

# my PI umbrella

An insurance-focused  
publication for people living with  
primary immunodeficiency

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# my PI umbrella

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### Across

2. Interchangeable  
6. Respiratory  
8. Diagnosis

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1. Morbidity  
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4. Adverse  
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## Welcome to

# My PI Umbrella!

## Empowered. Supported. Understood.

These were the words that came to mind as we set out to create *My PI Umbrella*, an insurance-focused publication for people with primary immunodeficiency (PI). As you read through the pages of our inaugural issue, you'll see that it is full of all things PI—expert advice, tips, and insurance-focused information, as well as some fun games and PI community updates.

As we wrap up this issue, we already have an eye to the future...and we want to hear from you! Your feedback, topic ideas, questions, and photos are what make *My PI Umbrella* great—so keep 'em coming! You can contact us by mail or fax us at the number below.

Helen Keller once said, "Walking with a friend in the dark is better than walking alone in the light." As members of the PI community, we know this to be so true. And we look forward to walking with you. Thank you for joining us under the "Umbrella"!

*Baxter's IgG Patient Team.*

The Baxter IgG  
Patient Team

## Contact us!

**Mailing address:** My PI Umbrella,  
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**Fax:** 1-877-556-2341

## Connection Corner

To subscribe to My PI Umbrella, visit  
[www.mygardian.com](http://www.mygardian.com)

**Make sure to fill out the enclosed  
card to get registered so that you  
don't miss an issue!**

# Health Insurance

## Basics

Health insurance coverage may be a confusing and complex topic, but understanding the basic structure of your insurance policy will make you a better advocate for your own health and well-being. Health insurance is typically available through commercial health plans or government-sponsored programs.

### Commercial Health Insurance

Commercial plans, such as those offered through employers or purchased individually, can be divided into two general types: indemnity or managed care plans. About 30 to 40 years ago, most Americans had indemnity, or fee-for-service, plans that paid a fee to doctors and hospitals for each service covered under the plan's benefits for insured patients.<sup>1</sup>

Most Americans today are enrolled in managed care plans, such as health maintenance organizations (HMOs), preferred provider organizations (PPOs), or point-of-service (POS) plans. All three types have contracts with doctors, hospitals, and other clinicians and have agreed on certain fees with these providers. As long as you receive care from a provider approved by the plan, you typically will be responsible only for any cost-sharing your plan requires. Individual plans vary in what is covered, the extent to which services are covered, and the approval requirements for services or specialists, so read the policy carefully.<sup>1</sup>

### Health Maintenance Organizations

Under an HMO, patients receive care from one primary care physician who should be aware of their total health picture. Medical care is received from network providers, except in emergencies, and people insured through an HMO typically make flat co-payments rather than deductibles or co-insurance. When necessary, a primary care physician will provide a referral to a specialist in the plan. Hospitalization must be approved (or pre-certified) prior to admission, unless it is an emergency.<sup>1</sup>

### Preferred Provider Organizations

Preferred provider organizations (PPOs) are networks of physicians, medical offices, and hospitals that work with a certain insurance company. Members of the network provide care to insured patients at a rate negotiated by the insurance company. To receive coverage in a PPO plan, primary and specialty care physicians must belong to the network. If you choose a physician or hospital not in the PPO network, you will be responsible for some or all of the cost.<sup>1</sup>

### Point-of-Service Plans

Also called "open HMOs," POS plans combine elements of the PPO and HMO. People insured through POS plans typically have a primary care physician who coordinates care and provides referrals to specialists if necessary. As with PPOs, care may be obtained from physicians or hospitals not included in the plan, but at a higher cost.<sup>1</sup>

### Government Health Plans

Government healthcare plans include Medicare, Medicaid, and high-risk pools for individuals who do not qualify for Medicare and Medicaid and cannot get insurance elsewhere.





## Medicare

Medicare is a federal healthcare plan for U.S. citizens who are age 65 or older, have disabilities, or have end-stage renal disease (kidney failure). Medicare has four parts:

- Part A is hospital insurance.
- Part B provides medical insurance for doctors and related services.
- Part D covers prescription drug coverage.
- Part C, or Medicare Advantage, allows individuals to receive the benefits of Medicare A, B, and D through a private health plan, such as an HMO or PPO.<sup>1</sup>

Payroll taxes help pay for Medicare Part A, so individuals do not pay a premium for hospitalization coverage. A monthly premium is assessed for Medicare Part B and Part D. Many individuals with Medicare also carry a secondary insurance policy, or supplemental insurance, through a Medigap policy offered through the Medicare program.<sup>1</sup>

## Medicaid

Medicaid is health insurance for people with low incomes or who are disabled and do not qualify for Medicare. Medicaid is funded by federal and state governments, so strict criteria for qualification may vary from state to state.<sup>1</sup>

### Insurance support is just a phone call away!

Did you know that just one call can get you connected with a team of Baxter reimbursement specialists? They are trained to help you walk through the insurance process for immunoglobulin (IgG) therapy, such as helping understand coverage options, managing prior authorizations, and providing the forms you need to get covered.

Give them a call today at **1-800-582-7990** to get connected!

## High-Risk Pools

In addition to Medicare and Medicaid, high-risk pools are offered by about 35 states<sup>2</sup> to help with medical insurance for people who do not have access to a group policy (such as through an employer) and are unable to purchase insurance independently because of a pre-existing condition.<sup>1</sup> These are self-funded insurance plans that generally provide a choice of health plan options and contract with a health insurance carrier to administer the paperwork and claims.

Coverage options are similar to traditional health insurance offerings, such as with a comprehensive medical plan and a range of deductible options.<sup>3</sup> A list of states with high-risk pools is available through the National Association of State Comprehensive Health Insurance Plans ([www.naschip.org](http://www.naschip.org)).<sup>2</sup>

## Ensuring Health Coverage

As a consequence of the Health Insurance Portability and Accountability Act, under certain circumstances, individual health coverage is guaranteed if you lose group coverage. This law also protects individuals with group insurance from discrimination for any medical condition and prevents providers from sharing information with employers without your approval.<sup>1</sup>

Through the Consolidated Omnibus Budget Reconciliation Act (COBRA), employers may offer group health insurance to employees and their families after certain events, such as job loss. In these circumstances, the former employee can continue the same insurance coverage at a group rate for between 18 to 36 months.

**References:** (1) *Questions and Answers About Health Insurance*, Agency for Healthcare Research and Quality, Editor. 2007: Rockville, MD. (2) *States that have risk pools*. 2011 [cited 2011 May 5]; Available from [http://www.naschip.org/states\\_pools.htm](http://www.naschip.org/states_pools.htm). (3) *Consumer Guide to High-Risk Health Insurance Pools*. 2011 [cited 2011 May 6]; Available from [www.nahu.org/consumer/HRPGuide.cfm](http://www.nahu.org/consumer/HRPGuide.cfm).

# Under the Umbrella

## letter to the editor

DEAR MY PI UMBRELLA :

I JUST GOT DIAGNOSED WITH PI. WHAT SUGGESTIONS DO YOU HAVE FOR TALKING WITH FAMILY AND FRIENDS ABOUT MY DISEASE?

PAUL  
PHOENIX, AZ

Hi Paul,

We caught up with Laura Guenther, a licensed Clinical Social Worker (and PI patient) who specializes in dealing with chronic illness, to learn some tips:

- **Have a plan**

Think ahead of time about what you want to say and what your goals are for the overall conversation. Do you want to educate them? Or ask for their support?

- **Keep it simple**

Don't go overboard with medical details. Remember—you've had time to digest the specifics of this disease, but they may be hearing about PI for the first time.

- **Be factual and direct**

When people hear that someone they care about is chronically ill, they may feel helpless. Be prepared with some ideas for ways they can help.

- **Location, location, location**

Make sure you pick a good time and place to have the conversation. Don't spring it on someone at a noisy restaurant or if they are dealing with a crisis of their own.

- **Have some face time**

In this day and age, it can be tempting to talk via email or text. But this is a conversation that you need to have face to face. Make sure to keep the dialogue open so you can talk again after they've had some time to absorb the news.

Talking to your family and friends about your PI is a great step toward managing your disease.

### BOOK REVIEW

## “As I Live and Breathe” breathes new life to the PI experience

Finding a book that is as honest about life with Congenital Immune Deficiency is about as rare as the disease itself. But to find a story that offers such a rich perspective as “As I Live and Breathe: Notes of a Patient-Doctor” is a jewel indeed.

Jamie Weisman was first a patient before she became a doctor. Diagnosed with an immune deficiency in her early 20s, she decided to tackle the rigors of medical school when her health was restored by monthly immunoglobulin replacement therapy. As she says, she knows illness “from the inside out.”

But before Weisman is a patient, doctor, mother, or child, she is surely a writer in the purest sense of the word. From grappling with misdiagnosis to the financial intricacies of our healthcare system, from facing mortality and infertility to basking in the joy of motherhood, this engaging read makes each moment so real it's as if you could bite it and feel the juice of life dripping down your chin.

### Connection Corner

#### Do you have a question?

Let one of our experts answer it! Send questions to **PO BOX 3304, Chicago, IL 60654** or fax to **1-877-556-2341**

# How to Keep Good Health Records

If you're having trouble tracking your insurance claims, appointment schedules, and medical expenses, it's time to get organized. Here are five tips to help maintain control of your medical information.

## 1 Put everything in one place:

Organize your information in a large binder or a Wellness Organizer, available for free to all patients regardless of brand used, through [www.myguardian.com](http://www.myguardian.com). Include contact numbers and addresses for your doctors, pharmacy, and insurance company; infusion records; and copies of legal documents, such as consents, durable power of attorney, or living will.

## 2 Keep a diary:

Keep a record of all phone calls to the insurance company in one section of the binder and doctors' offices in another. Write down who you spoke with, what was said, what decisions were made, and what follow-up is necessary. Ask for any promises to be sent to you in writing.

## 3 Track expenses:

Store your financial records in the binder, too, especially if you deduct medical expenses from your taxes or use a Medical Spending Account.

## 4 Ask for your medical records:

Visit medical records offices to get copies of reports, transcripts, and other important documents in your file. You'll need to show identification, sign a release, and pay a fee, but the effort and expense are worth it, particularly if you switch doctors or visit a specialist in a separate medical practice.

## 5 Make everything portable:

You might have to take your records with you on a medical visit, so use a briefcase, backpack, or small rolling suitcase to make them easy to transport.

"It doesn't take the disease away, but at least the Wellness Kit helps me manage it on a day-to-day basis. That, in itself, is such a relief."

*Christine,  
a patient with PI*



# All for One, One for All— the 2011 Wellness Kit

Overwhelmed. That's how patients with PI often feel. Overwhelmed with information, with paperwork, and with life in general.

Wouldn't it be nice if there were something out there to help organize it all?!? Now there is! Meet the 2011 Wellness Kit!

"Someone is finally listening to us..."

*William,  
a patient with PI*

## An idea comes to life

A few years ago, Baxter recognized the need for a tool to help patients with PI feel more in control of their disease. They needed something to help patients, caregivers, and healthcare professionals have accurate and relevant communication about the daily life of the PI patient.

So they gathered up all the resources that they had available at the time and took them to the experts—real PI patients—and asked them to design the "perfect organizational tool."

The result...the Wellness Kit.

## 2011 Wellness Kit highlights

Now in its third year, the Wellness Kit is better than ever. Developed specifically for adult and young adult PI patients as well as caregivers of children with PI, the new Wellness Kit is a way to conveniently record, organize, and manage all of the important information that goes with living with PI. Here are a few highlights:

### Wellness Tracker

- 2011 Calendar—so much more than a calendar! Track your general wellness and specific symptoms, with room to write in your daily activities and appointments. And that's not all. Now within the calendar pages are inspirational stories from PI patients just like you—because we all need a little boost now and then.

- Infusion Log—keeping logs of the immunoglobulin treatments you receive can help you and your treatment team. This log tracks brand, lot numbers, amount, and frequency so you can maintain a consistent infusion schedule.
- Medical Information—as an adult patient, this information can speak for you in the event you can't speak for yourself. For children with PI, the medical information can go with the kids to Grandma's in the event of an emergency.

### Wellness Organizer

- Organize and Strengthen—convenient folders to organize things like lab results, EOBs, and prescription information. It keeps everything you need in one easy-to-use binder!

### Suggestions?

The Wellness Kit is a patient-driven tool, and your feedback is important! Suggestions for improvement are taken very seriously. Once you've started using your Wellness Kit, we encourage you to send in your comments on the reply card included in the Wellness Kit.

### Need a Wellness Kit?

Go to [www.mygardian.com](http://www.mygardian.com) and order one!

# Knowledge Is Power: Maintaining Access to IgG Therapy

## Each Patient/Therapy Unique

Primary immunodeficiency occurs when defects in a person's immune system limit the ability to fight infection.<sup>1</sup> The reason for this deficiency can vary greatly from person to person. In fact, primary immunodeficiency is a category of more than 150 different diseases.<sup>2</sup>

Treatment for most primary immunodeficiency diseases involves clearing up the infection, avoiding germs, preventing exposure to new infections, and correcting the immunodeficiency<sup>3</sup> through regular IgG replacement therapy.

In the United States, physicians treating primary immunodeficiency can choose from at least 10 different brands of IgG therapies, all of which are manufactured using human plasma collected from thousands of donors who have been carefully screened and tested.<sup>2</sup>

Understanding your condition, the therapy your doctor recommends, and your insurance coverage are essential for maintaining access to the treatment that is right for you.

Each brand of IgG therapy is unique, however, because of differences in how the products are made, processed, and stabilized and in how people with primary immunodeficiency respond to them.<sup>4</sup>

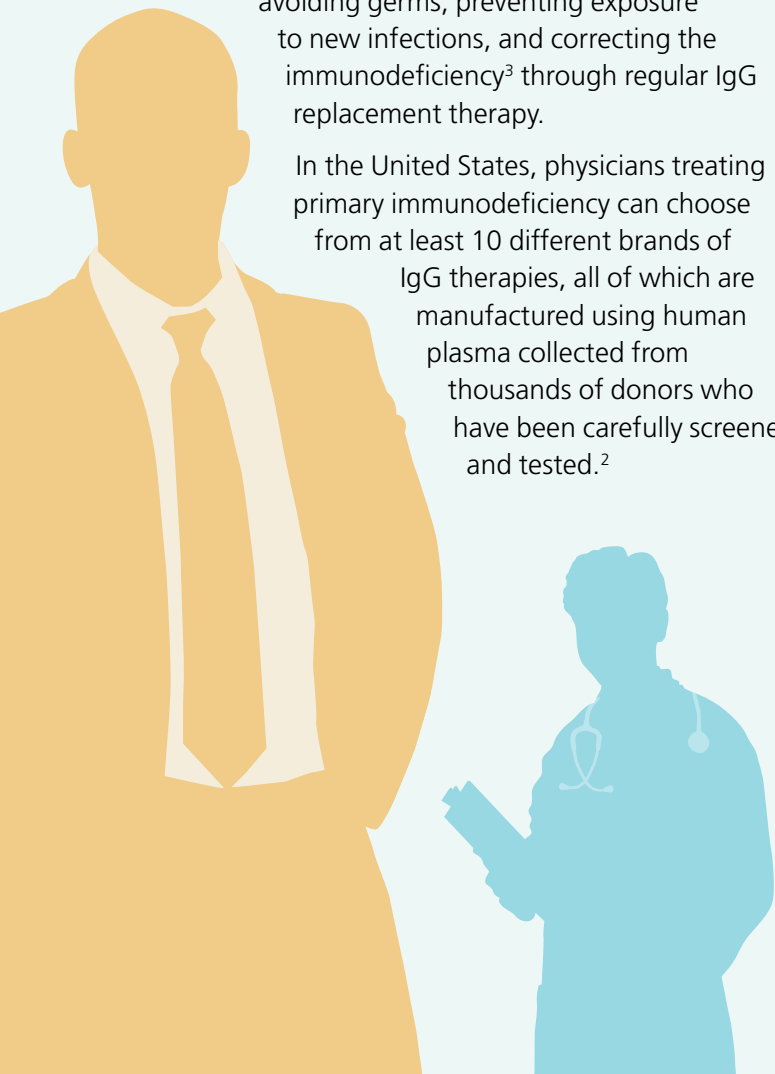
The FDA recognizes each IVIG brand as a distinct biologic, and therefore IVIG therapies are not interchangeable.<sup>5</sup> Side effects may occur more frequently when patients switch from one IVIG to another IVIG.<sup>6-9</sup>

## Physician Judgment Critical

As a result, experts in the treatment of primary immunodeficiency believe that insurance companies should include all brands and types of IgG therapies on their formulary to allow physicians to match specific products to their patients based on individual health status and needs.<sup>10</sup>

The Immune Deficiency Foundation (IDF) has taken a leading role in ensuring physicians have flexibility to choose the most appropriate treatments for their patients.<sup>11</sup> In January 2011, the IDF Medical Advisory Committee, comprised of more than 20 experts in the treatment of immunodeficiency, approved a resolution opposing any insurance company policy that interferes with a physician's ability to select the most appropriate IgG therapy or require a switch from current therapy without a medical reason to do so.<sup>10</sup>

In addition, the American Plasma Users Coalition, National Organization for Rare Disorders, and the American Academy of Allergy Asthma & Immunology (AAAAI) have issued statements in support of open formulary access to IgG therapies.<sup>1,12</sup> AAAAI guiding principles for safe, effective, and appropriate use of IgG therapies



state that treatments must be matched to patient characteristics and that IgG therapies should only be changed with the active participation of the treating physician.<sup>1</sup>

## Access and Reimbursement Growing Focus for Medical Groups

Statements from medical groups on formulary access for IgG therapies are the result of the potential for increased restrictions on IgG therapy by third-party payers, including commercial insurance providers. This year, the IDF launched a website and letter writing campaign when Highmark Blue Cross Blue Shield began limiting formulary access to just one type of IgG therapy for its customers.

With some exceptions, the policy would have required patients maintained on other therapies to switch to the formulary product. However, adverse reactions may occur more frequently in patients receiving immune globulin for the first time, upon switching to another brand, or if there has been a long interval since the previous infusion.<sup>6,8,9</sup>

In response to efforts by the IDF and the outcry from individual patients and physicians who would have been impacted by this change, Highmark agreed to allow patients with PI to stay on their existing treatment.<sup>13</sup>

## What You Can Do

As a patient, you have the right to be fully informed on your condition, to choose your healthcare providers, to be involved in your healthcare decisions, and to receive fair treatment. These rights are described on the IDF website.

Knowledge is power. To ensure that you have continued access to the therapy that is right for you, it is important to stay aware and involved.

You can help the IDF fight to encourage access and reimbursement for IgG therapies. Log on to the foundation's website and register to receive Action Alerts when your involvement can make a critical difference for all people with primary immunodeficiency.

Becoming an educated patient also will help ensure your own well-being. It's important to know what product you're on and why your physician recommends that brand of therapy.

In addition, read your insurance policy thoroughly so you and your physician's office are clear on what treatments your insurance will cover and in what settings. When speaking with your physician's office and your insurance company about treatment or coverage issues, be sure to take detailed notes and save all the paperwork you receive from providers and insurance companies. Thorough records may help protect you if your insurance company denies coverage for a treatment.

Your physician's office should work with you as a partner in seeking coverage for necessary treatments. If you are denied coverage, ask your physician's office for help in contacting your insurance company immediately. Sometimes the denial is a mistake, and a phone call can correct the error. If it is not an error, it is worth your time and effort to appeal. The Government Accounting Office estimates that 39% to 59% of all insurance appeals are granted.<sup>14</sup>



The first step in appealing is to file an informal internal appeal through the insurance company's customer relations department. Your physician's office may help in this process. If you contact the insurance company yourself, keep records of the call.<sup>15</sup>

If unsuccessful, most insurance providers have a formal appeals process, which will be described in your summary plan description. Take note of the rules and deadlines you must observe. If the formal appeal is unsuccessful, the new federal healthcare reform law requires insurance companies to allow an external appeal to an independent board of experts. In that instance, the health plan will have to pay for the external review, the decision from the panel will be binding, and it should be made within 45 days.<sup>15</sup>

## Other sources of help include the following:

- **The Patient Advocacy Foundation is a national nonprofit group that serves as an active liaison between patients and their insurance companies to resolve insurance matters.**<sup>16</sup>
- **The IDF offers a grassroots tool kit to help individuals launch an advocacy campaign.**
- **The GARDian Program provides access to live support, insurance help, and other resources.**



## What You Can Do

A number of resources are available to help understand treatment options and maintain access to therapy. The following were mentioned in this article:

### American Academy of Allergy Asthma & Immunology Guiding Principles

[http://www.aaaai.org/members/resources/initiatives/ivig\\_toolkit/ivig\\_coverage.pdf](http://www.aaaai.org/members/resources/initiatives/ivig_toolkit/ivig_coverage.pdf)

### Baxter Resources

[www.mygardian.com](http://www.mygardian.com) and [www.immunedisease.com](http://www.immunedisease.com)

### Immune Deficiency Foundation (IDF) Action Alerts

[www.primaryimmune.org/action\\_alert.htm](http://www.primaryimmune.org/action_alert.htm)

### IDF Grassroots Tool Kit

[www.primaryimmune.org/advocacy\\_center/about\\_advocacy.asp](http://www.primaryimmune.org/advocacy_center/about_advocacy.asp)

### IDF Patient Bill of Rights

[www.primaryimmune.org/patients\\_families/bill\\_of\\_rights.pdf](http://www.primaryimmune.org/patients_families/bill_of_rights.pdf)

### Patient Advocacy Organization

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

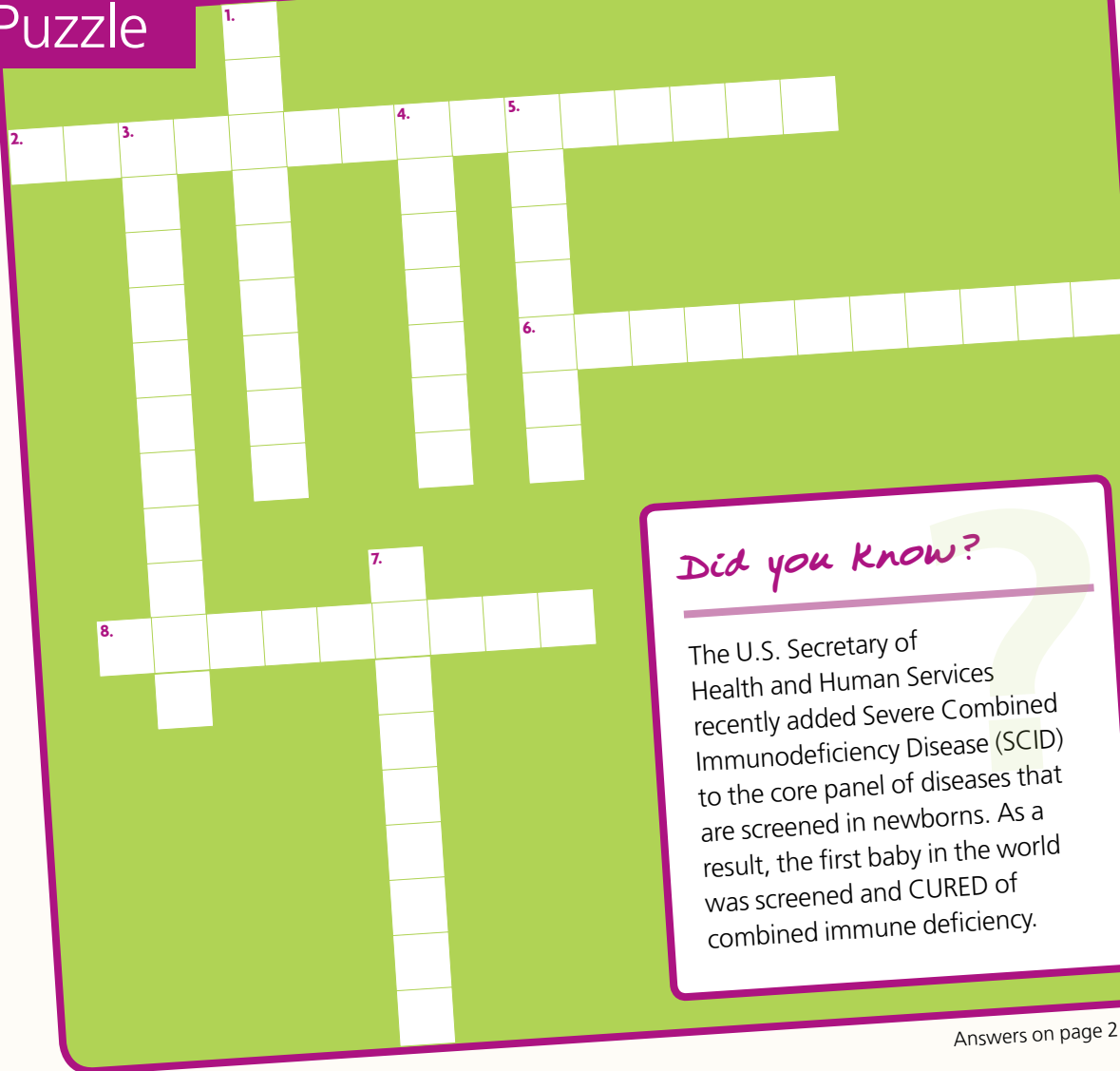
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## Glossary

## Crossword

## Puzzle



Answers on page 2

**Across**

2. Identical or very similar
6. Acute \_\_\_\_\_ distress: A serious reaction to treatment or injury that affects the lung
8. The identification of the nature of an illness or other problem by examination of the symptoms

**Down**

1. Co-\_\_\_\_\_: The presence of one or more disorders (or diseases) in addition to a primary disease or disorder
3. Of or relating to the healing of disease
4. \_\_\_\_\_ reactions: A new medical problem or a worsening of an existing medical problem due to a treatment
5. A consumer product having no brand name or registered trademark; characteristic of or relating to a class or group of things; not specific
7. An official list of medications that can be prescribed for a particular illness

# It's Party Time in the PI Community!

**Grab the party hats and streamers... 2011 is a year of celebration in the primary immunodeficiency community!** Two of the major PI advocacy groups—the Jeffrey Modell Foundation and the Immune Deficiency Foundation—are having milestone birthdays this year. And the party is on!



## JMF celebrates a quarter century!

**Jeffrey Modell *Jm* Foundation**

The Jeffrey Modell Foundation is celebrating its 25th anniversary with its first annual World Immunology Conference, which will bring together more than 300 researchers, scientists, and physicians from 55 countries. Take a look at some of the things JMF has done for PI patients worldwide:

- Launched a Public Service Announcement campaign to increase PI awareness and education that generated 33% annual growth in the number of patients referred to JMF Centers
- Helped to initiate the first population-based Newborn Screening Program for Severe Combined Immunodeficiency Disease (SCID)
- Designed the SPIRIT (Software for Primary Immunodeficiency Recognition and Tracking) Analyzer to identify patients at risk for PI; now used by managed care plans across the U.S.
- *Coming Soon!* Adding to 75 Centers started over the past 25 years, this year JMF will establish 25 new Centers throughout the world, bringing the total number of Jeffrey Modell Centers to 100

## Yee-Haaww! The IDF is turning 30



The Immune Deficiency Foundation partied Western-style for its 30th anniversary. This year's national conference in Phoenix, Arizona had a "Wild West" theme. With a great mix of networking soirées, life management sessions, and healthcare updates, the 6th national conference was a rootin' tootin' good time. Here are some highlights:

- ADA-SCID (Adenosine deaminase deficiency) pre-session—sharing your experiences and concerns with top immunologists, geneticists, and bone marrow transplantation teams
- IDF Electronic Personal Health Record (ePHR)—learning how this user-friendly tool can simplify your record keeping
- Age- and disease-appropriate connections—getting connected with others in the PI community in breakout sessions that are organized by age and disease groups
- Life management sessions—from managing depression to learning about chronic sinusitis and PI to speaking the language of health insurance
- Healthcare reform updates—gaining a little clarity on how healthcare reform and key public policy issues affect you

*If you couldn't find your boots in time for the conference, don't worry, Partner! Next year the IDF is hosting two family retreats. Check out the IDF website [primaryimmune.org](http://primaryimmune.org) for details in the coming months.*

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**Look for our follow-up article in an upcoming issue about these sessions!**

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