



XVIII IPOPI GLOBAL PATIENTS' MEETING

an **IPOPI** event

16-19 OCTOBER 2024
MARSEILLE, FRANCE

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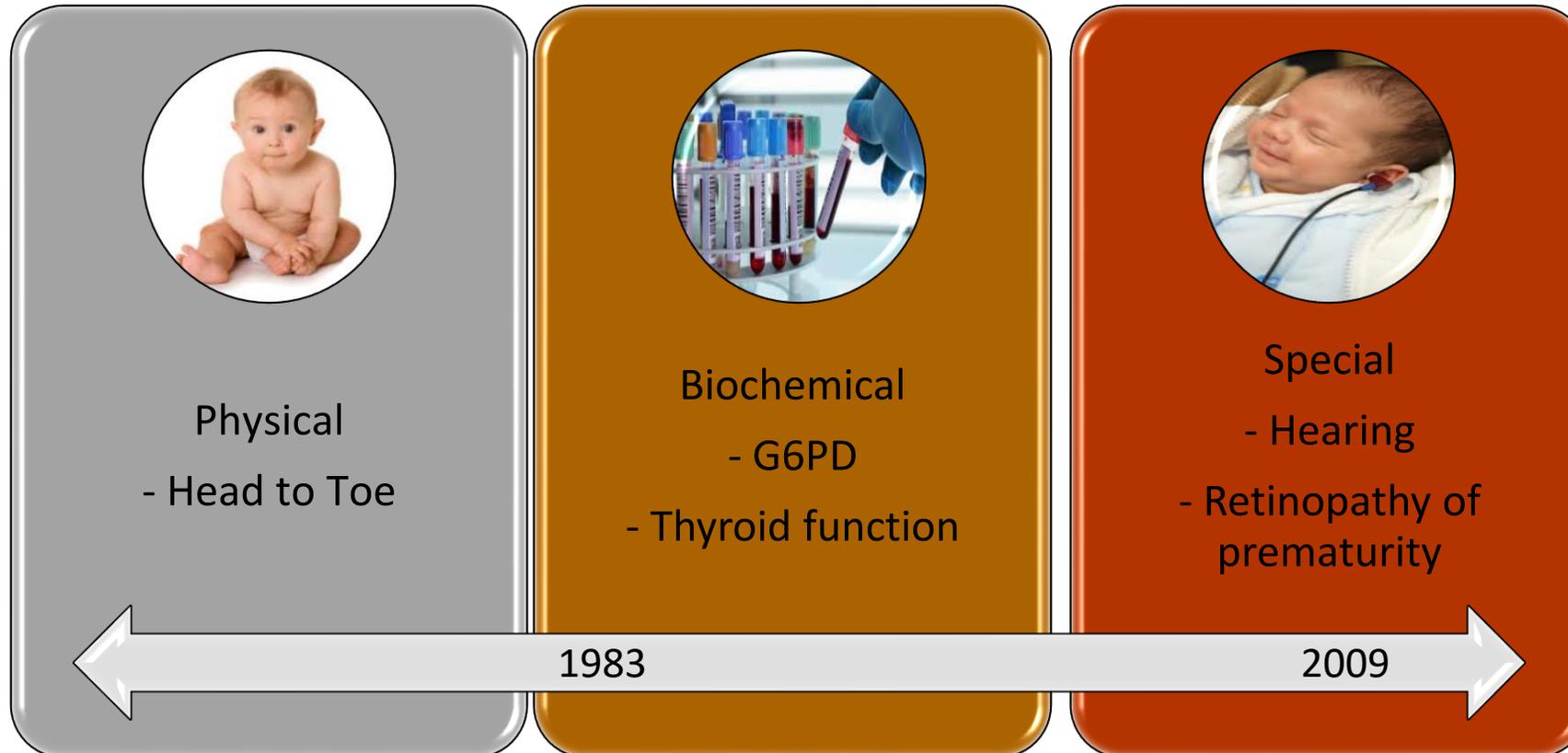
New Horizons for SCID Newborn Screening?, The case of Malaysia

Bruce W.D., Lim

NATIONAL NEWBORN SCREENING IN MALAYSIA



KEMENTERIAN KESIHATAN MALAYSIA



XVIII IPOPI GLOBAL PATIENTS' MEETING



MALAYSIA



an IPOPI event

EXPANDED NEWBORN SCREENING FOR TREATABLE RARE DISEASE FOCUSING ON SCID AND SMA

2023 – 09 MARCH 2024

Stakeholders:



Summary of the action:

- 18 November 2023: 1st Mutli-stakeholders workshop (Rep of Ministry of Health, Experts Physicians, Industries and patient organisations).
- 09 March 2024: RTD with MOH

Financial support: IPOPI NBS Project Grant

Challenges:

Difficult to align every stakeholder to the same mission & vision
Limitation on healthcare ecosystem. What's next after screening?

Outcomes:

- **MOH PIC agreed to include IEM, PID & SMA into their work policy of extended National NBS policy to be tabled for MOH/Parliament approval.**

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SHINE

Screening for Health, Intervention and Nurturing of Every child

PROGRAM

Way forward!



Malaysia Patients Organisation
for Primary Immunodeficiencies

SHINE Program aims to provide early detection and intervention for rare diseases

Value: Blueprint for implementing a thriving ecosystem for newborn screening program in Malaysia.

Private Initiative Spearheaded: MYPOPI
Assisted: Arcadia, Revvity and Clinicians



VISION AND MISSION

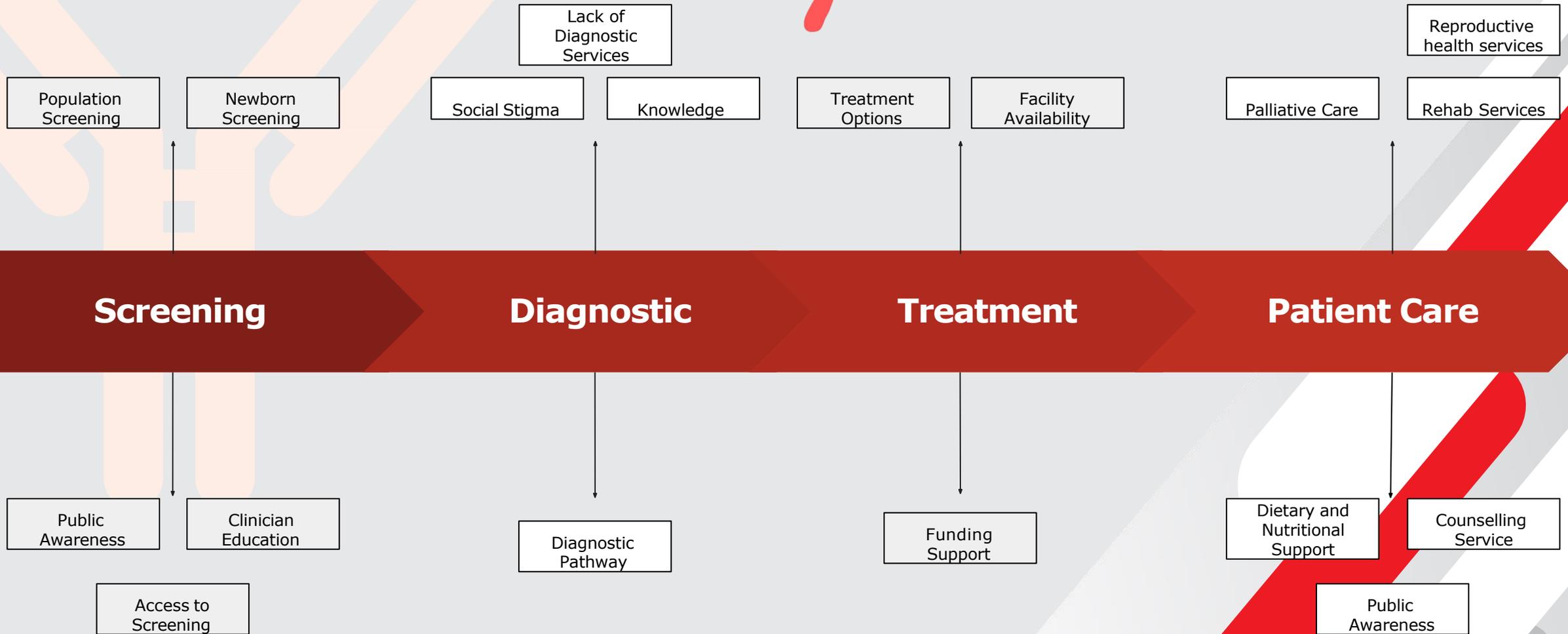
VISION

**Access to Expanded
Newborn Screening** for
Rare Diseases
in Malaysia

MISSION

Establish **infrastructure
and ecosystem** for
successful
implementation of
Expanded Newborn
Screening in Malaysia

ECOSYSTEM



Malaysia Patients Organisation
for Primary Immunodeficiencies

OBJECTIVES



SCREEN
20,000
NEWBORNS

Severe Combined
Immunodeficiency
X-linked Agammaglobulinemia
Spinal Muscular Atrophy
Inborn Errors of Metabolism
(68 diseases)

IMPACT



**ESTABLISH
ECOSYSTEM**

Malaysia s SEA

Identify and
Address Gaps

Generate
Data/Registry
on Rare
Diseases

Build network
for Rare
Diseases

COUNCIL

SHINE

Council Groups

Advocacy

Raising **Awareness** of Newborn Screening

Screening

Screen **20,000** Newborns

Treatment

Enable follow up for **Diagnosis** and **Treatment**

New initiative

Research and **Education**



Malaysia Patients Organisation for Primary Immunodeficiencies



ROADMAP



June 2024

Soft launch

SHINE introduced by Arcadia aiming for 20,000 newborn screening



September 2024

Council members establishment

Council members established from various expertise for varied tasks



October 2024

Commencement of SHINE: Way forward

Notice of next steps for SHINE given out by council and action plans drafted out

November 2024

Fundraising and screening

SHINE Program fully underway

- SHORT TERM:**
- Paperwork for SHINE under MYPOPI
 - Electing Head of Councils

- MID TERM:**
- Approaching state grants
 - Roadshow planning

- LONG TERM:**
- Malaysian NBS Registry
 - Ecosystem



Malaysia Patients Organisation for Primary Immunodeficiencies

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