



PRIMARY IMMUNODEFICIENCIES

# A GUIDE FOR SCHOOLS



## WHAT ARE PRIMARY IMMUNODEFICIENCIES?

**This booklet explains what primary immunodeficiencies (PIDs) are and what schools need to know if they have a student who has a PID.**

PIDs are a large group of different disorders caused when some components of the immune system (mainly cells and proteins) do not work properly. It is estimated that around 1 in 2000 people are diagnosed with a PID, but some PIDs are much rarer than others. Some are relatively mild, while others are severe. PIDs are caused by hereditary or genetic defects of the immune system. PIDs are not related to AIDS ('acquired immunodeficiency syndrome'), which is caused by a viral infection (HIV).

The immune system normally helps the body fight off infections by germs (or 'micro-organisms') such as bacteria, viruses, fungi and protozoa. As their immune systems do not work properly, people with PIDs are more prone than other people to infections. These infections may be more common than is usual, they may be particularly severe or difficult to clear, or they may be caused by unusual micro-organisms. They may occur whatever the season, even in summer.

PIDs are not related to AIDS ('acquired immunodeficiency syndrome'). PIDs are not contagious — it is not possible to 'catch' a PID or to spread it to other people.

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.

Children and adolescents with PIDs should be able to enjoy lives that are as full and normal as possible. There are lots of things that schools can do to help students with PIDs to stay healthy, such as:

- Ensuring that precautions for the prevention of infections are met.
- Facilitating treatment during school time and, if necessary, training the school nurse.
- Helping to inform the family of the course of illness.
- Helping to identify and address teasing and bullying related to PIDs.

This leaflet provides general information about PID care to help schools best support students with these conditions.

## PREVENTING INFECTIONS

**Importantly, schools should help students with PIDs to maintain good hygiene where possible. This means simple things, such as:**

### HYGIENE

- Encouraging and helping all students to wash their hands regularly and carefully, especially before meals and after using the toilet and outdoor activities.
- Cleaning and dressing cuts and scrapes, with first aid provided by the school nurse where possible.
- Ensuring good food hygiene, to help avoid food poisoning.
- Ensuring safe drinking water precautions, as necessary according to local practice and doctor's advice.
- Encouraging all students to cover the mouth and nose when sneezing and coughing, to discard tissues and to wash hands afterwards.

If a student with a PID becomes unwell at school, school staff should contact the parents promptly. Students with PIDs might wear a medical information pendant/bracelet. Individualised written information should be sought from parents/carers and updated as new information becomes available.

### ACTIVITIES

Exercise is just as important for students with PIDs as for everyone else. Students with PIDs can participate in most sports, and may excel.

However, depending on the individual student and the type of PID, it may be necessary to tailor a programme of sports or physical education specifically to their needs. For example, swimming may be inadvisable because of the risk of ear infections. If swimming is possible, rubber socks may be advisable to avoid verrucae.

### ANTIBIOTICS AND VACCINES

Students with PIDs often need to take antibiotics to treat or prevent infections, often for long periods. Doses may need to be given during school time and this should be facilitated.

Some vaccines (called 'live-attenuated' vaccines) can cause infections in people with PIDs. Students with PIDs must not receive any vaccination without the permission of their parents or carers.

School staff should also tell the student's parents if:

- Vaccination programmes are undertaken at the school.
- There are any outbreaks of infections (such as measles, influenza, chickenpox, meningitis, food poisoning).

## TREATMENTS FOR PIDS

### IMMUNOGLOBULIN REPLACEMENT THERAPY

Most people with PIDs receive immunoglobulin replacement therapy. Immunoglobulins are proteins that protect against infections and reduce other symptoms of PIDs. Immunoglobulin replacement is given as an infusion (or 'drip') either into a vein or under the skin. It must be given regularly (at least once a month and sometimes weekly) and treatment is usually life-long. Immunoglobulin is often given at the hospital or clinic, but sometimes it can be given at home by parents or patients themselves.

Students can sometimes feel unwell in the hours or days after immunoglobulin replacement therapy and this could affect their performance at school.

### OTHER PID TREATMENTS

People with PIDs are sometimes given injections of gamma interferon to boost their immune system.

Certain severe types of PID are sometimes treated with stem cell transplantation. In this procedure, immature immune cells called 'stem' cells are taken from the bone marrow or blood of a healthy donor and given to patients in order to replace the immune cells that are missing.

### OTHER COMMON TREATMENTS

Students with PIDs may require various other types of medicines, including treatments for asthma and allergies. It is important that anyone with asthma keeps their medication to relieve sudden attacks (usually an inhaler) close to hand.

Most people with PIDs do not need a special diet or supplements such as extra vitamins. Schools should ensure that food allergies among students with PIDs are documented.

## EDUCATION

**Having a PID should not prevent students from doing well at school and gaining a normal education. PIDs do present certain challenges, however, and schools can play a crucial role in helping to reduce their impact on a student's education.**

Students with PIDs will sometimes need to miss school lessons in order to visit the hospital or clinic for scheduled tests or treatments. They are also more likely than other students to miss lessons because of illnesses, such as infections. Schools can help by understanding the need for these occasional absences and by helping students to catch up, for example by:

- Providing homework plans or lesson notes.
- Rescheduling tests or assignment deadlines.
- Considering whether a reduction in the course load is possible and appropriate.
- Helping to arrange home tutoring where necessary.
- Taking advantage of technological aids such as video-conferencing to allow students with PIDs to participate in lessons from home.

PID or its treatments may affect a student's performance and attention during classes. As a result of this, students may occasionally need additional help from teachers.

Regular communication between schools and parents is vital, to help best understand and address a student's needs.



There is no reason why children with PIDs should not be able to participate in educational trips and other such activities. Schools should consult with parents so that the needs of the individual student are met.

## RELATIONSHIPS WITH OTHER CHILDREN

**Although this is not always the case, PIDs can make it harder for students to build friendships at school. This is particularly likely if the student has frequent or prolonged absences or if he or she is unable to fully participate in school activities, including playtime or recess activities. Students with PIDs are sometimes marginalised and even bullied because of their condition.**

Schools can help by:

- Helping to ensure that students with PIDs participate in as many activities as possible.
- Watching for signs that a student with a PID is having difficulties in forming relationships, or is being marginalised or bullied, or is suffering from stress or depression because of their illness.
- Discussing any problems and solutions with parents and carers.

School staff can also play a role in helping to remove the possible stigma associated with having a PID, such as in correcting any mistaken link between PIDs and HIV/AIDs. However, in order to protect the privacy of the student with a PID, school staff should consult the student and the parents about how much other students should be told about their own condition.

## WHAT DO SCHOOLS NEED TO DO?

**Students with PIDs vary in their need for support, and each student's needs change over time. All school staff should be aware of the individualised needs of a student with a PID. It is important for school staff to communicate regularly with the parents and carers, if necessary in collaboration with health professionals.**

Recommended steps include:

- Initial briefing to explain the student's needs and to agree how these can be met.
- Healthcare plan, including what to do and whom to contact if a student is unwell.
- Education plan, to minimise the impact of PID on the student's education.
- Regular liaison to update everyone, as necessary.

## FURTHER INFORMATION AND SUPPORT

This booklet has been produced by the International Patient Organisation for Primary Immunodeficiencies (IPOPI). Two companion booklets titled '*Primary immunodeficiencies — Treatments for primary immunodeficiencies: a guide for patients and their families*' and '*Primary immunodeficiencies. Stay healthy! A guide for patients and their families*' are also available.

For further information, and details of PID patient organisations in 61 countries worldwide, please visit [www.ipopi.org](http://www.ipopi.org).

Provided by



Supporting families affected by primary and secondary immunodeficiency

**Immunodeficiency UK is a national organisation supporting individuals and families affected by primary and secondary immunodeficiency.**

We are the UK national member of IPOPI, an association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for PID patients worldwide.

Our website has useful information on a range of conditions and topics, and explains the work we do to ensure the voice of patients with primary and secondary immunodeficiency is heard. If we can be of any help, please email us or call on the number above, where you can leave a message.

Support us by becoming a member of Immunodeficiency UK. It's free and easy to do via our website. Members get monthly bulletins.

Immunodeficiency UK is reliant on voluntary donations. To make a donation, please go to [www.immunodeficiencyuk.org/donate](http://www.immunodeficiencyuk.org/donate)

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