

Family Carers Toolkit



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I. Why World Primary Immunodeficiencies (PI) Week?

World PI Week's overarching mission is to raise awareness of the importance of primary immunodeficiency (PI) diseases globally and stimulate efforts to improve the recognition, diagnosis, treatment and the quality of life for people with PI world-wide.

The first World PI Week will be celebrated on **22-29 April 2011** and will focus on **increasing the understanding of these diseases and promoting optimal diagnosis.**

World PI Week offers a crucial, visible opportunity to inform and educate health policy-makers, schools and families, and the general public about primary immunodeficiencies (PI) to drive the earliest possible diagnosis and optimal treatment. Through events and activities promoting the **warning signs of PI**, seminars, public lectures, video-diaries, and press conferences, the global PI community can unite to bring about positive changes in healthcare systems and practices around the world in support of people living with PI.

For more detailed information about PI Week please visit the website: www.worldpiweek.org

II. How to prepare your child's school ?

Communication between school personnel, parents and students diagnosed with primary immunodeficiency diseases is of the utmost importance. It is essential for family members or school staff to initiate a meeting before the school year begins and maintain regular communication throughout the year. In some cases, it may be helpful for school personnel to speak directly with the student's healthcare provider for additional information, provided consent has been obtained from the student's parent or guardian.

In order to better inform and prepare your child's teachers and school, you can put together an information packet to help them provide a healthy and comfortable environment for your child.

Here's How:

1. Provide a **simple overview of the necessary information** for school staff from the World PI Week Website (ie. PI leaflet, posters, JMF 10 warning signs for PI, JMF Immune System Poster). Personalize these suggestions for your own child's strengths and needs, and write them in a note to the teacher.
2. **Print out the information you've chosen.** Print them on a good quality white paper so they're easy to handle and read.
3. **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're looking forward to working with the teacher this year; mention the specific things the teacher needs to; mention that you will be attaching more information; and end by giving your phone number and e-mail address and indicating your eagerness to discuss the material.
4. **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 discuss it further.

Tips:

1. Remember, the start of year school is a hectic time for teachers. Even with the best intentions, they may not want to spend their free time reading reams of material. If you can put together a package that looks manageable and well-thought-out, you'll move to the front of the class.
2. In your note, focus on the ways that using techniques appropriate to your child's special needs 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 in your particular child and his or her diagnosis, not as a pleading or pushy parent.
4. Make a copy of all correspondence for your records. Using a datebook/diary or a contact log, jot down when and what you sent to the teacher, and what follow-up you made.

III. Ideas for Events

- Distribute illustrative children's books in class on PI to educate fellow students and promote healthy habits to provide a health classroom
- Encourage teachers/schools to play interactive games, quizzes on PI and use coloring books during World PI Week to illustrate the role of the immune system
- Request teachers to incorporate a lesson on PI in science class during PI week
- Organize a fundraiser and/or sports activity to raise awareness of PI
- Distribute posters and leaflets on PI Awareness

IV. World PI Week Tools

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

- **PI Leaflet:** *provides information on PI, what it is, how to treat it, how to live with it*
- **Activities/Quizzes/Books:** *Interactive games, books and quizzes for students to learn about PI*
- **Campaign ideas:** *Message boards with events from around the globe to inspire*
- **JMF 10 Warning Signs of PI for children**
- **JMF Immune System poster:** *To prepare schools, teachers, nurses and parents for students living with PI*

V. World PI Week – Central Committee Contact Details

For further support with regards your participation in World PI Week , please feel free to contact us!

Julie Cooper,
Project Director, World PI Week
Greencoat House
Francis Street
London, SW1P 1DH, United Kingdom
+44 (0) 207 630 0341
+44 (0) 754 5209 874
info@worldpiweek.org