

Immune Deficiencies Foundation Australia (IDFA)

MEDIA KIT

What are Primary Immune Deficiencies?

An **Immune Deficiency** is a disorder where the immune response (the body's defence system) is reduced or absent. **Primary Immune Deficiencies (PIDs)** are caused by defects in the genes that control the immune system, so people with PID are born missing some or all of the parts of the immune system. Primary Immune Deficiencies (PIDs) diseases occur in people born with an immune system that either is absent or hampered in its ability to function.

PIDs are not related to AIDS, which is caused by a viral infection (HIV). While not contagious, these diseases are caused by genetic defects and can affect anyone, regardless of age or sex. The World Health Organisation recognizes more than 200 primary immunodeficiency diseases.

There is no cure for the majority of PIDs. **PIDs can be mild, severe and in some cases fatal.** The main issue is increased susceptibility to infections affecting the sinuses, ears, lungs, bowel and skin. If not diagnosed early, these organs become permanently damaged. Even with treatment, the damage cannot be reversed.

Many people with PID also have autoimmune conditions such as arthritis, lupus, thyroid disease and bowel disease.

Primary Immune Deficiencies include:

Common Variable Immune Deficiency (CVID), Hereditary Angioedema (HAE), Specific Antibody Disease (SAD), Chronic Granulomatous Disease (CGD), X-Linked Agammaglobulinaemia (XLA), Hyper IgM Syndrome and Severe Combined Immune Deficiency (SCID).

7 Warning signs:

1. An unusually large number of infections requiring treatment
2. Infections caused by unusual types of organisms
3. Infections in unusual places
4. Infections that do not respond to treatment as normally expected
5. A child that does not grow or put on weight as expected
6. A family history of immune deficiency or abnormal infections
7. Any other unusual symptoms related to infections

Diagnosis:

A Primary Immune Deficiency is diagnosed by an Immunologist.

Prognosis:

There is no cure for the majority of PIDs. PIDs can be mild, severe and in some cases fatal.

Early detection and correct treatment of PID can:

- Reduce the number and severity of infections
- Reduce the impact of on major organs
- Help many children and adults with PID have a better quality of life

Treatments include:

- 2-4 weekly infusions of IVIg (intravenous immunoglobulin) or SCIG (subcutaneous immunoglobulin)
- Injections (Gamma Interferon)
- Antibiotics
- steroids
- in some PIDs, Haemopoietic Stem Cell Transplantation (bone marrow transplant)

About IDFA

IDFA is a National not for profit health promotion charity raising awareness and supporting people with primary immune deficiencies in Australia. IDFA is committed to providing education and resources, linking members via teleconferencing and events, and improving patient care and quality of life for those affected by primary immune deficiencies. Membership is free.

Services:

IDFA provides education and emotional support for people with PID and their families. IDFA links the Australian PID community through education, resources, social media, communication and events.

For more information, visit www.idfa.org.au

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