

# Assistance Programs for PI: Help Is on the Way

By Heather Bremner Claverie



A **NEW** diagnosis is daunting for patients first learning they have a chronic disorder. From reviewing treatment options and infusion settings to understanding symptoms and side effects, navigating diseases like primary immunodeficiency (PI) that require immune globulin (IG) therapy can be scary and stressful for patients and their family members. Not only does researching the disease and its treatment options seem all-consuming, but sorting through health insurance and prescription drug coverage can be even more challenging. PI patients need help understanding their disease, paying for treatment and connecting with people suffering from the same condition, but they also need to know where to find it.

## Understanding a Lifelong Illness

PIs are a group of more than 450 rare, chronic disorders that occur when the body's immune system is impaired. PI patients are more vulnerable to infection and can face frequent health problems or develop serious and debilitating illnesses.

Not long ago, the wait for a PI diagnosis was often long, and once patients received the news, it “translated to an extremely compromised life for patients and their families,” according to the

Immune Deficiency Foundation (IDF). Unfortunately, the average length between the onset of symptoms and a diagnosis is still between nine and 15 years, says IDF — a long time for patients struggling to understand their condition, finance their healthcare and network with other people in a similar boat. But thankfully, IDF and organizations like them offer many support services and free resources to help patients find their footing.

## Costly Treatments

Pricey is an understatement when it comes to IG therapy. Whether treatments are administered in an infusion center, hospital setting or at home, even PI patients with excellent insurance coverage may end up facing costly co-pays and overwhelming medical bills.

Finding out which treatments patients' insurance covers, where treatments can be administered, if they will be administered intravenously or subcutaneously and how providers code the treatments for billing are just some of the questions new PI patients struggle to answer. Plus, since most PIs are lifelong illnesses, patients need to know whether their insurance benefits carry a lifetime maximum: If they do, then insurance will no longer cover treatments or medical care once it is reached.

Simply figuring out which questions to ask is a lot to handle, let alone dealing with the financial drain. Thankfully, patient advocacy groups, nonprofits and various drug manufacturers are working to help ease the financial burden. In fact, most IG manufacturers will assist uninsured patients who meet specific income level thresholds. Patients can contact the manufacturer of their IG

product to locate co-pay assistance.

In addition, organizations such as the National Organization for Rare Disorders (NORD) offer access to a network of assistance programs to “help patients obtain lifesaving or life-sustaining medication they could not otherwise afford.” In addition, the NORD programs offered through RareCare provide patients with a variety of services and products such as medication, financial assistance for insurance premiums and co-pays, diagnostic testing assistance, travel assistance for clinical trials and consultations with disease specialists.

## A Web of Kindred Spirits

Some patients will also need peer support. Patients often feel lonely and unsure about what the future holds. They typically have questions about the everyday effects of living with PI or where to find local resources, or they may just want to talk to someone who understands how they're feeling. Programs like IDF Peer Support give patients access to a caring community of people with similar experiences who can answer their questions or point them to a resource that can.

## Where to Get Help

Whether looking for financial support, a human connection or simply a trove of information, there *is* a network of support out there. While the journey of every PI patient may not be mapped out upon diagnosis, these organizations are ready to help them find their way.

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### *An Empowered Treatment Plan*



Looking for a network of like-minded patients? Want to keep up with public policies on primary

immunodeficiency disorders (PIs)? The Immune Deficiency Foundation offers a network of valuable resources for patients and families living with PI. The nonprofit gives patients access to a broad community and offers a variety of educational resources to help with navigating treatment options and care.

[www.primaryimmune.org](http://www.primaryimmune.org)

### *Lend Them Your Voice*

The National Infusion Center Association (NICA) makes



sure PI patients are heard by providing a portal filled with educational resources, patient stories, current initiatives, social media updates and advocacy archives. Sign up for any of the services or simply peruse its website to access a treasure trove of information on infusions.

[www.infusioncenter.org](http://www.infusioncenter.org)

# Shopping Guide for Assistance Programs



### *Assistance for the Rare Instances*

With more than 300 patient organization members, the National Organization for Rare Disorders (NORD) is committed to the identification, treatment and cure of rare disorders through various programs. One of those is RareCare, a network of assistance programs that NORD offers to help patients obtain lifesaving or life-sustaining medication they could not otherwise afford.

[www.rarediseases.org/for-patients-and-families/help-access-medications/patient-assistance-programs-2/#section-1](http://www.rarediseases.org/for-patients-and-families/help-access-medications/patient-assistance-programs-2/#section-1)

### *Journey with Jeffrey Modell*

Looking for a list of resources for all your PI needs? The Jeffrey Modell Foundation houses all the relevant resources on its site. Scroll through the three tabs, connect with the PI community, find an immunologist or read up on the latest news in this area, all on this super-organized site.

[www.info4pi.org](http://www.info4pi.org)



## *my Ig source*

### *A Community of Assistance*

MyIgSource is a community committed to helping patients and their loved ones manage a life with primary immunodeficiency (PI). The site provides information on PI and has links to help individuals connect through its Ig Community Support Team Advocates.

[www.myigsource.com](http://www.myigsource.com)

### *Cover Those Co-Pays*

Many immune globulin (IG) manufacturers provide co-pay assistance to help offset the high cost of IG therapy medications. Eligible insured patients can receive up to a certain dollar amount each year depending on their IG brand. [panzyga.pfizerpro.com/support/co-pay-program-for-patients](http://panzyga.pfizerpro.com/support/co-pay-program-for-patients); [www.xembify.com/en/xembify-connexions](http://www.xembify.com/en/xembify-connexions); [www.gammagard.com/primary-immunodeficiency/onepath](http://www.gammagard.com/primary-immunodeficiency/onepath); [www.bizentra.com/copay-assistance](http://www.bizentra.com/copay-assistance); [www.gamunex-c.com/en/hcp/cidp/gamunex-support-program](http://www.gamunex-c.com/en/hcp/cidp/gamunex-support-program)