

Family & School Guidelines

Good communication between school staff, parents and students diagnosed with primary immunodeficiency diseases is of utmost importance to ensure a healthy and comfortable environment for children and students with PID. The following guidelines serve to help parents as they communicate with schools about PID. It also provides guidance for teachers and school nurses to help them better understand and respond to student's needs. Ideas for awareness raising events in schools are also shared.

I How parents can prepare a child's school?

Parents are encouraged to provide schools with an information pack to explain the child/student's condition. It is important to communicate with the school before the school year begins and maintain regular communication throughout the year. In some cases, it may be helpful for school staff to speak directly with the student's doctor, provided consent has been obtained from the student's parent or guardian. Parents are urged to co-operate by giving consent to enable this to happen.

Here's How:

- Provide a simple overview of the necessary information for school World PI Week Website. Personalize these suggestions for the child's strengths and needs, and write them in a note to the teacher.
- Print out the required material on good quality white paper so they are easy to read.
- Make a final draft of your note to the teacher. It should be no more than a page long, whether handwritten or typed. Start with a positive sentence about how much you look forward to working with the teacher this year; mention the specific things the teacher needs to know; mention that you will be attaching more information; and end by giving your phone number and e-mail address and indicating your eagerness to meet and discuss the material. Send a copy of this correspondence to the headmaster/mistress and school nurse.
- Follow up. If you don't hear anything from the teacher, check back in a few days with a note or a phone call to make sure the teacher received the material and is reviewing it, and to repeat your offer to meet and discuss it further.

Tips:

1. Letters and attachments should be easy to read in a package that looks manageable.
2. Focus on the ways to respond to your child's special needs and how this will make things easier for the teacher, rather than insisting on rights and obligations.
3. Keep your tone friendly, helpful and no-nonsense -- one professional to another. You are writing as an expert on your child's diagnosis, not as a pleading or pushy parent.
4. Make a copy of all correspondence for your records. Using a datebook/diary to record when and what you sent to the teacher, and what follow-up you made.

We would like to thank World PI Week for the use of their materials in compiling these guidelines.



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II What can Teachers do?

- Learn about the student's primary immunodeficiency disease, provide support to the student
- Provide appropriate classroom accommodations/modifications for the student. For instance if the child is having homecare child, access to a separate room or nursing station might be needed.
- Provide information for substitute teachers.
- Treat the student the same as other students.
- Respect each student's confidentiality and right to privacy.

III What can School Nurses do?

- Learn about the student's primary immunodeficiency disease.
- Obtain and review the student's healthcare information from the healthcare provider and family.
- Obtain necessary medication and supplies from the parents, if needed.
- Provide education and act as a resource to school personnel.
- Notify the parents promptly if there is an outbreak of a contagious illness in the child's classroom or school.
- Obtain parental permission to act as the liaison between the school and the student's healthcare provider.

IV Awareness Raising Ideas for Parents and Teachers

- Distribute illustrative children's books in class on PID to educate fellow students and promote healthy habits.
- Teachers can play interactive games, quizzes on PID and use posters/books to illustrate the role of the immune system.
- Teachers can to include a lesson on PID in science class or during World PI Week.
- Organize a fundraiser and/or sports activity to raise awareness of PID.
- Distribute posters and leaflets on PID Awareness and post on notice boards.

V Tools

Below is a list of the types of documents and guidance that you can find on the IPOPI and World PI Week Website to help you maximize your activities in your schools and communities:

- IPOPI PID Leaflet
- JMF Activities/Quizzes/Books
- JMF How to support students with PID
- IPOPI living with PID
- IDF school guide - available at: www.primaryimmune.org

You should also check with your NMO website for additional information or tools.