

Immune Deficiency Foundation

Patient & Family Handbook

For Primary Immunodeficiency Diseases

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Chapter 41

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6th Edition

The development of this publication was
supported by Shire, now Takeda.



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Chapter 41

Health Insurance

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Treatment of primary immunodeficiency diseases (PI) has evolved over the years, and there are effective, lifesaving treatments available to those diagnosed with these rare, chronic disorders. However, these treatments often come at a significant financial burden to the individual with PI and their families. The majority of people with PI rely on some form of insurance to assist with expenses, but dealing with health insurance and understanding the maze of issues involved can be overwhelming.

Often health insurers require additional paperwork to justify the use of the therapy prescribed. Added red tape and follow-up phone calls can be frustrating. Even individuals who have adequate insurance coverage often face expensive insurance premiums or high co-payments or coinsurance. Many people living with PI may be confused about their insurance options. Others simply lack affordable health insurance. Medicare beneficiaries have additional questions to consider.

IDF Patient Insurance Center

The Immune Deficiency Foundation understands these challenges and maintains the IDF Patient Insurance Center: www.primaryimmune.org/insurance. While not designed to solve each and every problem, the information provided there will help prepare you to be your own best advocate. Regardless of how you and your family obtain your health insurance, it is ultimately your responsibility to understand your plan. It is up to you to choose the plan that is right for you and your family's healthcare needs.

Individuals living with PI need to make educated decisions about their coverage options. Do a thorough plan comparison to determine what plan best fits your needs. Things to look at include:

- What is my premium?
- What is my out-of-pocket maximum?
- What are my deductibles?
- Is deductible included in the out-of-pocket maximum or is it in addition to the maximum?


- How is immunoglobulin (Ig) replacement therapy covered?
- Do I have a coinsurance or a flat co-pay?
- Do I have options for site of care?
- Are my doctors in the plan's network?
- Are there out-of-network benefits?

These are basic things to consider. More information is available in the IDF Patient Insurance Center.

You may need to contact the insurance carrier or get assistance from your benefits or human resources department in obtaining the answers to these questions. Once you have these questions answered, you can make an informed choice.

Understanding your plan can have a huge impact on both your health and your finances. When it comes to your healthcare insurance coverage, never hesitate to ask questions and search for as many resources as possible.

Visit the IDF Patient Insurance Center: www.primaryimmune.org/insurance.



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