Healthcare team

Patients with PIDs are usually treated at immunology centres or clinics. Regular visits to the centre are usually required, depending on the specific PID and the treatment given. As well as the specialist doctor, several other staff members help care for people with PIDs. These include specialist nurses, physiotherapists, nutritionists or dieticians, and pharmacists.

The immunology centre will normally keep the general practitioner (family doctor) up to date about a patient's treatment. Patients or parents should make sure that other healthcare staff know about the condition — this includes surgeons, dentists, nurses and local pharmacists.

Further information and support

This booklet has been produced by the International Patient Organisation for Primary Immunodeficiencies (IPOPI). A companion booklet titled '*Primary immunodeficiencies. Stay healthy! A guide for patients and their families'* is also available. For further information, and details of PID patient organisations in 40 countries worldwide, please visit **www.ipopi.org**.

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For more information about Primary Immune Deficiency Disorders and Patient support services, please write to:

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Primary immunodeficiencies

Treatments for primary immunodeficiencies: a guide for patients and their families

IPOPI
INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES

Primary immunodeficiencies — Treatments for primary immunodeficiencies: a guide for patients and their families (1st edition), January 2012

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Other treatments that may be given include:

Granulocyte-colony stimulating factor (G-CSF): G-CSF is sometimes used to boost the production of immune system cells called 'granulocytes' in patients with certain PIDs, e.g. CGD and HIGM. G-CSF is given by SC injection.

Gamma interferon: Gamma interferon is a protein that helps immune system cells to kill invading micro-organisms. Patients with certain PIDs (particularly CGD) may be given gamma interferon to help protect against infections. Gamma interferon is given as a SC injection.

PEG adenosine deaminase (ADA): Patients with ADA-deficiency SCID, a form of severe combined immunodeficiency, lack an enzyme (a type of protein) called ADA. These patients may be given replacement therapy with PEG-ADA via an injection into the muscle.

Gene therapy: This involves correcting the faulty gene in the patient's stem cells. Currently, it has only been used to treat certain severe PIDs for which the faulty gene has been identified, e.g. SCID and CGD. This therapy is still being tested and is not routinely available.

Physiotherapy: People with PIDs sometimes receive physiotherapy to help their breathing, especially if the lungs have been damaged by chest infections.

Treatment for 'autoimmune' symptoms: PIDs can also cause the immune system to attack the body itself — this is called 'auto-immunity'. This can cause pain and swelling in the joints, known as 'arthritis'. It can also cause skin rashes, a loss of red blood cells (anaemia) or platelet cells involved in blood clotting, inflammation of blood vessels, diarrhoea and kidney disease. Patients with some PIDs are also more likely to have allergies and asthma.

Autoimmune problems (such as arthritis) are treated using various medicines that help to stop the immune cells attacking the body. Steroids (or 'corticosteroids') are used most commonly for this. As these medicines suppress the immune system they can increase the risk of infections. These medicines should be used under the guidance of a doctor who specialises in treating people with PIDs. It important to follow the instructions given with these and any other prescribed medicines.

Complementary medicine: Complementary (or 'alternative') medicines cannot replace the treatment given by the hospital or clinic. Patients or parents should speak with their healthcare team before taking any complementary medicines.