## **Primary immunodeficiencies**

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## 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 40 countries worldwide, please visit **www.ipopi.org**.

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# Immune Deficiencies Foundation of New Zealand

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

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Or visit our website: www.idfnz.org.nz

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# A guide for schools





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### 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.