other IEI, there is time to discuss a transplant, but here, there is no time – they will die.

"The majority of SCID babies will have an infection within the first few weeks of life.

"This can include URTI, pneu-

Jaasritha is not out of the woods yet and still needs IVIG treatment monthly, but Manonmani is happy that her baby's smile has returned. – Photos: GLENN GUAN/The Star

blood tests to check.

Possible to cure

While breastfeeding is generally beneficial for infants, it can pose risks for babies with SCID due to the potential transmission of cytomegalovirus through breast milk.

Treatment for SCID includes intravenous immunoglobulin (IVIG) replacement therapy, enzyme replacement therapy and gene therapy, but the latter two are not available in Malaysia.

At HSAAS, once a SCID child is diagnosed or referred from other hospitals, they are started on IVIG immediately, along with antibiotics, antifungals and anti-tuberculosis drugs to prevent infection.

"If they have recurrent viral infections, we also start them on antiviral medications – all these

"Thankfully, we can now get the donor's stem cells from the peripheral blood instead of the bone marrow directly, which is a less invasive procedure.

"The child has to be infection-free as much as possible before the transplant, but in some situations, this is not possible, so if the infection is minimal, the transplant can proceed," explains Assoc Prof Intan.

In most instances, only one transplant is required for a cure.

Inaccurate numbers

Currently, like most rare diseases, there is no national registry for IEI or SCID.

The prevalence of SCID worldwide is estimated to be one in 50,000 to 100,000 live births.

Based on that statistic, Malaysia should have 60-100 cases annually.

However, this number might

Prof Intan says babies with SCID seldom live past a ye
bone marrow transplant due to the frequent infections

"Our data from 2012 shows we have more than 1,000 IEI cases, but for SCID alone, it's 44, so we're definitely missing out on the actual numbers," says Assoc Prof Intan.

That's why she is fighting hard to get newborns screened for SCID.

She says: "We had two cases where the first child was born and died within three or four months.

"It was the same story with the second child, and only when the couple had their third child, we diagnosed the infant with SCID.

"The treating doctor didn't think of SCID as a possibility, or maybe he wasn't aware of the disease.

"Sometimes, the child may be too sick to travel to HSAAS, so we ask the hospitals to send us their blood sample first, as we have labs here that can deliver the results within 24 hours."

'Blessed child'

When Jaasritha Sai was born in 2023, she weighed 2.1kg – a low birth weight – but she was otherwise healthy.

A beautiful, smiley baby, she gained weight quickly, but at three months old, started developing flu symptoms and skin issues.

"We thought her rashes were due to the diapers and we changed the brand, but it didn't help.

"And despite her phlegm, she could drink the whole bottle of milk at one go.

"But suddenly, at six months, Jaasritha would become breathless after drinking two ounces, vomit and purge.

"She became considerably weak and we took her to the hospital's emergency department where she was warded after being diagnosed with pneumonia," recalls her mother Manonmani Suparamany, 42.

Upon discharge, the diarrhoea didn't stop and Jaasritha's weight dropped drastically.

Manonmani sensed something was wrong and consulted multiple specialists from various hospitals before she was referred to Assoc Prof Intan, who confirmed a SCID diagnosis.

That was in November 2023 when Jaasritha was nine months old.

The single mother from Klang, Selangor, says: "I didn't even

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You can read more about this article on our website: https://mypopi.org/2025/07/21/she-had-no-immune-system-a-childs-fight-against-scid/

MYPOPI

MYPOPI EVENTS

RARE DISEASE DAY - HOSPITAL KUALA LUMPUR (HKL)

RARE DISEASE DAY™

28 FEB 2025

ORGANISED BY

RARE DISEASE DAY

Image Source: Malaysian Rare Disorders Society

OPENING CEREMONY 10:15AM
SESSION WITH RARE DISEASE PATIENT ADVOCATES & GROUP LEADS 2:45PM
at Auditorium Perdana,
Hospital Tunku Azizah

BOOTH EXHIBITION 9AM - 5PM
at Foyer,
Hospital Tunku Azizah

FREE Gift for Booth Visitors

SUPPORTED BY

pharm-d health science

JARANG™

PATIENT & COMMUNITY ORGANISATIONS

Malaysian Rare Disorders Society

MYPOPI

PROGRAMME

~ MAJLIS PERASMIAN~
Opening Ceremony

10:15AM PENDAFTARAN
Registration

10:30AM
- BACAAN DOA
  Doa Recital
- NYANYIAN LAGU NEGARAKU
  National Anthem
- UCAPAN PENDAHULUAN OLEH DR NGU LOCK HOCK, KETUA JABATAN GENETIK & METABOLIK, HKL
  Opening Speech by Dr Ngu Lock Hock, Head of Genetic and Metabolic Department, HKL
- PERSEMBAHAN FISIOTERAPI PESAKIT JARANG JUMPA
  Physiotherapy Session with Rare Disease patients
- PERSEMBAHAN VIDEO PESAKIT JARANG JUMPA
  Rare Disease Patient Video Presentation
- UCAPAN PERASMIAN OLEH YBHG DATO' DR HARIKRISHNA K. RAGAVAN NAIR, PENGARAH HKL
  Launching Speech by YBhg Dato' Dr Harikrishna K. Ragavan Nair, HKL Director
- PERASMIAN BUKU-BUKU PENYAKIT JARANG JUMPA
  Launching of Rare Disease Books
- PENYAMPAIAN MOCK CHEQUE & CENDERAHATI
  Presentation of Mock Cheque and Souvenirs

11:30AM
- LAWATAN PAMERAN OLEH VIP
  Booth tour by VIP
- JAMUAN VIP
  VIP refreshments

~ SESSION WITH RARE DISEASE PATIENT ADVOCATES & GROUP LEADS ~

2:45PM Registration

3:00PM
- Landscape of Rare Disease in Malaysia by Puan Nadiah Hanim, Malaysian Rare Disease Society (MRDS)
- Rare Disease Journey by En Azhar Talib, Prader-Willi Syndrome Association, Malaysia (PWSA Malaysia)
- Challenges in Work & Employment for People with Rare Disease by Ms Meizan (KLSAA)
- Living with Motor Neuron Disease: Challenges & Solutions by Motor Neuron Disease Malaysia (MND Malaysia)
- Clinical Trials in Rare Disease: A Hope for the Future by Ms Asha Thanabalan, Clinical Research Malaysia (CRM)
- Table Talk: More Than You Can Imagine
  Moderators:
  - Puan Nadiah Hanim (MRDS)
  - Puan Azween, Genetic Counselling Society Malaysia (GCSM)

  Participating parties:
  - Malaysia Lysosomal Diseases Association (MLDA)
  - Persatuan Pesakit Imunodefisiensi Primer Malaysia (MyPOPI)
  - Persatuan Epilepsi Malaysia (PEM)
  - Spinal Muscular Atrophy Society Malaysia (SMA)
  - SMA Care

5:00PM Closing remarks by MOH Representative

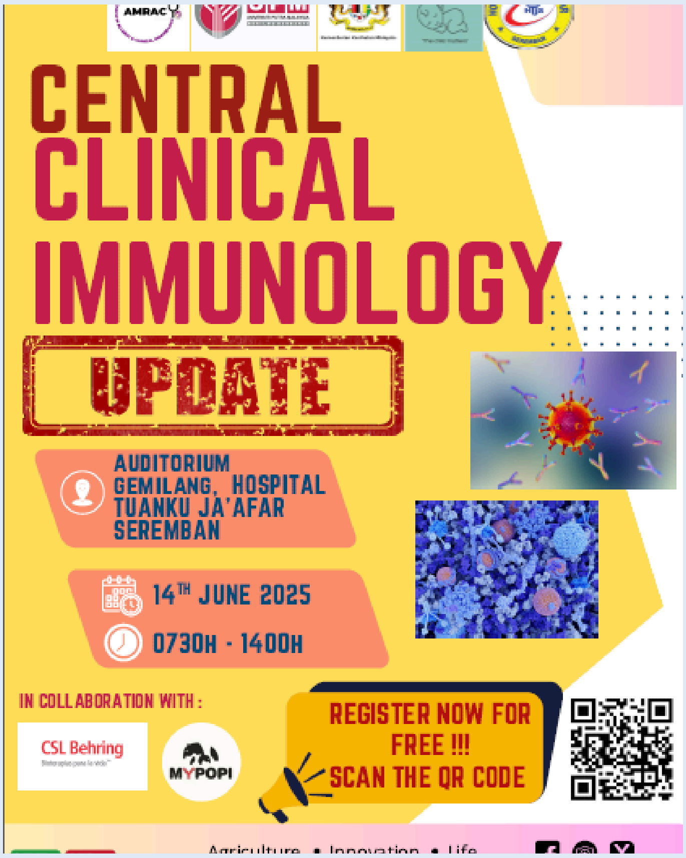
On 28 February 2025, Hospital Kuala Lumpur (HKL) organised a programme called Rare Disease Day to raise awareness. MYPOPI was honoured to be one of the community organisations invited to contribute to this meaningful event.

During the programme, MYPOPI set up an awareness booth to share information on rare diseases, particularly Primary Immunodeficiency. MYPOPI was also one of the speakers in a storytelling session, where a rare disease patient shared personal experiences to raise understanding, empathy, and awareness of early diagnosis and support.

The session aimed to raise awareness, foster empathy, and highlight the importance of early diagnosis and support for those with rare diseases.

MYPOPI

CENTRAL CLINICAL IMMUNOLOGY



AMRAC

CENTRAL CLINICAL IMMUNOLOGY

UPDATE

AUDITORIUM GEMILANG, HOSPITAL TUANKU JA'AFAR SEREMBAN

14TH JUNE 2025

0730H - 1400H

IN COLLABORATION WITH :

CSL Behring

MYPOPI

REGISTER NOW FOR FREE !!!
SCAN THE QR CODE

Agriculture • Innovation • Life

On 14 June 2025, MYPOPI was honoured to be invited as one of the speakers in the segment “A Life Story: Diagnosis, Treatment, and Beyond.” During this session, we shared insights into the challenges faced by individuals with rare diseases, highlighting the importance of early diagnosis, treatment, and ongoing support.

In addition to participating as a speaker, MYPOPI also set up an awareness booth at the event, providing educational materials, guidance, and resources to help the public better understand rare diseases. Through these efforts, we aimed to increase awareness, foster empathy, and encourage support for patients and families affected by rare conditions.

NATIONAL NURSING SYMPOSIUM ON CLINICAL IMMUNOLOGY 2025

MAIN AUDITORIUM HOSPITAL SULTAN ABDUL AZIZ SHAH (HSAAS) UPM

UPM PUTRA

FAKULTI PERUBATAN & SAINS KESIHATAN

MYPOPI

NACLIS 13

13th NATIONAL CLINICAL IMMUNOLOGY SYMPOSIUM

1 - 2 AUGUST 2025
(Friday & Saturday)

Main Auditorium,
Hospital Sultan Abdul Aziz Shah (HSAAS),
Universiti Putra Malaysia (UPM)

SPONSOR:
CSL Behring
TRUST

Agriculture • Innovation • Life
With Knowledge We Serve

CONTACT US
paediatricdepart.medic@upm.edu.my

30th - 2nd August 2025

At the 13th National Clinical Immunology Symposium hosted by UPM Hospital from July 30th to August 2nd, MYPOPI played a significant role in advancing Primary Immunodeficiency (PID) awareness. MYPOPI delivered a focused presentation on patient and family engagement in PID care, highlighting key challenges and practical approaches to improving support.

MYPOPI also featured an interactive exhibition booth showcasing educational materials and resources, enabling attendees to gain a clearer understanding of PID.

Their active participation throughout the symposium reinforced the importance of sustained advocacy and community awareness for PID.

ADULT INBORN ERROR OF IMMUNITY (IEI) & ADVANCES IN SUBCUTANEOUS IMMUNOGLOBULIN THERAPY

Auditorium, Hospital Tunku Azizah, KL

ADULT INBORN ERROR OF IMMUNITY (IEI) & ADVANCES IN SUBCUTANEOUS IMMUNOGLOBULIN THERAPY

SEPTEMBER 13, 2025
08:00 AM - 17:00 PM
Auditorium, Hospital Tunku Azizah, KL

Lecture Highlights

"Introduction to Inborn Error of Immunity and Immune-dysregulation with Autoimmunity"
A. Prof Intan Hakimah Ismail
Universiti Putra Malaysia

"Current Advances in Management of Inborn Error of Immunity"
A. Prof Intan Juliana Abd Hamid
Universiti Sains Malaysia

"The Hidden Diagnosis : Adult PID and Treatment Strategies"
Prof Martin van Hagen
Professor of Clinical Immunology
Department of Internal Medicine, Erasmus Medical Centre, Rotterdam

"Transition Care From Paediatric To Adult Immunology Services"
Dr Nizar Mahlaoui
Necker-Enfants Malades

Event Highlights
- Clinical Case Discussions
- Updates on SC Immunoglobulin Therapy
- Hands on Workshop on SC Immunoglobulin administration

Who Should Attend
Immunologists, Paediatricians, Internal Medicine Specialists, Clinical Fellows, Medical Officers, Nurses, Pharmacists, all Healthcare Professionals with an interest in Immunology

Registration Fees
Specialist: RM 70
Medical Officers /Pharmacist/ Allied Health Professionals: RM50
Nurses/Medical Student: RM30

CLICK/SCAN QR code to register
Dateline: 8th September 2025

On 13 September 2025, Hospital Tunku Azizah invited us to help spread awareness and advocacy on subcutaneous immunoglobulin (SCIG) therapy. In partnership with SHINEE, our team delivered an educational session to provide valuable information to participants.

Patient and parent stories were showcased through informational posters for public viewing. In addition, leaflets highlighting the 10 warning signs were explained to attendees and distributed to the public, with materials jointly prepared in collaboration with SHINEE.

OF PRIMARY IMMUNODEFICIENCY

Primary Immunodeficiency (PI) causes children and adults to have infections that come back frequently or are unusually hard to cure.
1 in every 500 people has one of the Primary Immunodeficiency Diseases.
If you or someone you know is affected by two or more of the following warning signs below, speak to the physician or doctor about the possible presence of an underlying Primary Immunodeficiency.

1. Four or more new ear infections within one year.
2. Two or more serious sinus infections within one year.
3. Two or more months on antibiotics with little effect.
4. Two or more pneumonias within one year.
5. Failure of an infant to gain weight or grow normally.
6. Recurrent, deep skin or organ abscesses.
7. Persistent thrush on the mouth or fungal infection on the skin.
8. Need for intravenous antibiotics to clear infections.
9. Two or more deep -
10. A family history of

Official Portal :
Ministry Of Health Malaysia
SCAN ME
Source :
MYPOPI

SHINE

Initiative to Expand Newborn Screening for Rare Diseases

What?
Screening for **H**ealth, **I**ntervention and **N**urturing of **E**very Child (**SHINE**) is a private - public initiative for the purpose of advancing early detection in Malaysia for Rare Diseases.

How?
We are building an early intervention ecosystem to support ongoing efforts to tackle rare diseases, starting with 68 rare diseases, with the potential for expanding the disease list.

Why?
SHINE firmly believes that early screening would have a large effect on the management and outcome of rare disease patients in Malaysia.

Call to Action
SHINE is looking for collaborators, sponsors and advocates to join the initiative

Spearheaded by: MYPOPI, Arcadia, Malaysian Rare Disorders Society
Supported by:
Collaboration with: IMR

SINGAPORE PID AWARENESS 2025

26-28 September 2025

Urban Park, Guoco Tower, Singapore

MYPOPI

At Urban Park, Guoco Tower, Singapore, MYPOPI collaborated with the Singapore PID Committee to organize an advocacy event aimed at raising awareness, strength, and hope for children and adults living with Primary Immunodeficiency (PID), who face unseen challenges every day.

This initiative brought together healthcare professionals from various hospitals, as well as patients and families affected by PID, who generously volunteered their time to support this first-ever awareness event. The event was held from 26 to 28 September 2025.

With the support and dedication of doctors from Singapore, the event ran smoothly and strengthened our efforts to advocate further for PID awareness. We also extend our gratitude to the volunteers from AMSA for their valuable contribution.

MYPOPI

RARE DISEASE PROGRAMME MALAYSIA

PROGRAM PENYAKIT JARANG JUMPA MALAYSIA

BAHAGIAN PERKEMBANGAN PERUBATAN, KKM

6 Oct 2025: A meaningful day for the Rare Disease (RD) community. We were honoured to be part of today's meeting with the Director-General of Health, together with fellow rare disease patient advocacy groups (PAGs). History was made — this was the largest gathering of RD PAGs to date. It was a clear and productive meeting, paving the way forward for rare diseases in Malaysia.

I believe there will be brighter days ahead for the rare disease community as we strengthen this partnership and work together to improve diagnostics, treatment, and care for people affected by rare diseases in Malaysia.

SCIG PATIENT TESTIMONIAL VIDEO

In collaboration with CSL Behring Sdn Bhd, we produced a patient story video highlighting a real-life treatment journey from living with IVIG therapy to transitioning to SCIG treatment, which has brought significant improvements in quality of life.

Through this collaboration, we aim to strengthen awareness and advocacy around SCIG as an effective and empowering treatment option for patients with Primary Immunodeficiency. By sharing authentic patient experiences, we hope to provide insight into how SCIG offers greater flexibility, independence, and continuity of care compared to IVIG.

Visit our website to read real patient stories and understand how SCIG is transforming lives.

Visit our website to read real patient stories and understand how SCIG is transforming lives.

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MYPOPI COLLABORATION WITH ASTRO AWANI – SCID AWARENESS

MYPOPI collaborated with Astro Awani on 27th - 28th December 2025 to raise awareness about SCID (Severe Combined Immunodeficiency), a rare disease that is not widely known.

During the collaboration, Dr Adli and Encik Fadzhairi provided insights on SCID and highlighted the importance of newborn screening for early detection of the disease.

To learn more and view the event video, please visit: https://mypopi.org/2026/01/08/astro-awani-breaking-the-cycle-of-severe-combined-immunodeficiency/

MYPOPI

TABUNG KEBAJIKAN

MYPOPI

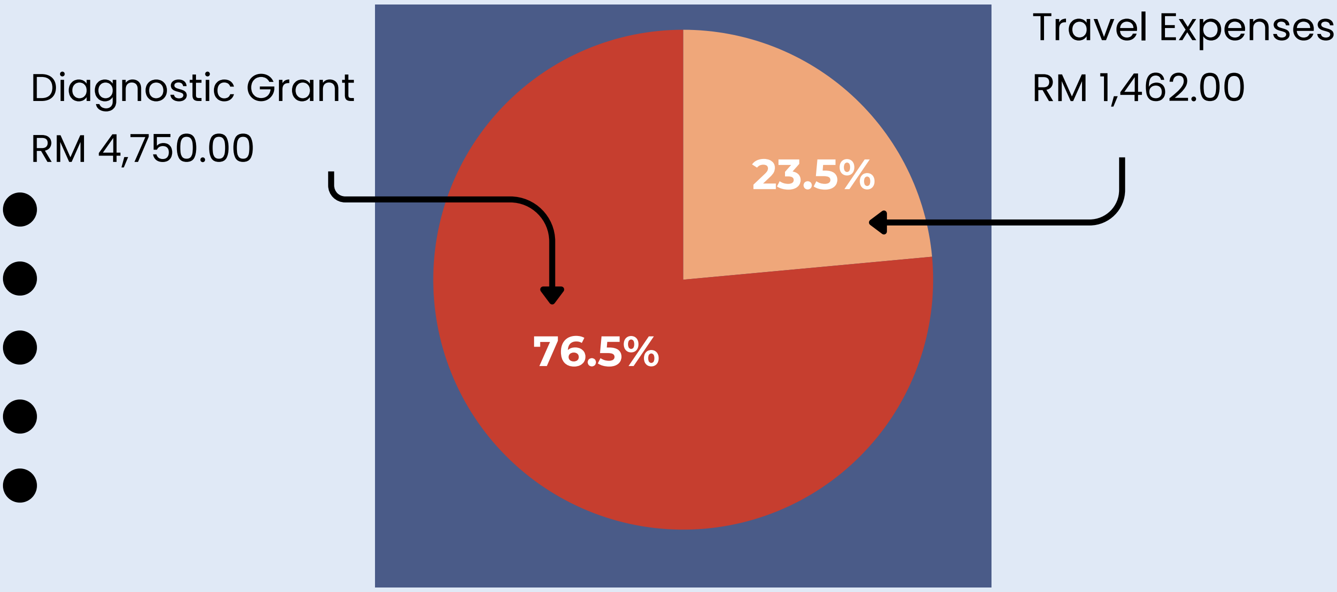
TABUNG KEBAJIKAN

Established in 2015, the MYPOPI Tabung Kebajikan Pesakit (Patient Welfare Fund) was created to provide timely financial assistance to individuals and families affected by Primary Immunodeficiency (PID). The fund serves as a vital source of support for patients facing financial hardship by helping to reduce the burden of essential medical and healthcare-related expenses, enabling them to access the care they need with greater confidence and dignity.

	2024	2025
Income Total	MYR 14,732.58	MYR 10,000
Expenses Total	MYR 6,211.53	MYR 7,439.96
Surplus / Deficit (-) for the year	MYR 8,521.05	MYR 2,560.04
Total funds brought forward at 1st Jan	MYR 2,339.89	MYR 10,860.94
Total fund carried forward as at 31st DEC	MYR 10,860.94	MYR 13,420.98

In 2025, the Tabung Kebajikan Pesakit continued to play a meaningful role in supporting patients through targeted financial assistance. The fund recorded a total income of RM10,000 (allocated from MYPOPI general fund) and disbursed RM7,439.96 in patient assistance, resulting in a year-end surplus of RM2,560.04. As at 31 December 2025, the fund balance increased to RM13,420.98, strengthening MYPOPI's capacity to continue assisting patients in need.

TABUNG KEBAJIKAN



The majority of financial assistance provided during the year was channelled towards diagnostic grants for genetic testing, which accounted for 76.5% of total disbursements. These grants help patients obtain essential diagnostic investigations that are often critical for achieving an early and accurate diagnosis. The remaining 23.5% was allocated to travel assistance, helping patients and their families overcome transportation costs when accessing specialised medical care and treatment centres.

Behind every grant awarded is a patient seeking answers, a family travelling long distances for specialised treatment, or a child taking the first step towards an accurate diagnosis. Through the generosity of our donors and supporters, the Tabung Kebajikan Pesakit continues to provide more than financial assistance—it offers hope, relief, and reassurance to families navigating the challenges of living with a rare disease.

As awareness of Primary Immunodeficiency continues to grow, so too does the demand for patient support. MYPOPI remains committed to strengthening the Tabung Kebajikan Pesakit through sustainable fundraising and strategic partnerships, ensuring that more patients can receive timely assistance when they need it most. Every contribution made to the fund is an investment in better access to care, improved quality of life, and a future where no patient is left behind.

MYPOPI

FINANCIAL REPORT

MYPOPI

FINANCIAL OVERVIEW

MYPOPI remains committed to maintaining sound financial governance while ensuring that every contribution entrusted to us is used responsibly to improve the lives of individuals and families affected by Primary Immunodeficiency (PID).

	2024	2025
Income Total	MYR 271,903	MYR 57,270
Expenses Total	MYR 204,351	MYR 98,726
Surplus / Deficit (-) for the year	MYR 67,552	MYR (41,456)
Total funds brought forward at 1st Jan	MYR 113,474	MYR 181,389
Total fund carried forward as at 31st DEC	MYR 181,389	MYR 132,268

During the financial year ended 31 December 2025, the Association recorded a total income of RM57,270, primarily derived from donations, including tax-exempt contributions, support from the International Patient Organization, donations related to medical devices, and membership fees.

Total expenditure for the year amounted to RM98,726, resulting in an operating deficit of RM41,456. While this represents a planned reduction in accumulated funds, it reflects MYPOPI's strategic investment in expanding patient advocacy, strengthening organisational capacity, and delivering programmes that directly benefit the PID community.

FINANCIAL OVERVIEW

The Association continued to prioritise spending on initiatives that create meaningful impact. Key areas of expenditure included patient assistance through medical equipment and aids, awareness campaigns, programme and event implementation, staff support, professional services, and administrative governance. These investments enabled MYPOPI to deliver nationwide awareness programmes, strengthen collaborations with healthcare institutions, advocate for improved access to Subcutaneous Immunoglobulin (SCIG) therapy, and amplify the voices of patients and families through education and public engagement initiatives.

As at 31 December 2025, MYPOPI maintained cash and bank balances of RM132,268, with net accumulated funds of RM127,900, providing a stable financial foundation to support ongoing operations and future advocacy initiatives. The Association's liabilities remained low at RM4,368, reflecting prudent financial management and responsible stewardship of available resources.

The financial statements have been independently audited by Wong Chau Hwa & Co., who expressed the opinion that the financial statements present a true and fair view of MYPOPI's financial position as at 31 December 2025 and its financial performance for the year in accordance with the applicable approved accounting standards in Malaysia.

FINANCIAL OVERVIEW

Although income in 2025 was lower than the previous year, MYPOPI remained focused on its mission rather than short-term financial outcomes. The Association consciously utilised its accumulated reserves to sustain essential patient support services, strengthen advocacy efforts, and invest in initiatives that will deliver long-term benefits to the PID community.

This approach reflects MYPOPI's commitment to ensuring that available resources are translated into meaningful outcomes for patients and their families.

As we move forward, MYPOPI will continue to strengthen its financial sustainability through responsible governance, diversified fundraising, strategic partnerships, and transparent financial management.

We extend our heartfelt appreciation to every donor, sponsor, healthcare partner, volunteer, and supporter whose generosity has enabled us to continue advocating for earlier diagnosis, better treatment access, and improved quality of life for people living with Primary Immunodeficiency in Malaysia.

YOUR DONATION BRINGS HOPE TO PID PATIENTS IN MALAYSIA

Your contribution to Tabung Kebajikan Pesakit is more than just a donation — it is hope, dignity, and relief for patients in need. Every ringgit you give helps ease the burden of those battling illness, ensuring they receive the care, treatment, and support they deserve. Together, we can lift lives, heal hearts, and create a greater impact for a healthier tomorrow. Be the reason someone finds strength in their hardest moment — donate today and be part of this greater cause.

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Persatuan Persakit PID

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Refference:

#TabungKebajikanPesakit

Dermaan Tunai kepada MYPOPI adalah ditakluk kepada "Potongan Di Bawah Subseksyen 44(6), Akta Cukai Pendapatan 1967, No. Rujukan: LHDN.01/35/42/51/179-6.8744

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Tempoh Kuatkuasa Kelulusan: 01 Januari 2023 Sehingga 31Disember 2027"

OUR DEEPEST GRATITUDE TO:

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S.M.A. MALAYSIA

We sincerely thank you for your invaluable support, which has played a key role in our achievement.

MYPOPI

MYPOPI

Persatuan Pesakit Imunodefisiensi Primer Malaysia

MYPOPI is a non-profit charity registered in Malaysia (ROS Reg. No: PPM-008-14-15082014), MYPOPI also is a member of IPOPI, an international non-profit association registered in UK.

email: mypopi@yahoo.com - website: mypopi.org