

MyGuide to:

PI Basics

Whether you've just been diagnosed, or you've been living with primary immunodeficiency (PI) for years, we created this quick guide to help you better understand the basics of PI.

PI is

- A term that covers more than 400 different deficiencies; we call this an “umbrella term”
- When some part or all of the immune system is missing or not working correctly
- Usually genetic or inherited

What kind of infections do people get if they have PI?

- **S**evere
- **P**ersistent
- **U**nusual
- **R**ecurrent
- **R**un in the family

PI isn't

- A single condition
- Contagious
- A secondary immune deficiency caused by:
 - Another disease, such as cancer
 - Medications, such as chemotherapy or steroids
 - Infections, such as human immunodeficiency virus (HIV)
- An autoimmune disease, such as Crohn's or multiple sclerosis



On average, it can take 15 years to diagnose PI.

PI is often considered a rare condition. However, with diagnoses on the rise, PI is not as rare as was once believed. So, even though infections are common, their underlying cause may be rare and, therefore, difficult to find.



Why have most people never heard of PI?

PI was first described in medical literature in 1952. For comparison, the earliest description of cancer dates back to 3000 BC!



How many people have PI?

It's estimated that:

- In the U.S., there are 250,000 people currently diagnosed with PI
- An additional 500,000 may have PI but remain undiagnosed
- Six million people worldwide may have PI



PI & genetics—what we know:

- Genes are responsible for some types of PI
- Some people are born with it
- Some people develop it later in life
- It runs in families
- Both males and females get it



My PI Team

Life with PI often brings a whole new set of people and programs to manage as part of your care team. It may feel a little overwhelming at first, but you'll get the hang of it. To make things easier, we provided space below for you to write the names and contact information for your very own PI team. Fill it out, laminate it, and put it in a safe place where you can reference it quickly and easily whenever you need it.

My Primary Care Doctor

Name: _____
 Phone: _____
 Email: _____

My PI Doctor

Name: _____
 Phone: _____
 Email: _____

My Medication

The company that makes my medicine:

 Brand Name: _____
 Dose: _____
 Rate: _____
 Frequency: _____

Co-Pay Assistance Program

Name: _____
 Phone: _____

Resources

MylgSource:
MylgSource.com

Immune Deficiency Foundation:
primaryimmune.org

Jeffrey Modell Foundation:
info4pi.org

Infusion Clinic / Specialty Pharmacy

Name: _____
 Phone: _____
 Name: _____
 Phone: _____

24-Hr Pharmacy

Name: _____
 Phone: _____
 Address: _____

Regular Pharmacy

Name: _____
 Phone: _____
 Address: _____

My Insurance

Name: _____
 Phone: _____

MylgSource

My Advocate is:

 Phone: 855-250-5111

MyGuide to PI Basics is part of an educational series from MylgSource. If you'd like more information, please visit MylgSource.com or contact a Patient Advocate at 855-250-5111.

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