Patient FAQs & Resources

CME Outfitters

Primary Immunodeficiency (PI)

FAQs

Q: What are primary immunodeficiency disorders (PI)?
A: PIs are a group of more than 400 distinct disorders caused by defects of the immune system. As the main function of the immune system is to fight infection, patients with PI have an increased susceptibility to infections. PIs are often attributable to genetic mutations and can affect anyone regardless of age or gender.

Q: What are the symptoms of PI?
A: The most common presentation of PI is an increased number of infections frequently of the sinuses and or lungs that are difficult to treat or are unusually severe. Infection severity can range from mild to more serious infections. In the case of mild disease, it can take a pattern of recurrent infections before PI is suspected. Serious PIs on the other hand are often apparent in infancy. Public health efforts such as newborn screening play an important role in the early identification of infants with PIs.

Q: How is PI diagnosed?
A: When PI is suspected, medical and family history of illnesses, physical exam, blood and skin tests, serum immunoglobulins and antibody measurements following vaccine challenges, can aid in the diagnosis process.

Q: How is PI treated?
A: The cornerstone of PI treatment is immunoglobulin replacement therapy that is either injected into a vein through an intravenous (IV) line or inserted under the skin as a subcutaneous infusion. Treatment aims to prevent severe infection and associated long-term chronic damage, as well as improve quality of life.

QUESTIONS TO ASK YOUR HEALTHCARE PROVIDER

Screening/Diagnosis
What else could cause these symptoms?
How can I keep myself/my child from getting sick?

Living with PI
Is there a special diet I should follow?
Should I modify my diet during an infection?
What steps can I take to prevent infection?
Should I/my child avoid sports?
Are there any other general health measures that could help?

Treatments
Can you provide me with written instructions concerning medicines/treatment?
What reactions should I expect from the treatment?
Should my child get all the usual vaccines?
What if I choose one type of immunoglobulin replacement therapy and I am not satisfied?
Which immunoglobulin product is more effective?
Can I travel if I am receiving immunoglobulin replacement therapy?
What is the difference between the manufacturer and the specialty pharmacy?
Why can't I get my immunoglobulin at the local pharmacy?
Can I stop the immunoglobulin replacement therapy?

FOR MORE INFORMATION VISIT:
https://primaryimmune.org/sites/default/files/publications/IDF%20Guide%20to%20Ig%20Therapy.pdf

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