

## Genetic Testing & PID

## An unusually large number of infections requiring treatment

## Infections in unusual places

A child that does not grow, or put on weight as expected

Any other unusual symptoms related to infections

used by unusual types of organisms

infections that do not respond to treatment as expected

Family history of an immune deficiency or abnormal infections



**IDFNZ**  
Immune Deficiencies Foundation  
of New Zealand

Any infection needs medical attention so please see your doctor if you or your child is unwell, has any of the above signs or if you have any other concerns with ongoing infections

## Living with Primary Immune Deficiency



Over any year a typical child with PID will miss, 70 days of school, make 30 trips to the doctor, spend 15 nights in hospital, have blood transfusions every month and annual medical costs of several thousands of dollars.

## Contact Us

### What is Primary Immunodeficiency?

The human body fights infection by means of the immune defence system. Some people are born with an immune system that is faulty. They are missing some, or all of the body's defense weapons. Such people are said to have a Primary Immunodeficiency Disorder (PID).

There are many different PID's, each has different symptoms depending on which part of the immune system is affected. Some deficiencies are deadly and some mild, but the main problem in PID is increased susceptibility to infections.

For people with PID these infections may be common, severe, lasting or hard to cure. Even healthy youngsters may get frequent colds, coughs and earaches. PID children get one infection after another and are chronically ill.

Persistent infections can in turn lead to permanent damage to ears and lungs. Other health problems may involve the heart, digestive tract or nervous system or lead to anaemia, arthritis or autoimmune diseases. Some PID's retard growth and increase the risk of cancer.

### Signs and Symptoms of PID's

PID's are not uncommon, they are sometimes mild and can occur in teenagers and adults as often as children and infants.

Very serious PID's usually become apparent just after birth, many are discovered during a baby's first year. Others, usually the milder forms may not show up until people reach their 20's or 30's. Some inherited PID's never show symptoms.

"Whenever PID is present, the most common problem is repeated infections that are often difficult to treat."

**IDFNZ is a not-for-profit Organisation dedicated to providing families with Support, Advocacy and Education on Primary Immune Deficiency Disorders.**

**Patient membership.** We offer free memberships as it is our belief the price to be eligible to join is high enough.  
**Support.** Staff keep in direct contact with members and have direct experience of PIDs and the day-to-day issues, and are able to offer practical support and understanding. We can introduce families with similar disorders and organise get-togethers bringing groups of families together. We issue a regular newsletter to all members to keep in touch and advise on any current issues affecting members. The welfare arm of IDFNZ is the Immune Deficient KIDS Foundation which offers financial support to PID children and their families.

**Advocacy.** With chronic illness, it often feels like you are battling alone to gain quality of life. When you join IDFNZ we ask that you readily use the advocacy service when accessing health care or gaining income support.

**Education.** IDFNZ is dedicated to the provision of the latest information on disorders affecting members, empowering families to make well informed life affecting decisions.

**PID Awareness.** IDFNZ is dedicated to raising awareness of PID symptoms, diagnosis and treatment. IDFNZ has access to an expert medical advisory panel, offering regular information and seminars to medical professionals and the public.

**PID Research.** IDFNZ founder members have been instrumental in establishing PID research and testing, and in enabling PID patients to have access to an expert panel of scientists specialising in the genetics of PID. This expertise is now available internationally to all members.

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Address: \_\_\_\_\_

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Country: \_\_\_\_\_

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Contact Phone Number: \_\_\_\_\_

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Email: \_\_\_\_\_

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☐ I would like to be sent a PID patient application pack.

☐ I would like to be sent a Medical Professional's information pack.

☐ I wish to support the work of IDFNZ and enclose a donation for \$ \_\_\_\_\_

Post this completed form to:  
PO BOX 75-076,

Manurewa,

Manukau 2243, Auckland