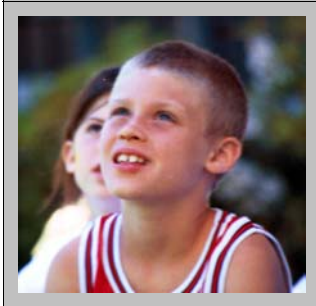


PI = Primary Immunodeficiency



PI is a set of more than 70 hereditary disorders caused by a defect in one or more genes responsible for the development of

key components of the human immune system.

PI afflicts 500,000 Americans, one in every 500, mostly children. It affects more children than childhood leukemia and lymphoma combined. Because the condition does not have unique symptoms, no one is sure how many cases go undiagnosed for long periods of time, but it is estimated that there are more than another 500,000 undiagnosed. PI presents itself in the symptoms of "ordinary" childhood illnesses, such as sinus and ear infections, pneumonia and high fevers. The condition can be overlooked or misdiagnosed as an allergy or common infection found among newborns such as asthma or bronchitis. Often, physicians treat each ailment without addressing the underlying cause.

PI, when not addressed immediately, can leave a patient vulnerable to prolonged illness, permanent organ damage, and in more severe cases, death.

The diseases range in severity from chronic sinusitis to SCIDS, the so called "Bubble Boy Disease".

Most forms of PI can be diagnosed through a series of simple blood screenings that test immune function. Once diagnosed, physicians have a number of treatments at their disposal, from low-level doses of antibiotics to gammaglobulin infusions and new treatments including bone marrow transplants and gene therapy. Each treatment varies in effectiveness and is prescribed based on the form and severity of the affliction.

PI is NOT AIDS. While both involve the immune system, primary immunodeficiency occurs as a result of a genetic flaw while AIDS is acquired. AIDS is one form of immunodeficiency, while primary immunodeficiency is known to encompass more than 70 forms and never is acquired. The treatments are drastically different.

Parents who suspect their child may have PI, can call the 24-hour hotline at 1-800-JEFF-844 for information and referrals.



4 Vital Facts about PI

- 1) There are over 70 forms of PI, ranging widely in severity. Together, they affect more people than leukemia and lymphoma combined.
- 2) PI often presents itself in the form of "ordinary" infections. Physicians can treat the infections while missing the underlying cause, allowing the illnesses to recur, and leaving the patient vulnerable to permanent damage to vital organs, physical disability ... and even death.
- 3) Families struggling with immunodeficiency often face misunderstandings and discrimination born of ignorance. Schoolmates, teachers, neighbors, employers, and insurers just don't understand. They think it's "all in the mind"... or confuse the condition with AIDS. The social, emotional, and financial burdens can be overwhelming.
- 4) The problems presented by PI have challenged researchers and immunologists to reach improved diagnoses, treatments, and new therapies. Promising results are being reported for PI patients using intravenous gamma globulin, bone marrow transplantation, enzyme replacement and genetically engineered proteins such as gamma interferon. The research and new therapies in this area of immunology are yielding benefits for victims of cancer, AIDS, asthma, autoimmunity and a wide range of pulmonary and allergic conditions.

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Ten Warning Signs for PI

PI causes children and adults to have infections that come back frequently or are unusually hard to cure. In America alone, up to 1/2 million people suffer from one or more of the 70 known forms of PI. If you or your child are affected by more than one of the following conditions, speak to your doctor about the possible presence of PI.

- 1) Eight or more new ear infections within one year.
- 2) Two or more serious sinus infections within 1 year
- 3) Two or more months on antibiotics with little effect
- 4) Two or more pneumonias within one year
- 5) Failure of an infant to gain weight or grow normally
- 6) Recurrent, deep skin or organ abscesses
- 7) Persistent thrush in mouth or elsewhere on skin, after age 1
- 8) Need for intravenous antibiotics to clear infections
- 9) Two or more deep-seated infections such as meningitis, osteomyelitis, cellulitis, or sepsis.
- 10) A family history of PI.

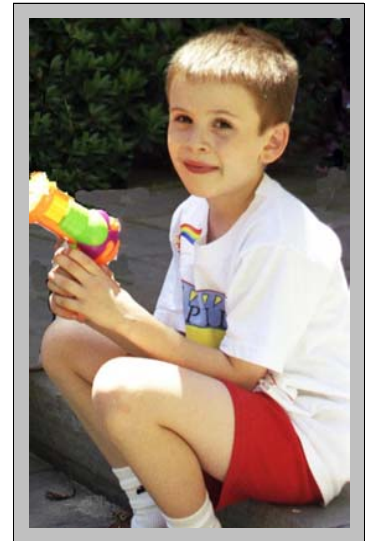
Contributions to support research into PI are tax deductible. Checks payable to NEPIN can be mailed to the address

NEPIN
P. O. Box 692
Atkinson, NH 03811-0692
www.nepin.org

New England Primary Immunodeficiency Network

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What is PI?



Children with PI have suppressed immune systems from birth, but may not be properly diagnosed until their teens or later.

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