Global access to SCID newborn screening:

A PID Life Index perspective

June 2026

SCID is one of the **most severe forms of primary immunodeficiency** (PID) and is considered a paediatric emergency.

Babies with SCID appear healthy at birth but are unable to fight off bacterial, viral, parasitic or fungal infections. This makes newborn screening essential, as **clinical symptoms only appear once severe infections have already developed.**

Without early diagnosis and treatment, infants with SCID will succumb to infections, usually within the first years of life.

Newborn screening enables allows for:

- Diagnosis shortly after birth (preventing the diagnostic odyssey)
- Timely referral to specialist care
- Prevention of prolonged hospitalisations and life saving intervention

Treatments

Hematopoietic stem cell transplantation (HSCT)

A curative treatment for SCID. Outcomes have significantly improved over time, with survival rates exceeding 90% when performed before 3–4 months of age, in the absence of infection and with a compatible donor for the stem cells the baby receives in the proccedure. This highlights the importance of fast diagnosis.

Gene therapy

A treatment option that takes place in few expert centres. It involves correcting the underlying genetic defect in the child's own blood-forming cells and reinfusing them to restore immune function.

Thymic transplant / culture thymic tissues

Thymic transplantation – a procedure in which the child affected by congenital athymia and associated conditions receives a thymus tissue from a healthy donor. The new thymus would help training stem cells into T cells that work adequately. There are only 2 centres in the world that perform this transplantation.

Cultured thymic tissue – this is a specialised procedure indicated for children born with congenital athymia in which donated healthy tissue from the thymus is engineered and then implanted, enabling the child's pre-T cells to develop into T cells that work adequately to fight infections.

Screening is effective only when paired with prompt follow-up care.

Newborn screening for SCID enables:

- **Immediate diagnosis**
- **Fast referral to a specialist centre**
- **Timely access to most suitable and available treatment or thymic transplant / cultured thymic tissues**

Newborn screening for SCID can be performed using **dried blood spot samples routinely collected** from newborns worldwide, making it feasible to integrate into existing screening programmes for rare diseases.

The implementation of newborn screening programmes for SCID are the result of a joined effort from **patient advocates, treating immunologists and transplanters, screening experts.**

Newborn screening for SCID **allows as well for the identification of other severe primary immunodeficiencies** (other than SCIDs, or severe T cell deficiencies) in which the child also benefits from an early treatment.

Newborn screening for SCID is a proven, cost-effective public health intervention that saves lives, reduces suffering, and should be universally accessible and linked to timely and fully covered treatment and care.

No child should die from an undiagnosed but treatable condition like SCID.

Incidence

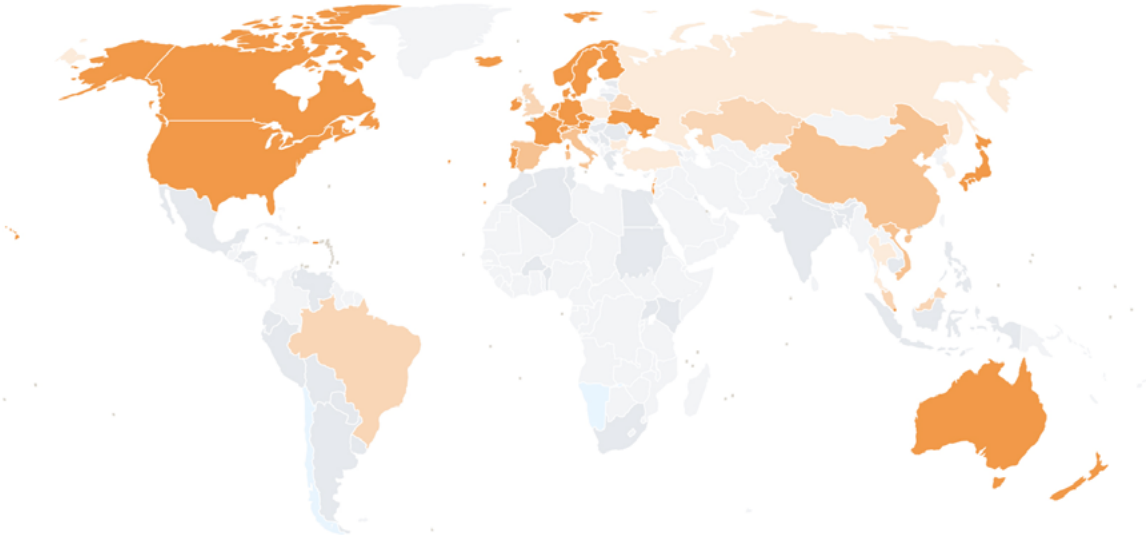
The estimated incidence of SCID is approximately **1 in 50,000 to 1 in 100,000** live births globally.
Higher incidence rates are observed in certain regions:

Israel, approximately **3-4 per 100,000 births**, certain regions.

The Eastern Province of Saudi Arabia has the highest reported incidence at around **19 cases per 100,000 births.**

In some communities in Nunavut, SCID is estimated to occur in **1 in 500 births.**

Newborn screening for SCID – **Breakdown by country in 2026**



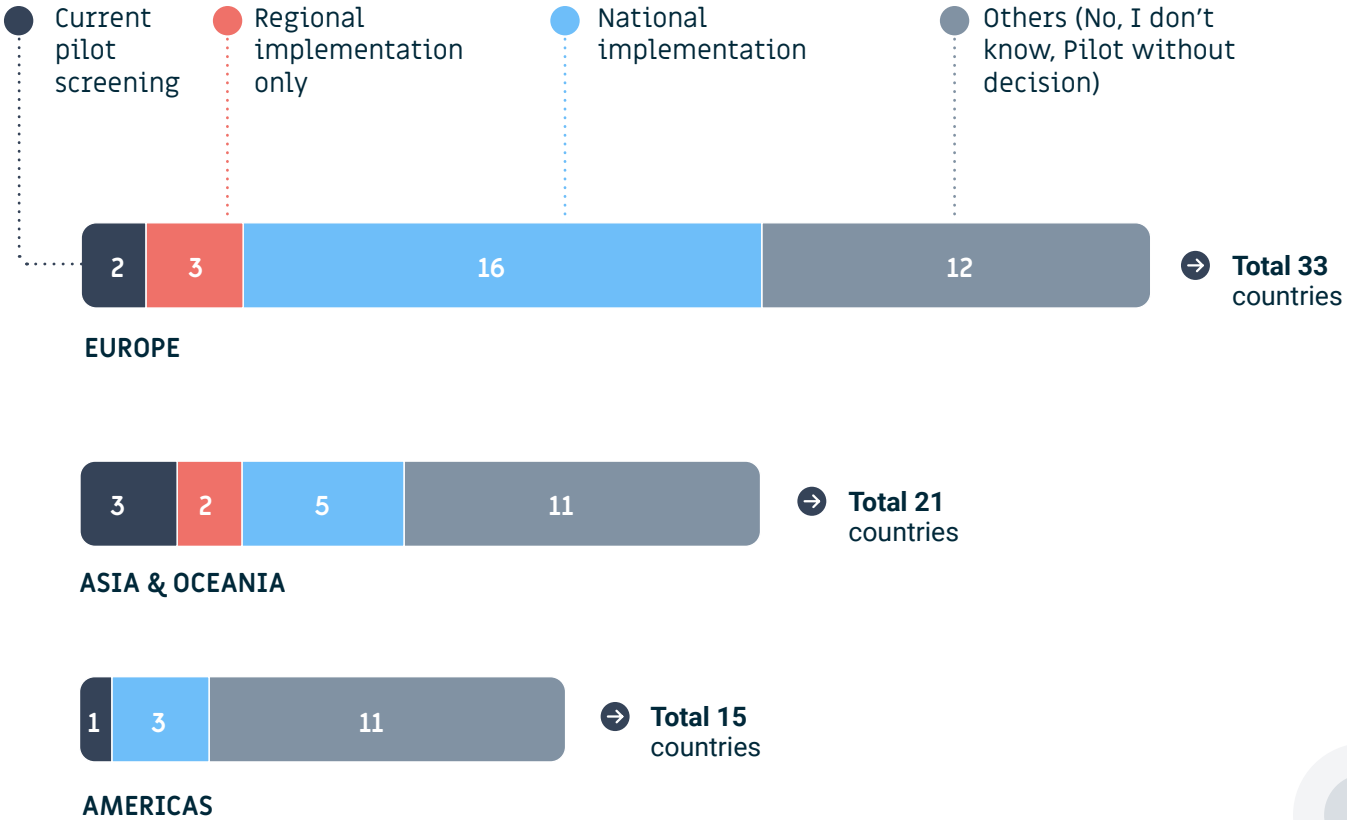
PID diagnosis-newborn screening for SCID

- No
- I don't know
- Pilot without decision
- Current pilot screening
- Regional implementation only
- National implementation

Number of countries with newborn screening for SCID - **Changes between 2020 and 2026**

The countries were given the option to say if at the time of the survey, there was: 1) no SCID newborn screening; 2) a pilot done without a decision, 3) a current pilot project for SCID newborn screening, 4) regional implementation, 5) national implementation or 6) I don't know. In 2026, 80 countries were included in the PID Life Index.

Number of countries with newborn screening for SCID – **By continent**



PID diagnosis and curative treatment

Number of countries with newborn screening for SCID **and PID diagnosis**

Total 29 countries

Biological diagnosis availability

Genetic diagnosis availability

Number of countries with newborn screening for SCID **and curative treatment**

Total 29 countries

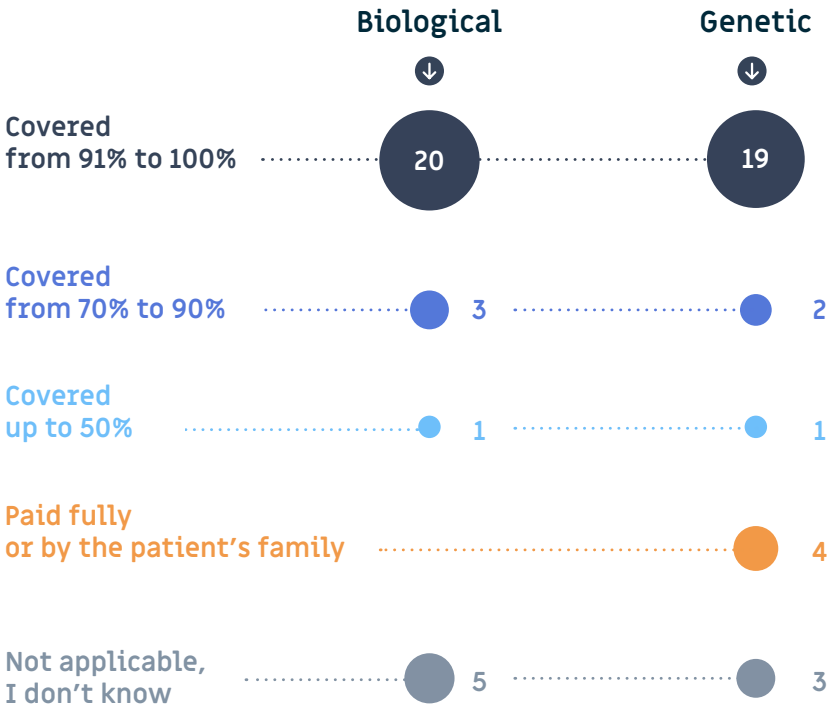
BMT/HSCT

Gene therapy

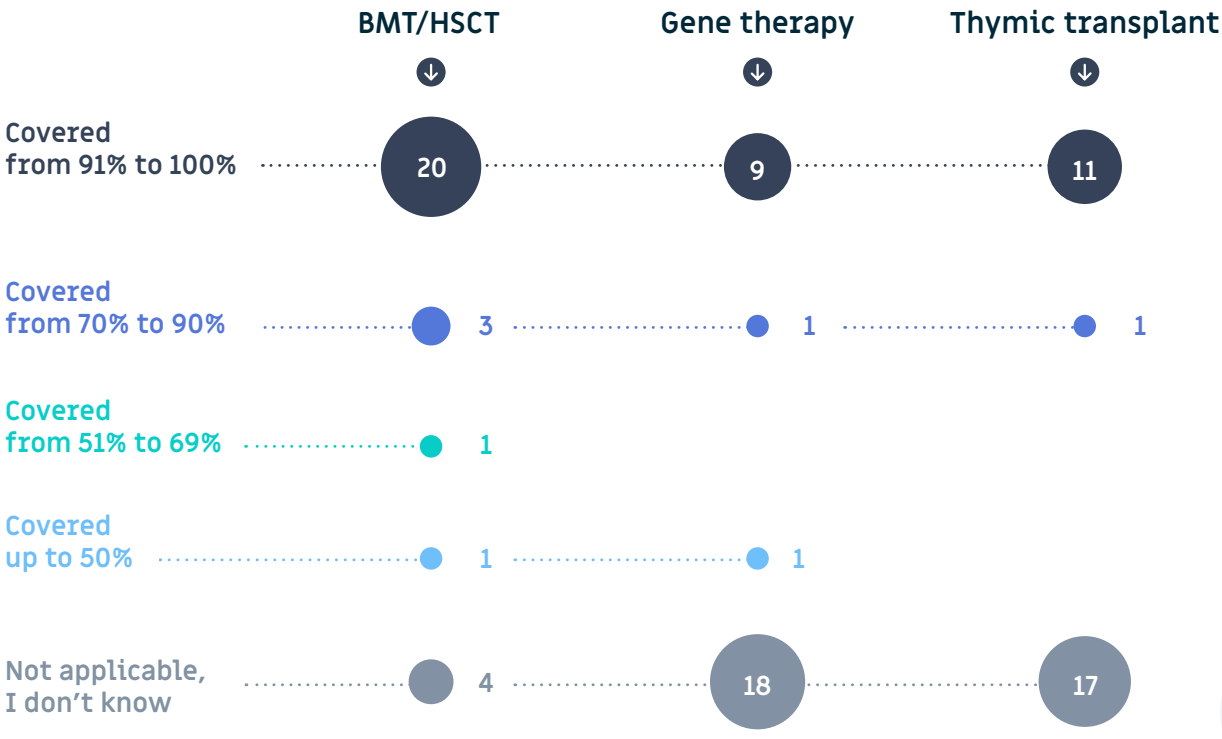
Thymic transplant

Reimbursement

Number of countries with newborn screening for SCID **and diagnosis reimbursement**



Number of countries with newborn screening for SCID **and curative treatment reimbursement**



SCID newborn screening implementation worldwide

Over the past two decades, evidence from countries implementing SCID newborn screening has demonstrated that it is feasible, effective, transformative for affected children and families and cost-effective for healthcare settings.

The United States recommended SCID newborn screening in 2010, achieving nationwide implementation in 2018.

Israel was the first country to implement nationwide SCID screening in 2015.

Focus on Malaysia

The **SHINE** (Screening for Health, Intervention and Nurturing of Every Child) initiative, launched in 2024, is a multi-stakeholder effort to expand access to newborn screening for treatable rare diseases, including SCID.

The project aims to:

- Screen approximately 20,000 newborns over two years
- Demonstrate feasibility in the local context
- Build the case for policy adoption and nationwide implementation
- Generate national data

SHINE represents an important step toward equitable access to early diagnosis and care in a country from the Southeast Asian region.

What's next? How does the future look?

Despite increasing adoption, universal access to SCID newborn screening remains a **major global challenge**. Key barriers include:

- Limited implementation of national screening programmes
- Very few countries cover the costs of and associated to HSCT, gene therapy or other SCID.

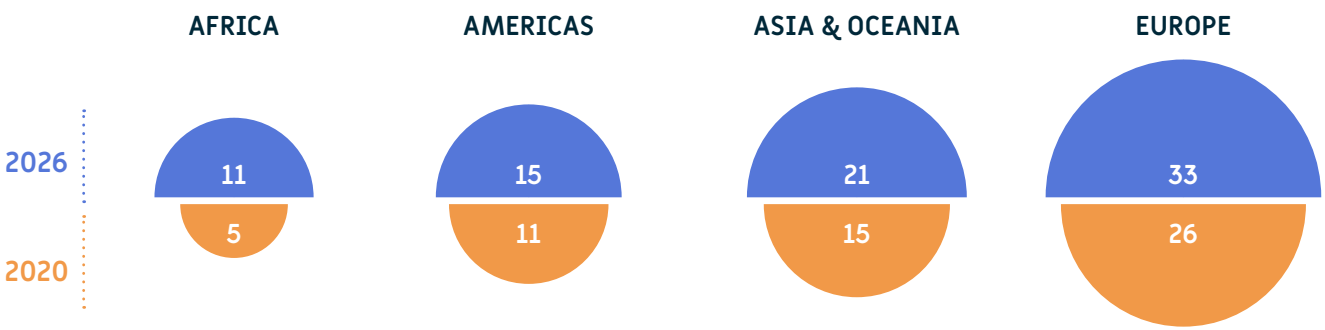
At the same time, **technological advances** are shaping the future of screening:

- Most programmes currently use T-cell receptor excision circle (TREC) testing
- More advanced approaches are emerging, including:
  - Combined TREC/KREC assays
  - Genomic technologies such as next-generation sequencing

These innovations may enable the detection of a broader range of primary immunodeficiencies and other treatable conditions, further expanding the impact of newborn screening.

About the PID Life Index

Number of countries
included in the PID Life Index

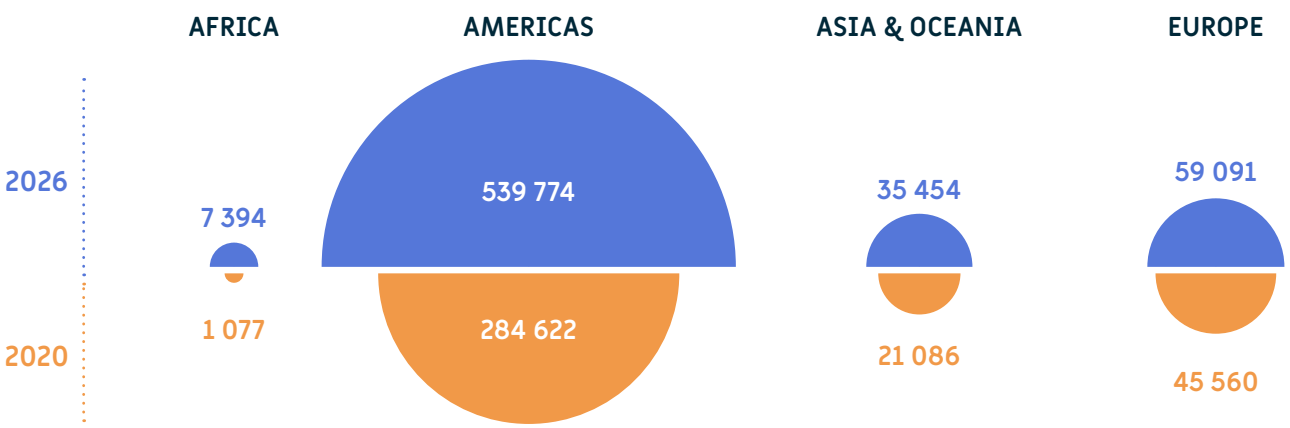


59 countries were included in the PID Life Index in 2020, 80 in 2026

In total, **59 countries** were included in the PID Life Index in 2020, representing **352,345 patients**.

In 2026, **80 countries** representing **641,713 patients**.

Number of patients
included in the PID Life Index



352,345 patients were included in the PID Life Index in 2020 and 641,713 in 2026

Resources

To know more about International Neonatal Screening Day (INSD)

https://neonatalscreeningday.org/

To know more about SHINE initiative, in Malaysia

https://mypopi.org/

1 · A. Lev, I. Sharir, A.J. Simon, S. Levy, Y.N. Lee, S. Frizinsky, et al. Lessons learned from five years of newborn screening for severe combined immunodeficiency in Israel J Allergy Clin Immunol Pract, 10 (2022), pp. 2722-2731.e9

2 · Suliaman, Fawzi & Al-Ghonaium, Abdulaziz & Harfi, Harb. (2006). High Incidence of Severe Combined Immune Deficiency in the Eastern Province of Saudi Arabia. Pediatric Asthma, Allergy & Immunology. 19. 14-18. 10.1089/pai.2006.19.14.

3 · Immunity Canada and NRBDO. Rare Disorders, Remote Realities: Mapping the gaps in care in rural Canada. Toronto, ON. (April 2026)

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