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October-November 2008



## Medicare

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Supplemental

Medigap  
(A-L)

Part D  
Prescription

Original  
Medicare

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ADVANTAGE  
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# Buyer Beware!

Is There an Advantage to Medicare Advantage?

A community service from FFF Enterprises, Inc.

Our mission is to support the IG community through education, communication and advocacy

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Publisher **Patrick M. Schmidt**

Editor **Amanda M. Traxler**

Assistant Editor **Cheryl Brooks**

Proofreader **Jackie Logue**

Creative Director **Sheryl Perez**

Artistic Director **Allan Bean**

Graphic Artists **Allan Bean**

**Ben Drolet**

**Caroline Carlson**

Contributing Writers

**Louis Aronne**

**Cheryl Brooks**

**Ever Fecske**

**Patricia Haynes, GSW**

**Cheryl L. Haggard**

**Mark T. Haggard**

**Jennifer Kester**

**Jim Trageser**

**Amanda M. Traxler**

**Michelle Vogel, MPA**

**Shirley German Vulpe, EdD**

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Please direct editorial, advertising and marketing communications to  
41093 County Center Drive  
Temecula, CA 92591

Ph: 800-843-7477

Email: editor@IGLiving.com  
www.IGLiving.com

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#### About *IG Living*

*IG Living* is the only magazine dedicated to bringing comprehensive healthcare information, immune globulin information, community and reimbursement news, and resources for successful living directly to immune globulin consumers and their healthcare providers.

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## Join an IGL Readers Group!

We hear from many, many patient and family member readers who would like to connect with others in their geographic areas—to share their experiences living with chronic diseases or maybe just to have a cup of coffee with folks who understand.

We can help you determine if there's a patient organization support group in your area or help you start an *IG Living* Readers Group.

To join a group or start one in your own area, visit [www.IGLiving.com](http://www.IGLiving.com) and click on IGL Readers Groups.

# Musings on Medicare

Our original idea for the cover of this issue was quite different from the one that you see. Initially, we intended to use the meditating guru from the August-September cover. Our reasoning? We hoped to bring serenity to the complexities of Medicare that are featured in this issue. During the photo shoot, we instructed our model to look inquisitive but still serene as he read about Medicare, Medigap, Medicare Advantage and Part D. No problem for a guru, right?

Well, after a few minutes of sifting through the morass of Medicare choices, the shoot was called off. Our guru—quickly overwhelmed by the confusing quagmire—had, quite simply, lost his composure.

Oh wait, no, that was me—the author of this month's feature—who is no longer quite sure, after having tried to understand our social healthcare system, that she will live long enough to apply for its benefits.

OK, I hope that got a chuckle out of you. Because I assure you, there are no jokes to be had in the article. I can't tell you how many times during its writing that I felt some serious pangs of sympathy for anyone who has to deal with a chronic condition and try to determine what Medicare plan is best for them.

And while we're on the subject, I don't think I'll ever be able to eat an *actual* doughnut hole as long as I live. Counter-intuitive, the Part D doughnut hole (which is actually a prescription coverage gap) has left many a mouth agape in confusion. A recent report finally shows how this gap has affected the prescriptions that are supposed to fill some of those very same mouths.

In August, the Kaiser Family Foundation released a study of Medicare enrollees who reached the doughnut hole in 2007, the first year that most beneficiaries would be enrolled in a Part D plan for a full calendar year. Titled "The Medicare Part D Coverage Gap: Costs and Consequences in 2007," the report can be found at [www.kff.org/medicare/7811.cfm](http://www.kff.org/medicare/7811.cfm). The first of its kind, the study also tracked how medication use and out-of-pocket spending changed after the gap was reached. Here are some findings: When required to pay the full cost of medications in the gap, patients changed their medication use. According to the study: *Across the eight classes of drugs examined, 15 percent of Part D enrollees who reached the gap stopped their drug therapy for that condition, 5 percent switched to another medication in the class, and 1 percent reduced the number of drugs they were taking in the class.*

Change in medication use is a serious concern for patients. Take, for example, individuals with diabetes, who risk immediate and potentially serious consequences if they stop taking their medicine. According to the study, 10 percent of Part D enrollees taking oral anti-diabetic drugs who reached the gap stopped taking their medication. Clearly bad for beneficiaries' health, this doughnut-hole consequence may also have an unintended (and fiscally undermining) effect on Medicare too. According to the study: *Ultimately, both stopping and switching medications could result in higher costs for other parts of the Medicare program if beneficiaries have health issues that are not being controlled by medication, or if they simply require more physician visits to prescribe and monitor changes in medications.*

Perhaps, then, the doughnut hole is really a bullet hole—you know, the one left after Medicare shot itself in the foot?

Policy mocking aside, I'm more interested in how beneficiaries can best avoid the doughnut hole's detrimental effects. To that end, the study offers advice, which—along with my hope that no one finds his/her health at risk due to the doughnut hole—I'd like to pass on: *Physicians can play an important role in helping beneficiaries who reach the coverage gap identify opportunities to switch to lower-cost alternatives, but in order to do so, physicians and patients need to talk with each other about drug costs ... Careful attention is needed to ensure that gains to Medicare beneficiaries from the addition of the Part D drug benefit are not undermined by the coverage gap—especially for those who are highly dependent on medications to manage ongoing chronic conditions.*

## On Another Note

In the June-July *IG Living*, Let's Talk featured Ken Hobbs, an advocate who helped start the Coachella Valley Neuropathy Association. In the interview, Ken mentioned a chronicle of his experience, "No Cure, No Surrender." If you'd like to find out more about his story, or to ask him a question about his role as advocate, he can be reached by phone at 760-449-0284, or by email at [khobbs@msn.com](mailto:khobbs@msn.com).

I hope you enjoy this issue; as always, please send any feedback to [editor@igliving.com](mailto:editor@igliving.com). ■



Amanda M. Traxler, Editor

# Readers Write

Your feedback, opinions, suggestions and anything else you'd like to share are important! Email us at [editor@IGLiving.com](mailto:editor@IGLiving.com) or visit [www.IGLiving.com](http://www.IGLiving.com) and go to the Contact Us page to send your comments.

Dear Editor,

I would like for you to know what a blessing Kris McFalls has been to me!

I have CVID and have fought to obtain approval for IG treatment for two years, which was denied numerous times. I found Kris on your website after a former co-worker of mine in an oncology office told me that *IG Living* may be able to help me. I had exhausted every resource that had been recommended to me. I emailed Kris and she emailed me right back asking about a time when she could call me to visit more about my situation.

I now cannot count the many times Kris and I talked on the phone and corresponded via email about my situation. This has been such a long, difficult battle for me, and Kris kept me going with her phone calls. She is so knowledgeable regarding insurance and IG. She is also a very compassionate and genuine person. Kris tried everything and I was amazed at her knowledge.

However, it soon became apparent that no matter how much evidence we submitted to my provider, they would find a reason to deny it. I was very close to giving up, but Kris continued to call and email me. Some days, she just listened to me vent. In July 2008, I had the opportunity to obtain insurance through my employer. (The other provider was through my husband's employer.) Because of Kris' persistence, expertise and friendship, I have now changed insurance companies and have received my first Vivaglobin treatment for my CVID. I would have given up a long time ago if it were not for her encouragement. She taught me so much through this whole process.

Kris was the most helpful and knowledgeable person that I talked to regarding getting approval for IG (and I talked to a lot of different people). Her constant follow-up with me is what kept me going. She even called the first provider with me also on the line—asking the representative direct questions to try to get straight answers. That was so helpful as the insurance maze was all very overwhelming to me. Because of her help through *IG Living*, I now have hope of getting my life back. I still may have a long road ahead of me, but at least now there is hope of getting better. What Kris does every day has truly made a difference in my life, and I am sure in the lives of many others. I am so

thankful for her. What a wonderful asset she is to *IG Living*. God Bless!

Thanks so much!

—Jenise, Kansas

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One of your recent issues floored me (Let's Talk, April/May 2008)! CIDP? How refreshing! Could I please receive about five or more hard copies to give to my doctors and others who might get a better understanding of it all? Somehow putting a glossy bunch of paper into their hands might get their attention in a way nothing else can. I can always hope, can't I?

All my best wishes to you and all on board at *IG Living*! Your hard work and advocacy for the IVIG and SCIG community is exhibited at the many support groups in which I participate. You have been invaluable to those of us who depend on IVIG!

—A reader in Virginia

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I wanted to tell you that I love your magazine. When we first became aware of my son's diagnosis, we had never heard of PIDD and had no idea where to start learning. The doctor had a copy of *IG Living* in his office and I asked if I could borrow it. Let me tell you—a magazine has never been more closely studied. My husband and I devoured it, and then we passed it to my mom to read. Thank you for doing this; you do not know what a difference it has made in our lives. All the information we needed was at our fingertips so that we could educate ourselves and make informed decisions for our son, and ourselves. (Since his diagnosis, we have found out that my mom, my daughter and I also have immune issues. Ours is an immune insufficiency, so it's not as bad.) Thank you for publishing this magazine. From a PIDD parent and patient! ■

—Laura, Alabama

# The Getaway

By Mark T. Haggard

“Shots fired!” A voice echoes along the hallways.  
“Man down! Send help! Repeat, man down!”

Gunfire sounds as my wife and I scurry along the bottom floor. “Let’s go,” I call. “We have to go!”

As we round a corner, I hear a gasp and then the sound of a body helplessly tumbling down stairs.

“I don’t think I can make it,” my wife mutters.

“We have to get out of here! Move!”

She makes her way to the front door, ducking and covering her head. More shots are fired as I try to interpose myself between my wife and the action above.

In my hands I carry important documents. Were they to fall into the wrong hands, our lives would be doomed.

We make it to the car, slamming doors behind us. “Come on,” I mutter, fumbling through the keys. When I find the right one and the Honda finally starts, I jam the car into reverse. The tires squeal as we pull away.

Three people emerge from the house, none of them over 5 feet tall. The guns they wield: index fingers and thumbs. I roll down the window and yell, “Be good for Nana and Papa! We’ll be home tomorrow!”

We make the getaway. The important documents—reservations at The Anniversary Inn—intact.

This year it’s an overnighter to The Anniversary Inn. Though unfortunate that it’s only an 18-hour vacation, it’s 18 hours that we need.

Some people question why my wife and I take time to get away from our kids when they need us so much. The answer is that we can’t afford not to get away. Spending time alone together is essential. It’s kind of like air—without it, things don’t turn out so well. We can’t spend every waking hour confronting our family’s immune deficiencies; their weight would crush our marriage. So it doesn’t matter how badly we blow our budget, we have to get away from the stress that chronic illness inflicts on our lives.

I chose The Anniversary Inn because it has themed rooms, like the Madonna Inn in California (except there’s no waterfall urinal). We stay in the Fisherman’s Wharf room, with the bed shaped like a boat, and the shower located in

the boathouse. Across the way is the Oregon Trail room, where couples sleep in a covered wagon. Other rooms include Biker Roadhouse and Jungle Safari.

After checking in, my wife starts peeking inside other rooms, searching for the Children’s Hospital Cafeteria room, the Ambulatory Treatment room, or the Ear, Nose and Throat Clinic room.

There are none to be found.

We arrive at Fisherman’s Wharf and settle in. Then Cheryl climbs on the boat and promptly falls asleep. I have learned not to take offense at my wife sleeping at the beginning of a getaway. With all of the kids’ issues that she deals with while I’m at work, she deserves the rest.



Four hours later, at 9 o'clock that night, we are ready for dinner. We go to a restaurant for grown-ups—elegant and quiet with no clowns, colonels or kings. We have surf-and-turf and coconut prawns without having to bark at the kids to wash their hands, wipe their noses or stay away from the five-story play structure.

When we return, we go to the boat—uh—bed without having to administer antibiotics, inhalers or nebulizer treatments to anyone.

At 9 o'clock the next morning, we are both awakened by a knock at the door. Cheryl sits up quickly, startled, and asks, "Is that Nurse Nancy?"

"No, it's breakfast," I assure her. "Go back to sleep."

Then our 18 hours are up.

As we check out of The Anniversary Inn, we look at each other and smile. We know that the getaway is for mental health, and that we must work at our marriage a bit harder than the average couple. In a way, we have to treat our marriage as carefully as we treat our children with their immune deficiencies.

On our way out, we hear another couple complain, "There was no place for our children to sleep."

"Yeah!" I say. "It's The Anniversary Inn. They don't exactly cater to kids."

"Of course not," Cheryl laughs. "Where would we hang the I.V. pole?" ■





**Infl**

# amed Joints?

## What to Expect If You Suspect Rheumatoid Arthritis

By Patricia Haynes, GSW

For Joanne, a cook at an elementary school in Washington, every morning used to start with an ice bath.

“When I would get up in the morning, my feet were like concrete. After a bath, I would loosen up so that by the time I got to work, I could almost walk normally.”

Diagnosed with rheumatoid arthritis (RA) about four years ago, Joanne says that she dealt with the autoimmune condition for about three years before figuring out what was going on.

“I just thought maybe it’s gout, or something like that,” Joanne said. “Or maybe it’s what I’m eating. But I changed that, and it didn’t help. It kept getting progressively worse.”

Still, somehow, Joanne managed.

“As long as I kept moving, I was OK. My hands and feet were the worst. They hurt so bad I didn't notice that it was in my elbows, knees, hips, ankles and shoulders. I took out a policy for disability insurance because at that point I still had 17 years left before I retired.” >

Finally, though, Joanne found help for this progressive disease, which, according to The Arthritis Foundation, affects between 0.5 percent to 1 percent (2.1 million) of the population in the United States. Although the cause of RA is not known, certain conditions may make some more susceptible to developing it than others. This applies to genetic immune deficiency, which “can increase the likelihood of ... diseases like rheumatoid arthritis and the kind of anemia that results from premature destruction of red blood cells.”<sup>1</sup>

For Joanne, the diagnostic process took about 12 weeks. During that time, multiple sets of tests were conducted. Although this was arduous, it was also necessary, because on the other side, as Joanne found, help was waiting.

## Defining RA

RA develops in three stages. The first stage is the inflammation and swelling of the synovial membrane, or joint lining, which causes pain, warmth, stiffness, redness,

## Available Medications<sup>3</sup>

Though RA is not currently curable, numerous treatments are available. Determining which treatment will be the most successful will likely be a process of trial and error. The goal is to find medications that help keep the swelling, pain and joint damage from affecting activities of daily life. The following list of medications and other treatments are some common choices. Not all medications or side effects are included here. RA medications can relieve symptoms and slow or halt disease progression.

**Nonsteroidal anti-inflammatory drugs (NSAIDs)** are a group of medications that help relieve both pain and inflammation if taken regularly. Over-the-counter NSAIDs include aspirin, ibuprofen (Advil, Motrin) and naproxen sodium (Aleve). These are available at higher dosages by prescription, or your doctor may prescribe other NSAIDs that provide better relief of symptoms. Side effects can include indigestion and stomach bleeding. Other potential side effects may include damage to the liver and kidneys, ringing in your ears (tinnitus), fluid retention and high blood pressure. NSAIDs, except aspirin, may also increase your risk of cardiovascular events such as heart attack or stroke.

**COX-2 inhibitors**, a class of NSAIDs, may be less damaging to your stomach. Like other NSAIDs, COX-2 inhibitors—such as celecoxib (Celebrex)—suppress an enzyme called cyclooxygenase (COX) that’s active in joint inflammation. Unlike other NSAIDs, COX-2 inhibitors suppress only COX-2, the enzyme involved in inflammation, and not COX-1, the enzyme that seems to protect stomach lining. Side effects may include fluid retention and causing or exacerbating high blood pressure. Furthermore, this class of drugs has been linked to an increased risk of heart attack and stroke.

**Corticosteroids**, such as prednisone and methylprednisolone (Medrol), reduce inflammation and pain, and slow joint damage. In the short term, corticosteroids can make you feel dramatically better. But when used for months or years, they may become less effective and can cause side effects that include easy bruising, thinning of bones, cataracts, weight gain, a round face and diabetes. Doctors often prescribe a corticosteroid to relieve acute symptoms, with the goal of gradually tapering off the medication.

**Disease-modifying antirheumatic drugs (DMARDs)** are prescribed to limit the joint damage that occurs in RA. Taking these drugs at early stages in the development of RA is especially important in the effort to slow the disease and save the joints and other tissues from permanent damage. Because many of these drugs act slowly—it may take weeks to months before you notice any benefit—DMARDs typically are used with an NSAID or a corticosteroid. While the NSAID or corticosteroid handles your immediate symptoms and limits inflammation, the DMARD goes to work on the disease itself. Some commonly used DMARDs include hydroxychloroquine (Plaquenil), sulfasalazine (Azulfidine) and minocycline (Dynacin, Minocin). Other forms of DMARDs include tumor necrosis factor (TNF) and Interleukin-1 (IL-1) blocking drugs.

**Immunosuppressants** (a class of DMARDs) are medications that act to tame out-of-control immune systems. In addition, some of these drugs attack or eliminate cells that are associated with the disease. Some of the commonly used immunosuppressants include leflunomide (Arava), azathioprine (Imuran), cyclosporine (Neoral, Sandimmune) and cyclophosphamide (Cytoxan). These medications can

swelling and fatigue. During the second stage, there is a rapid growth of cells in the joint lining that causes the synovium to thicken. This thickened, overgrown synovium is called a pannus. During the third stage, the inflamed cells release enzymes that may begin to digest bone and cartilage, often causing the involved joint to lose its shape and alignment, causing more pain, and eventually the loss of movement in those joints.

RA is also typically symmetrical, affecting both sides of

the body at the same time, with the same intensity. That is one of the factors that suggests a diagnosis of RA instead of another type of rheumatoid disease.<sup>2</sup> During Joanne's diagnosis, symmetry was observed.

"When I finally got to the rheumatologist, he said 'I can see it in both your feet, both your knees. I imagine it's in your hips. The only thing I notice that's not symmetrical is that one hand has the bent swollen fingers, and the other hand has swollen fingers that aren't bent.'" ➤

have potentially serious side effects such as increased susceptibility to infection.

**TNF blockers** are a class of DMARDs known as biologic response modifiers. TNF is a cytokine, or cell protein, that acts as an inflammatory agent in RA. TNF blockers, or anti-TNF medications, target or block this cytokine and can help reduce pain, morning stiffness and tender or swollen joints—usually within one or two weeks after treatment begins. There is evidence that TNF blockers may halt progression of disease. These medications often are taken with methotrexate. TNF blockers approved for treatment of RA are etanercept (Enbrel), infliximab (Remicade) and adalimumab (Humira). Potential side effects include injection site irritation (adalimumab and etanercept), worsening congestive heart failure (infliximab), blood disorders, lymphoma, demyelinating diseases, and increased risk of infection. If you have an active infection, don't take these medications.

**Interleukin-1 receptor antagonist (IL-1Ra)** is another biologic response modifier and is a recombinant form of the naturally occurring interleukin-1 receptor antagonist (IL-1Ra). Interleukin-1 (IL-1) is a cell protein that promotes inflammation and occurs in excess amounts in people who have RA or other types of inflammatory arthritis. If IL-1 is prevented from binding to its receptor, the inflammatory response decreases. Anakinra (Kineret) is the first IL-1Ra that has been approved by the Food and Drug Administration for moderate to severe RA that doesn't respond to conventional DMARD therapy. It may be used alone or in combination with methotrexate. Anakinra is given as a daily self-administered injection under the skin. Potential side effects include injection site reactions,

decreased white blood cell counts, headache and an increase in upper respiratory infections. There may be a slightly higher rate of respiratory infections in people who have asthma or chronic obstructive pulmonary disease. If you have an active infection, don't use anakinra.

**Abatacept (Orencia)** is a type of costimulation modulator approved in late 2005 that reduces inflammation and joint damage by regulating T cells—a type of white blood cell. People who haven't been helped by TNF blockers might consider abatacept, which is administered monthly intravenously. Side effects may include headache, nausea and mild infections, such as upper respiratory tract infections. Serious infections, such as pneumonia, can occur.

**Rituximab (Rituxan)** reduces the B cells (another type of white blood cell) in your body, which are involved in inflammation. Though originally approved for use in people with non-Hodgkins lymphoma, rituximab was approved for RA in early 2006. People who haven't found relief using TNF blockers might consider using rituximab, which is usually given along with methotrexate. Rituximab is administered intravenously. Side effects include flulike symptoms such as fever, chills and nausea. Some people experience extreme reactions to the infusion, such as difficulty breathing and heart problems.

**Antidepressant drugs** can help those who also experience symptoms of depression. The most common antidepressants used for arthritis pain and nonrestorative sleep are amitriptyline, nortriptyline (Aventyl, Pamelor) and trazodone (Desyrel).

## The Diagnostic Process

Your primary physician will likely recommend a rheumatologist (a rheumatoid disease specialist). According to Joanne, her primary physician sent her to a podiatrist, who then sent her to the rheumatologist. The rheumatologist will request a family history, especially Great-aunt Sally's "rheumatism" and your mother's "knotty knuckles," which may be genetic links to a possible type of rheumatoid disease.

Given the complex nature of the diagnostic evaluation of autoimmune disease, no single test confirms a diagnosis of RA (especially for patients who have had symptoms for less than six months). Rather, a skillful evaluation of appropriate symptoms, along with physical examinations, laboratory tests and X-rays, will help establish a diagnosis. According to the American College of Rheumatology, certain laboratory abnormalities commonly found in RA can help in establishing a diagnosis.

These include:

- Anemia (a low red blood cell count).
- Rheumatoid factor (an antibody eventually found in approximately 80% of patients with RA).
- Elevated erythrocyte sedimentation rate or "sed rate" (a blood test that in most RA patients tends to correlate with the amount of inflammation in joints).<sup>4</sup>

X-rays, which can be useful in the diagnosis process, may not show abnormalities in the first three to six months. However, X-rays are useful in determining if the disease is progressing.<sup>5</sup>

Ultimately, while a diagnosis of RA may not be what you want to hear, once you know what you are dealing with, you can begin to determine your treatment options.

That was something Joanne was grateful for: "When I got to the end of the 12 weeks, he [the rheumatologist] said, 'I can promise you when you pick up your prescriptions



and take them, by 10 o'clock tonight you will feel 100 percent better.' And I thought, 'Oh, my, this is cool,' and he was right." (Please note, most patients won't necessarily feel better this quickly.)

For Joanne, treatment has continued to be successful.

"There's days when something will ache, like a shoulder, elbow or wrist, but it goes away. I work with my hands, I do a lot of lifting when I'm at work, and I'm on my feet all day—but I do quite well."

She's even been able to keep up with her favorite hobby: camping.

"I was convinced I couldn't do that anymore, because I couldn't get out of the tent," Joanne said. "I had to crawl out on all fours and find something, like a table or a tree, so I could stand up. I don't have to do that now."

In fact, upon finishing with the 2007-2008 school year, Joanne went on a month-long camping trip.



## Other Procedures Available

Although a combination of medication and self-care is the first course of action for RA, surgical or other procedures are available for severe cases.

### Surgery<sup>6</sup>

If medications fail to prevent or slow joint damage, you and your doctor may consider surgery to repair damaged joints. Surgery may help restore your ability to use your joint. It can also reduce pain and correct deformities. Surgery carries a risk of bleeding, infection and pain. Discuss the benefits and risks with your doctor. RA surgery may involve one or more of the following procedures:

- Total joint replacement (arthroplasty). During joint replacement surgery, your surgeon removes the damaged parts of your joint and inserts a metal and plastic prosthesis.
- Tendon repair. Inflammation and joint damage may cause tendons around your joint to loosen or tighten. Your surgeon may be able to repair the tendons around your joint.

- Removal of the joint lining (synovectomy). If the lining around your joint (synovium) is inflamed and causing pain, your surgeon may recommend removing the lining of the joint.

### IVIG

Intravenous immune globulin (IVIG) has been helpful for some RA patients. However, studies have not definitively proven its efficacy in all cases. According to a work group report on the appropriate use of intravenously administered immunoglobulin (IGIV), published by the American Academy of Allergy, Asthma & Immunology, "IVIG has been used with varying efficacy in several other autoimmune diseases. The results in rheumatoid arthritis are controversial, but some benefit was suggested from case reports and open label trials."<sup>7</sup>



## Warning Signs of RA<sup>®</sup>

- Morning stiffness that lasts longer than 30 minutes
- Pain in three or more joints at the same time
- Pain in a joint all night long
- Pain in the same joints on both sides of your body; this is called a symmetrical pattern

RA may start gradually or with a sudden, severe attack with flulike symptoms. RA symptoms vary in individuals. In some people the disease will be mild with periods of activity or joint inflammation (flare-ups) and inactivity (remissions). For others, the disease will be continuously active and appear to get worse, or progress, over time. You may feel weak and tired, you may have a fever or lose weight, but joint pain will be the main problem. If any warning sign lasts more than two weeks, see your doctor. If your doctor believes that you have RA, it is important to see a rheumatologist right away.



## Other Ways to Care for Yourself<sup>9</sup>

### Exercise

Exercise can help reduce RA symptoms. Range-of-motion exercises reduce stiffness and help to keep joints moving. A range-of-motion exercise for your shoulder would be to move your arm in a large circle. Strengthening exercises maintain or increase muscle strength. Endurance exercises strengthen your heart, give you energy and control your weight. These include walking, swimming and cycling. Consult a doctor before you start an exercise program.

### Heat/Cold

Applying heat to an arthritic area can help relax aching muscles and reduce pain and soreness. Heat also promotes blood circulation, which nourishes and detoxifies muscle fibers. Hot showers can help reduce pain and stiffness, though heat should not be applied to an already inflamed joint. Cold applied to inflamed joints reduces pain and swelling by constricting blood flow. When joints are inflamed, ice or cold packs can be used to help decrease inflammation.

### Protect Your Joints

To protect your joints, you should avoid excess mechanical stress from daily tasks. Three main techniques to protect your joints include:

- Pacing, alternating heavy or repeated tasks with easier tasks or breaks, reduces the stress on painful joints and allows weakened muscles to rest. Pacing and planning also provide you with ways to deal with the fatigue that is often associated with RA.

- Positioning joints wisely helps you use them in ways that avoid extra stress (for example, use larger, stronger joints to carry loads and change position frequently). Use splints or orthotic devices to help affected joints, such as the fingers, remain in a good position.
- Assistive devices such as canes, raised chairs, grip and reaching aids can help simplify daily tasks. Grab bars and shower seats can conserve energy and help avoid falls.

### Weight Control

For people with RA, maintaining a healthy weight is essential. RA patients are generally not obese, and, if so, it's usually because they have become less active. Staying at your recommended weight can help lessen pain by reducing stress on the joints. If you plan to lose weight, discuss the best program for you with your doctor and a dietitian.

### Relaxation

Relaxing the muscles around an inflamed joint reduces pain. There are many ways to relax: deep breathing, listening to music or relaxation tapes. Meditate or pray. Another way to relax is to imagine or visualize a pleasant activity such as lying on the beach, or sitting in front of a fireplace. Good relaxation and coping skills can give you a greater feeling of control over your arthritis and a more positive outlook. ■

## More Resources

### The Arthritis Foundation

Toll-free 800-283-7800

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

Become a member, receive monthly information and find local support groups.

### Endnotes

1. "Immune Deficiency Disease," Microsoft® Encarta® Online Encyclopedia 2008 <http://encarta.msn.com> © 1997-2008 Microsoft Corporation. All Rights Reserved.
2. Arthritis Foundation, [www.arthritis.org](http://www.arthritis.org).
3. Mayo Clinic, [www.mayoclinic.com](http://www.mayoclinic.com).
4. American College of Rheumatology, [www.rheumatology.org/public/factsheets/ra\\_new.asp#4](http://www.rheumatology.org/public/factsheets/ra_new.asp#4).
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# Helping Little Patients Cope

By Jennifer Kester

At first, Matahna Erickson's son, Quentin, started crying uncontrollably during IVIG treatments. Then his antics escalated to kicking, next to thrashing his arms. But the real trouble began when Quentin ran and hid whenever his nurse arrived, forcing Erickson to frantically search her house for the 7-year-old. Finally, he started pushing his nurse.

"It was getting to the point where it was getting physically and emotionally hard for me to keep it up and try his treatments," says Erickson, who also has a 4-year-old and 7-month-old.

Erickson tried to make the nurse's visits a positive experience. She and her husband made a "treatment bin" filled with games, movies and Hot Wheels—Quentin's favorite—that he could dip into only on those days. She tried to make treatment days special, planning scavenger hunts, allowing him to indulge in a treat, or letting him choose dinner.

"We make it about him," the Washington mom says. "We still have to be obedient and follow house rules, but we try to make it fun."

But Quentin's disruptive behavior continued. Erickson had to start pinning down his legs during the treatments. She held his hand, let him hold his special treatment bear, and allowed him to sit on her lap or

in a chair. She even made paper fans with him to disperse the smell of alcohol, which Quentin hates. But still he would run and hide.

"We don't have a whole hour to get him out since nurses usually have another patient [after us]," she says. "No matter what we say prior, at that moment he could care less about anything. At that time in the situation he loses it all."

According to Ashley Thomas, an outpatient child life specialist at Texas Children's Hospital, it's not uncommon for children to act out during treatments. She says one way to prevent the run-and-hide game is for the family to rehearse the scenario in a nonstressful situation: "It prepares them, basically, and gives them time to build mastery over those skills."

There are other ways to help kids deal with their treatments. Medical play allows them to practice the treatment on a doll (or an inanimate object), which familiarizes them with the procedures and reveals any misconceptions the children have. This is a great way for the children to rehearse coping skills, including deep breathing, counting, guided imagery, and looking away or toward the procedure site, Thomas says. She suggests assigning a specific responsibility during the treatment. You can also have them hold something or help the nurse prep for treatment. Thomas reminds parents to validate their child's feelings and offer praise, such as, "I know it's no fun to get pokes, but I'm so proud of how still you were." If it's the pain that's prompting the bad behavior, Thomas recommends pharmacological anesthetics such as EMLA, LMX or ethyl chloride spray, some of which are over-the-counter. To encourage good behavior, she recommends a reward chart, where after getting a certain amount of stars or stickers, the child gets to pick out a new toy or book, or perhaps earns a trip to the park.

It can be difficult for parents to be firm about not tolerating unruly behavior since they feel sympathetic to their child's plight with chronic illness.

"Don't be afraid to discipline," Thomas says. "It's not uncommon for caregivers to feel guilty for their child's medical conditions, therefore they are reluctant to provide limits and boundaries."

But she says it's a bad idea not to set strict boundaries.

"Children—no matter what their circumstances—need structure and security," she says. ➤



She also warns about overemphasizing the child's reward. "Moderation is OK, but if you overdo it [offering rewards] you won't be benefiting the child down the road," she says. "You want the child to gain mastery over it rather than try to get something out of it." She stresses that the best way to help children is by being honest about their treatments, which are a normal part of life, like brushing their teeth. "It's something your child has to do, so they do not have an option whether they get the treatment or not."

When Kelliann Conner's daughters, Abigail, 10, and Madison, 11, were younger, they didn't act up so much as get nervous and worried during treatments. Conner's solution was redirection. The Arizona mother came up with routines: counting backwards when the needle was inserted and focusing on wiggling their toes.

"We were never big fans of 'If you do this, then you get that,'" she says. "You can't do that with IVIG because you can't say, 'You'll only get two treatments and you're done.' It's forever. You don't do that with these kids."

Conner, who also undergoes IVIG treatments, says that honesty is the best policy.

"Some parents try to make those promises and they can't. And I never lie to them—ever—about a procedure. Is it going to hurt? Yeah, it's going to hurt," she says. "I tell them, 'If you want to scream, fine. Just try not to move.'"

To relieve her kids' anxiety, Conner suggests doing treatments at home. She also helps her children deal with the emotional stress of their illnesses by writing. Abigail wrote a book about what treatments are like and how she prepares for them. But Conner says her daughters coped with their conditions best by helping others. Abigail spoke to a group of nursing students and told the story of her disease, which was incredible therapy for her, Conner says. The girls also offer support to newly diagnosed kids. The girls want to do a training video to teach kids about dealing with treatments.

Connie Radzwion, whose daughter, Madeleine, 8, has juvenile dermatomyositis, says that a mistake she sees is letting nurses have too much control over the children, something that she says happened to her.

"The worst, most traumatic time was when a nurse wanted to put eye drops to dilate her eyes," Radzwion says. "It was done against my wishes and it took quite a while for her to allow anyone to come near her. Something as simple as eye drops became a big ordeal."

Radzwion finds that incentives help Madeleine. She has been doing her daughter's IVIG on the road. Once, they

hooked everything up at home and brought it to the salon where they got their hair done. But that's just not an option for parents who are beginning treatments with their kids.

"We have been doing it for four and a half years, so we know what to anticipate at this point," says Radzwion, who had a nurse along for the beauty outing.

Ways to maximize your child's feeling of security, Radzwion says, include talking in a calm voice; sitting whenever possible; and using a child life specialist. But above all else, she is a proponent of telling the truth.

"Be honest and give the reason for the procedure and what to expect," the Texas resident says. "Allow your child to be involved ... that's the healthiest way to approach it."

Quentin's case may be more extreme, given his display of aggressive behavior. Anytime violence is involved, Thomas says, it's best to have the child see a psychologist, because there may be underlying issues.

"The actual aggression part is him acting out what he feels inside. They can use play to help kids develop skills to cope more effectively," she says.

Other ways to let out that aggression include syringe painting or having the child throw foam balls.

"That's the way children communicate—through play," she says. "They don't have the verbiage to express themselves. They should try to find an avenue of play to get his aggression out."

With a child struggling to cope with chronic illness, it's easy to forget the parents struggle, too. "Sometimes when I get him hooked up I have to go to my room and cry for a little because it's emotional for me," Erickson says.

One of the best ways for parents to cope is support groups. The problem is that there aren't many organized for kids with chronic illnesses. Radzwion, who is president of the Cure JM Foundation, suggests checking out the group's message board ([www.curejm.com/phpbb/index.php](http://www.curejm.com/phpbb/index.php)), where parents swap tips. She also suggests befriending people during visits to the doctor's office.

For more support, you can also get involved in a national organization such as the Immune Deficiency Foundation (IDF) or the Jeffrey Modell Foundation. Or you can attend national conferences to meet others. IDF will host a conference next year ([www.primaryimmune.org/conferences/conf\\_2009.htm](http://www.primaryimmune.org/conferences/conf_2009.htm)).

For Conner, one answer was found at church. "That kind of thing helps me get through. But it also took me a while to find the right people to open up to and look to for support. It's always easier when you're talking to someone who's been through it." ■

# ASK KRIS



Kris McFalls has two adult sons with chronic diseases who are treated with IG. Formerly a physical therapist assistant, Kris is IG Living's full-time patient advocate, and she is eager to find answers to your questions. Email them to [editor@IGLiving.com](mailto:editor@IGLiving.com). Your confidential information will not be used for any purpose but communicating with you about your questions.

**Kim:** The authorization for my child's infusions ran out in April, but the hospital kept giving her infusions without having retained another authorization. Who is responsible for the bill? Who is responsible for keeping track of the authorization timeline?

**Kris:** The responsibility for keeping track of an authorization timeline is that of both the patient (or in this case, the parent of the patient) and the provider. Given the infusions have already taken place, if payment has been denied, both the hospital and you will need to file an appeal for payment. Sometimes if authorization was required and the infusion provider was to retain authorization beforehand, the responsibility of the payment will fall back on the provider and not the patient. The contract your provider has with your insurance company will determine if that is applicable in your case. Your explanation of benefit (EOB) statements should tell you whether or not you are responsible for the charges. You may also call the customer service phone number listed on your insurance card to ask about the infusion dates in this case.

Going forward, make sure that you always get a copy of all authorization letters. Most insurance companies will automatically send you a copy; however, some will only send it to your provider. Once you have a copy of the letter, make note of the end of the authorization period and mark it on your calendar. Two months before that date, make sure to

have your child seen by the treating physician. At that appointment make sure the doctor knows your authorization is about to expire and ask the doctor to send in another request. Follow up on the next infusion to make sure your request for reauthorization was sent in. It is helpful if the doctor also sends you a copy of the reauthorization request. Again, make sure to get and keep a copy of the new authorization letter.

There was a time when as parents we didn't need to worry about these kinds of details. Those days are gone. The old Scout motto of being prepared also applies in today's world of red tape and paperwork. To avoid these kinds of problems we need to be prepared. Keeping a notebook with all lab work, health information and insurance notes will help you be prepared. That way when these timelines come up, you will have all that you need at your fingertips. In the event that your doctor's request got lost in transmission you can then simply send it in yourself.

Please remember doctors and clinic staff are trained as just that. They are not trained in insurance red tape, deadlines and appeals. While it is their job to help you through all of it, it is also our responsibility as patients and parents of patients to do our part. As a team we can work together to cross the t's and dot the i's so that treatment is not disrupted because of paperwork and red tape. I hope that helps! ■

# Medicare Part D Primer

By Michelle B. Vogel, MPA, and Louis Aronne

One of the largest problems for the immune globulin (IG) community is inadequate reimbursement for physicians, who are then unable to afford providing intravenous immune globulin (IVIG) to Medicare beneficiaries. This has caused beneficiaries to be shifted to different sites of care, many of which are also being affected by reimbursement issues. When insurance providers eliminate access to IVIG, beneficiaries are often left in a tough position, either switching to an alternate treatment that's not as effective (if it is at all), or paying out of pocket. In cases where patients pay out of pocket, beneficiaries often reduce their dosage and increase the time between infusions. This can be dangerous, potentially allowing the disease state to progress to the point where patients develop life-threatening infections, paralysis or even death.

Unfortunately, even with all of the efforts of the IG community to prompt Congress to fix reimbursement for Medicare beneficiaries, IVIG reform was not included in the new Medicare law. Even worse, Medicare is now recommending to further reduce reimbursement for hospital infusions. On top of that, coverage determinations are affecting more community members in both Medicare and private insurance situations. In these cases, patients who have a diagnosis that is not a Food and Drug Administration (FDA) approved indication for IVIG are being denied coverage after years of effective treatment. The reason? IVIG is now considered experimental or not medically necessary; therefore, beneficiaries are deprived of coverage.

## Medicare Part D

In an attempt to provide better prescription drug coverage for Medicare and Medicaid beneficiaries, Medicare Part D was enacted under the Medicare Modernization Act (MMA) of 2003. This drug benefit, created to halt skyrocketing Medicare prices, is controlled by private health insurance plans but is reimbursed by the Center for Medicare & Medicaid Services (CMS). Although approved in 2005, Part D took effect on Jan. 1, 2006, and Jan. 1 is the first day of every Part D cycle. Part D comes as a benefit to people who already have either Medicare Part A or B and comes at a premium to traditional Medicare, requiring the beneficiary to voluntarily enroll. In some states, beneficiaries with dual eligibility (someone with both Medicare and Medicaid) are required to accept Part D to remain with Medicaid. You must register with a Part D plan that is in your geographical region. Re-enrollment is required annually; enrollment begins Nov. 15 and ends Dec. 31, and your new plan begins Jan. 1.

For patients in the IG community, diagnosis and treatments must be considered to determine which plan best fits your needs. For primary immune deficiency disease (PID) patients utilizing IVIG, Part D does

not cover IVIG (which is covered under Medicare Part B for all sites of care). For non-PIDD patients, most likely your diagnosis is covered under Part D, though only in the homecare setting. With due consideration to your healthcare situation, Part D may be a viable option.

## Choosing a Plan

Once you decide you want Part D, you must choose a plan. This can be onerous, especially when receiving IVIG is a primary concern. The Part D plans are not required to offer all brands of IVIG, therefore patients must select a plan with care. Additionally, Part D covers IVIG only in the homecare setting. Factors to consider include the plan's formulary, the current price of drugs you seek within the formulary, the cost of the plan, and which specialty pharmacies are within the plan's network (this has a direct relationship with your home infusion care provider). Some plans may name CVS, Caremark or Accredo as the only company where you can get your drugs; therefore, if you are currently using another home infusion company, such as NuFACTOR, you would not be able to continue to have that choice.

Private insurers offer prescription drug benefits to Part D beneficiaries through a traditional Medicare fee-for-service stand-alone prescription drug plan (PDP) or through a Medicare Advantage plan with a prescription drug benefit (MA-PD). In some cases, Medicare Advantage special needs plans (MA-SNPs) are available, which include HMOs or PPOs and which must always offer Part D coverage. The benefit of a plan must be at least as valuable as the standard benefit; therefore, plans' formularies differ in number of drugs covered, reimbursement rates, and most importantly, which brands of IVIG are covered. All formularies differ yet must cover all antidepressants, antipsychotic drugs, anticonvulsants, immunosuppressants, and HIV/AIDS categories as well as certain off-label drugs.

A beneficiary must be careful when choosing a plan for several reasons:

- Although a plan may cover a certain off-label drug, coverage may be discontinued at any time without notice.
- All formularies are subject to change, but you are given 60-days notice to change your plan if you are affected.
- Injectables (covered in Part B) can be covered if they do not require a practitioner to administer them. A temporary exception applies when an injectable is newly approved; it is assumed to be covered under Part D until otherwise noted and placed in Part B.

Plan formularies can be checked on a provider's website; by calling a toll-free customer call center; through a plan description from a sponsor; or by submitting a written beneficiary request. After doing research and finding that your drug requires too much out-of-pocket cost, you may file for an exception. (Each plan must allow an enrollee

to request coverage for a nonformulary drug or to reduce cost-sharing for a drug already in the formulary. A doctor, who must agree that no other drug in the formulary is suitable for this condition, must request an exception. A CMS-approved form is available at [www.cms.hhs.gov/PrescriptionDrugCovGenIn/Downloads/PartDP\\_harmacyFaxForm.pdf](http://www.cms.hhs.gov/PrescriptionDrugCovGenIn/Downloads/PartDP_harmacyFaxForm.pdf). If the request is rejected, an appeal begins. If the enrollee wins, he or she will be reimbursed for the nonformulary drug or for reduced cost-sharing for the current treatment.)

### Doughnut Hole Ahead

The standard Part D drug benefit, designed to assist Medicare beneficiaries in paying prescription drug costs, makes the plan more viable for beneficiaries with drug costs less than \$2,510 or more than \$4,050. The standard benefit from 2008 requires the beneficiary to pay a \$275 deductible to get a coinsurance rate of 25 percent. However, this initial benefit period lasts only until drug costs reach \$2,235. If a beneficiary's costs exceed this initial benefit amount, another deductible dubbed the doughnut hole requires the recipient to pay the full cost of drugs. These out-of-pocket costs of 100 percent continue until total out-of-pocket expenses equal the \$275 deductible, the \$558.75 (25 percent) paid during the initial benefit period, and the \$3,216.25 paid in the doughnut hole. So to this point, required out-of-pocket expenses reach \$4,050.

This lopsided benefit structure may impose large out-of-pocket costs early, but once a beneficiary reaches catastrophic coverage, there is a 5 percent coinsurance rate. At this point, Part D covers 95 percent, leaving you coinsured at a flat 5 percent or \$2.25 for generic drugs and \$5.60 for other drugs, whichever is greater. One must be careful when evaluating the out-of-pocket expenses incurred in Part D because drugs not included in a plan's formulary do not count toward the deductible and out-of-pocket limits.

Although Part D aims to give beneficiaries prescription drug coverage, it often neglects cost savings and allows beneficiaries with poor plans to incur large expenses. IVIG users must be aware of this when choosing a plan since formularies differ from plan to plan.

There are currently 34 PDP regions and 26 MA-PD regions; these plans vary greatly depending on your region. ■

### Resources

- **Formulary Finder**  
[www.medicare.gov/MPDPF/Shared/Include/Formulary/FormularyFinder.asp?language=english](http://www.medicare.gov/MPDPF/Shared/Include/Formulary/FormularyFinder.asp?language=english)
- **Medicare Drug Plan Rating Tool**  
[www.aarp.org/health/medicare/drug\\_coverage/new\\_medicare\\_drug\\_plan\\_rating\\_tool.html](http://www.aarp.org/health/medicare/drug_coverage/new_medicare_drug_plan_rating_tool.html)

## Commonly Asked Questions

### 1. Should I sign up for Medicare Part D?

If you have a secondary health insurance plan, not a Medigap plan, that covers your medications, including IVIG, then you probably do not need to sign up for Medicare Part D, but check with your secondary insurance to make sure that your coverage allows for access to the brand of IVIG that works best for you in the site of care that you wish to receive the therapy and that the site of care is still treating Medicare patients with IVIG.

If you have a Medigap policy, check to see if that policy will continue to cover your medications. Many Medigap policies discontinued covering medications once Medicare Part D was implemented. Also, with Medigap policies, if Medicare does not cover your IVIG, Medigap will not cover it. However, a secondary health insurance may still cover your therapy.

### 2. Is IVIG for my diagnosis covered under Part D?

If you have a primary immune deficiency disease (PIDD), your IVIG is covered under Medicare Part B for all sites of care: hospital, physician's office, and homecare. However, supplies and nursing are covered only in the hospital setting.

If you are a non-PIDD patient, most likely your diagnosis is also covered under Medicare Part D; reimbursement under Part D for IVIG is currently higher than Part B. Since Part D covers only patients in the homecare setting, make sure that your physician agrees that the homecare setting is right for you if you are currently receiving IVIG in a hospital or physician's office. You should find that there are home infusion companies able to work with you because current reimbursement under Part D is adequate. If you choose this method, make sure to ask if the cost of nursing and supplies is included in the cost of medication. Also note that under Part D, the doughnut hole still applies.

### 3. How can I afford my IVIG infusions under Medicare Part D with the doughnut hole and other out-of-pocket expenses?

When looking into different Medicare Part D plans in your area, get a listing of the participating home infusion companies/specialty pharmacies. Many of these companies offer financial assistance programs that you may be eligible for that will help eliminate the out-of-pocket expenses. If you are looking into a Medicare Advantage plan, some of those plans also have financial assistance programs. To see if you meet their criteria, call the plan to discuss what financial assistance is offered.

# Buyer Beware!

## Is There an Advantage to Medicare Advantage?

*Editor's Note: This article is intended to educate you about the myriad products available across the Medicare landscape. Though some plans may appear to be better choices than others, IG Living is not endorsing any specific plan type. Deciding whether a plan is good for you requires close inspection of that plan's benefit structure alongside due consideration of your healthcare situation. Further, readers should realize straightaway that Medicare Advantage (MA) plans are not the same as supplemental plans (Medigap). Clarifying this is crucial to resolving much of the confusion surrounding plan choices. To understand the difference between the two, please see "A Plethora of Choices" on Page 28.*

By Amanda M. Traxler

**S**andy, who has common variable immune deficiency (CVID), is not a fan of Medicare Advantage (MA) plans.

"The only thing I have to say about an Advantage plan is that you are going to get cheated at some point," Sandy said. "There's no way around it."

A strong statement, her sentiment is understandable given an unannounced plan change in 2007 that left her with thousands of dollars in bills.

In 2008, Sandy was able to switch to a supplemental (Medigap) plan, which is what she thought she had in the first place.

Sandy's not alone in her frustration. Many consumers and healthcare advocates are criticizing MA plans. Much of the attention is falling on one plan in particular—

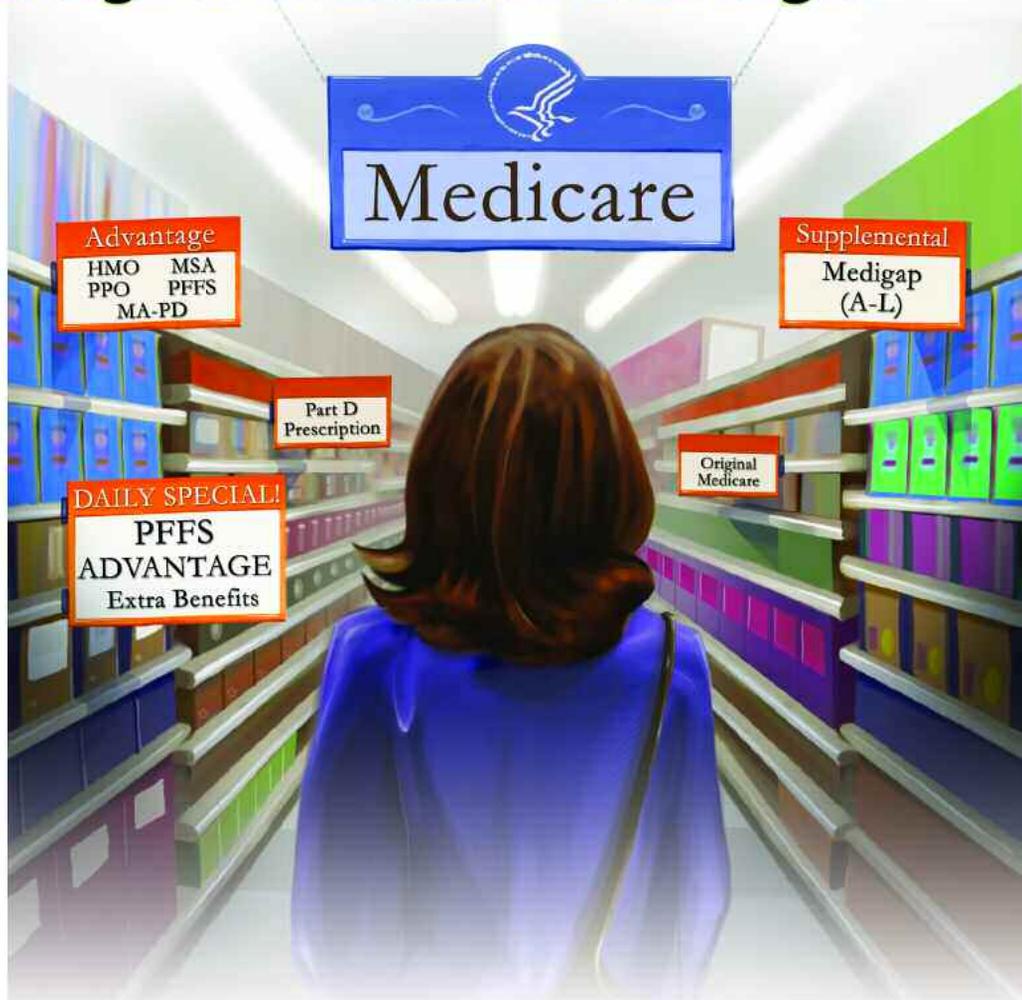
private fee for service (PFFS), which is also one of the fastest-growing plans on the market.

But does that mean a blanket statement can be made, in that, just because Sandy had a horrific experience with an MA plan, that all MA plans are bad?

The situation is too complex to extrapolate a hard-and-fast truth from Sandy's story. In reality, consumer experiences in MA plans run the gamut—ranging from individuals in plans that meet their healthcare needs, to a woman who was signed up for a plan without her knowledge and had to fight months to disenroll,<sup>1</sup> to Sandy, who thought she had bought a Medigap supplemental plan, but who'd actually purchased an MA plan.

What, then, can be concluded?

First, consumers must realize that the diversity of MA plan



types is astounding, with benefits and cost-sharing varying significantly. Take, for example, that some MA plans include prescription coverage (eliminating the need for Part D)—which many consumers find attractive. This alone is why many choose MA plans versus going with Original Medicare, a supplemental (Medigap) plan, and a Part D prescription plan.

This diversity is considered a plus by many, but there's also a flip side to it—namely, confusion, says Dave Evans, CFP and senior vice president of the Independent Insurance Agents & Brokers of America.

“There's definitely a fair amount of confusion,” Evans said. “It's a question of where you sit in terms of the plethora of choices.”

And where one sits in terms of choices has a lot to do with one's individual healthcare needs. An MA plan that is right for patient A may not be right for patient B. And when it comes to patient IG, extra care must be taken when choosing a plan, as coverage will depend on one's diagnosis, treatment site, and whether one uses subcutaneous immune globulin (SCIG) or intravenous immune globulin (IVIG).

No doubt about it: The burden here sits squarely on consumer shoulders to research plan choices carefully.

Further, consumers must also be aware of another issue currently plaguing MA plans: unscrupulous sales tactics that some agents have been using, including false promises, “to market Medicare-related products with little or no concern for the needs of the consumer.”<sup>2</sup>

On a less-sinister note, even well-intentioned salespersons may not understand the specifics of a plan they're selling: for example, “that a beneficiary's co-payments may be higher than in traditional Medicare.”<sup>3</sup>

Or, from an IG patient's perspective, that an MA plan's out-of-pocket cost of IG (which can vary from zero to 25 percent and can change when a plan changes) will far outweigh the financial savings incurred from the MA plan's cheaper monthly premiums. (Please see the sample chart on Page 29 for an example of this.)

A lot to stay on top of? It sure is.

### Sandy's Story

According to Sandy, her eligibility for disability coverage came through in the nick of time: Diagnosed in 2003, she had just moved to a new state. After becoming eligible for Medicare, Sandy went to the state's biggest HMO provider.

“I went to our local senior center and listened to the presentation,” Sandy said. “And what I thought I was buying—the way they explained it and everything—was supplemental insurance to my Medicare. And of course, I had no prior experience before this about this insurance or anything else

about it.”

For the first few years, things went smoothly.

“From 2003 until 2006 they pretty well paid my IVIG. They [infusions] were done in the hospital. I would go down to the hospital every three weeks and have IVIG.”

In 2007, things changed.

“In 2007, all of a sudden, we weren't getting EOBs [explanation of benefit statements]. We weren't getting any information on where we stood with the medications, and it just became a nightmare, and they were charging me 20 percent of whatever, and I couldn't get them to talk ➤

## How to Find a Plan

Contact your State Health Insurance Assistance Program (SHIP), which can provide one-on-one health insurance counseling to Medicare beneficiaries.<sup>16</sup> Each state's SHIP often has specific information about plans in your area; to find your state's office, go to [www.medicare.gov/Contacts/static/allstatecontacts.asp](http://www.medicare.gov/Contacts/static/allstatecontacts.asp).

Use Medicare.gov, which offers a Medicare Prescription Drug Plan Finder as well as a tool that finds and compares supplemental (Medigap) policies.<sup>17</sup> The drug plan finder can also be accessed at 1-800-MEDICARE. Again, take care when searching, as the toolbar for Medigap plans is right next to the toolbar for Medicare Advantage plans.

Use an independent agent to help determine plan options versus one who is selling a specific company's policies. Because independent agents are typically mainstream agents, make sure to find one who specializes in what you're looking for, whether Part D, supplemental (Medigap), or Medicare Advantage coverage. If your insurance agent doesn't sell Medicare-related policies, ask if he or she can recommend someone; or ask friends or other family members who have Medicare policies if they can recommend an agent.<sup>18</sup> According to Dave Evans, CFP and senior vice president at the Independent Insurance Agents and Brokers of America, “one of the most important elements that an independent agent can bring is choice and customization.” Evans advises that consumers should ask how familiar an agent is with Medicare coverage: “The first thing I would do is to ask [the agent] ... how much do they do in this arena.” If they're dabbling in it, Evans said, they're not going to bring a wealth of experience.

## Questions to Ask

To find out about coverage, call a plan and ask these questions. Further, remember to keep up to date on this information even after you've enrolled, as plans can change.

**Is IG covered?** If there's a formulary, use the following J Codes to determine if your brand is on it. Remember, a plan may change a formulary at any time; ask how often it updates its formulary.

- J1561 Gamunex
- J1562 Vivaglobin
- J1566 Lyophilized Powder (Gammagard S/D, Carimune N/F)
- J1568 Octagam
- J1569 Gammagard Liquid
- J1572 Flebogam
- Q4097 (J code coming) Privigen

**What site of care is covered?** A provider may limit site of care. For example, it may cover only certain locales such as a homecare company or a specific specialty pharmacy. If your physician has an infusion suite, or if your site of care is a hospital, check that these are covered.

**What is the coverage for your diagnosis?** Ask your doctor for your ICD9 code (your diagnostic code). Once you have the diagnostic code, you can call the insurance company to find out what is covered.

to me. I'm not exactly a stupid person but I couldn't figure out what I was supposed to be paying 20 percent of."

Shortly thereafter, Sandy learned she didn't have the plan she thought.

"Then I found out they [the insurance company] didn't even have a supplemental plan when I became eligible for Medicare and bought a plan. I was flat lied to because they did not even have a regular supplemental plan until 2007."

Though her plan wasn't called an MA plan, Sandy believes it falls in the same category.

"What I found out is that I had a Cost Plus plan, which is, as far as I can tell, very similar to what other companies call Advantage plans." (According to the nonprofit Henry J. Kaiser Foundation, a Cost plan is a type of MA plan.<sup>4</sup>)

If Sandy had been in traditional Medicare, which she was no longer officially enrolled in given that she'd chosen a Cost Plus plan, 80 percent of her IVIG would have been

covered. A true Medigap/supplemental plan (which, again, is what Sandy thought she had) most likely would have picked up the other 20 percent. (Two of the 12 options, K and L, would have picked up only 50 percent and 75 percent of that extra 20 percent, respectively.)

In 2008, Sandy was able to switch into a true Medigap policy. What happened in 2007, however, has had dire financial consequences. And because the provider was charging 2 percent interest per month, or 24 percent APR, Sandy decided to pay what the company said she owed.

"What this company is doing is they are charging people who can't pay interest. I never did quit paying," Sandy said. "The interest just keeps ballooning, and you can't get ahead of it, you can't pay it off. I kept working with them and, finally, they let me pay \$4,000 or \$5,000 and they dropped the interest. But up to that point, I had to do that because here we were at almost \$10,000. It kept ballooning."

In 2008, Sandy appealed. Her first two appeals failed. Currently, she is waiting to appeal a third time before the Department of Health and Human Services.

Her mood, however, is grim.

"I really don't expect it to happen, to be honest with you. They just flat-out charge you whatever they want to charge you. You can't do anything about it."

## The Theory Behind MA Plans

The policy on which MA plans are based had a specific intent: provide access to health maintenance organizations (HMOs).

"Medicare Advantage ... builds on prior policy efforts that aimed to establish private plan options in Medicare intended to operate in a competitive marketplace. Its original intent is to provide access to health maintenance organizations (HMOs)."<sup>5</sup>

Opening Medicare to the market force of competition would also, in theory, benefit the patient through improved healthcare.

"One rationale for Medicare Advantage is that its focus on networks and decentralization would encourage greater innovation and more localized structures better suited to managing care than is available from a centralized model."<sup>6</sup>

However, overall benefit structure was not meant to be altered profoundly—as the benefits of MA plans are supposed to be the actuarial equivalent of those provided under Medicare.<sup>7</sup>

That being said, private insurers still have a large say in deciding what those benefits are.

"Under MA, Medicare continues to exercise overall oversight on policy, but it delegates substantial authority to private firms to configure the benefits they offer, determine

provider access, and develop structures and processes to improve quality and care management. MA also provides beneficiaries with diverse plan choices regarding how they receive Medicare benefits.”<sup>8</sup>

Some plans do offer benefit structures that carry out the original intent. Responding to a healthcare blog about MA plans, one employee of an MA-PD HMO plan wrote glowingly about hers: “Our plan is designed and directed by physicians within each community we serve. We clear the roadblocks for our members by empowering our physician partners to make the most appropriate care decisions for their patients, and we afford them time to provide true care coordination and focus on patient long-term health. We consistently have the lowest out-of-pocket costs of any competing plan and we offer additional benefits beyond Medicare such as dental, vision and transportation to and from the doctor. I believe our approach is what MA was intended to be, i.e., a private company that can offer more benefits and drive better health outcomes but do so more efficiently and effectively. Not all MA plans are created equal, but I think it is important to not throw the baby out with the bath water here. A clear distinction needs to be made between Medicare Advantage PFFS plans and Medicare Advantage HMOs. There are countless seniors, most of which are on tight fixed incomes, who benefit from MA-PD HMOs, and I hope our legislators continue to make a clear distinction going forward.”<sup>9</sup>

The employee is right, a clear distinction is needed. Because just as there are those who may be benefiting from the plan mentioned above, there are also those—such as Sandy—who are not benefiting in the slightest.

### Choices Gone Wild

To Sen. Tom Coburn, R-Okla., the vast array of MA plans offers seniors personal choice and control over their healthcare decisions.<sup>10</sup> Pretty much no one argues the choice part.

“There is no doubt that MA has expanded the number and types of plan choices available to Medicare beneficiaries. Virtually all Medicare beneficiaries, including those in rural areas, now have some choice of an MA plan. The vast majority have access to plans under at least three contract types (PFFS, MSA, R-PPO).”<sup>11</sup>

Many critics, however, vociferously oppose his next contention, arguing that the overwhelming number of benefit structures—which often leads to confusion about benefits—virtually negates a beneficiary’s control over healthcare decisions.

As healthcare blogger Maggie Mahar points out, “But if benefits aren’t transparent, how can seniors make a real choice?” ➤

## Enrollment Periods<sup>19</sup>

Enrollment periods in and of themselves can be confusing. Below is an overview of each period; for more thorough information, please visit [www.medicareadvocacy.org/Medicare\\_EnrollmentPeriods.htm](http://www.medicareadvocacy.org/Medicare_EnrollmentPeriods.htm).

**Annual Coordinated Election Period (AEP):** Nov. 15–Dec. 31  
Beneficiaries may change prescription drug plans, change MA plans, return to original Medicare, or enroll in an MA plan for the first time. Changes take effect on Jan. 1.

**General Enrollment Period (GEP):** Jan. 1–March 31  
Medicare beneficiaries who did not enroll in Part B when they first became eligible for Medicare may elect Part B coverage effective July 1 of the same year.

**Open Enrollment Period (OEP):** Jan. 1–March 31  
Medicare beneficiaries may enroll in, disenroll from, or change an MA plan. Unlike enrollment in Part B, the change in MA enrollment or disenrollment becomes effective the month after the change is made. Only beneficiaries who are eligible to enroll in an MA plan may make a change. Beneficiaries may not add or drop Part D. Those who already have drug coverage can only change to another option with drug coverage. Those who do not have drug coverage may not change to an option that provides it. Permissible changes include:

- MA-PD to a different MA-PD
- MA-PD to Original Medicare and a PDP
- Original Medicare and a PDP to an MA-PD
- MA-only plan to a different MA-only plan
- MA-only plan to original Medicare
- Original Medicare to an MA-only plan

**Special Enrollment Period (SEP):** Variable Time Frame  
SEPs allow enrollment changes outside of the GEP, the AEP and the OEP for certain circumstances. Beneficiaries who delay enrolling in Part B because they are covered by employer-sponsored health insurance as an active worker or as a dependent of an active worker are not limited to enrolling in Part B during the GEP. They have an eight-month SEP from the time they (or their spouse) retire or they lose coverage. Part B coverage starts the month after the election is made, and there is no late premium penalty. Other SEPs exist for MA and PDP enrollment and disenrollment. CMS has the authority to create SEPs for exceptional circumstances.

Many opponents are specifically attacking the PFFS plan, which Congress has voted to phase out by 2011—but which is still one of the fastest-growing types of MA plan.<sup>12</sup>

According to Mahar, one problem with these plans is that benefits may change from year to year (which is what happened in Sandy's case). Other concerns about PFFS plans include:<sup>13</sup>

- Many doctors and hospitals don't accept PFFS plans, which can limit choice and access to care.
- Though PFFS plans offer additional benefits, such as hearing aids or eyeglass coverage, other important benefits can be modified (such as limited hospital days or higher co-pays for nursing homes than Medicare). Retirees who require more medical care may be worse off under the plan.
- PFFS plans more frequently deny claims to hold down costs.
- Appeals processes are more difficult under private plans. No longer enrolled in traditional Medicare, beneficiaries

must go through the company rather than Medicare's transparent appeals process.

- The plans are not stable, which means that they can and do pull out of markets, disrupting healthcare services for beneficiaries.

### Industry Action

Both Medicare and the insurance industry are aware of these problems. In May, Leslie Norwalk, the acting administrator of the Center for Medicare & Medicaid Services (CMS), announced a requirement that PFFS plans would have to start calling beneficiaries prior to enrollment to ensure that they understand the plans and have decided to enroll in them. Norwalk also said that CMS allows Medicare beneficiaries to leave plans in which they enrolled because of unethical or illegal practices by sales agents and penalizes health insurers involved with the

## A Plethora of Choices

Distinguishing among supplemental (Medigap), Medicare Advantage (MA), and Part D prescription plans (which can be stand-alone Part D plans or MA-PD plans) is important.

### Part 1: Supplemental Plans (Medigap)

According to AARP.org, a supplemental plan is coverage that will help pay some of the costs in the Original Medicare program and for some care it doesn't cover. Private insurance companies sell Medigap policies. By law, companies can offer only 12 standard Medigap insurance plans (A-L); while all 12 cover basic benefits, each plan has different additional benefits. However, all plans with the same letter cover the same benefits. Though premiums may vary, all Plan C policies will have the same benefits. Supplemental plans do not include long-term care to help you bathe, dress, eat or use the bathroom; vision or dental care; hearing aids; private-duty nursing; or prescriptions.

### Part 2: Medicare Advantage Plans (MA)

The first thing to realize about MA plans is that enrolling in Medicare Advantage effectively disenrolls one from Original Medicare Part A and Part B.

"A Medicare Advantage plan replaces traditional Medicare altogether and usually limits a member's choice of doctors and hospitals."<sup>20</sup>

Beyond that, here's what the government says about MA plans:<sup>21</sup> MA plans are health plan options that are part of the Medicare program. If you join one of these plans, you generally get

all your Medicare-covered health care through that plan. This coverage can include prescription drug coverage. MA plans include:

- Medicare Health Maintenance Organizations (HMO)
- Preferred Provider Organizations (PPO)
- Private Fee For Service Plans (PFFS)
- Medicare Special Needs Plans (SNP)

When you join an MA plan, you use the health insurance card that you get from the plan for your healthcare. In most of these plans, generally there are extra benefits and lower copayments than in the Original Medicare plan. However, you may have to see doctors that belong to the plan or go to certain hospitals to get services.

### Part 3: Medicare Part D

According to the Center for Medicare Advocacy, the Medicare Part D program, which began in January 2006, provides beneficiaries with assistance paying for prescription drugs. Unlike coverage in Medicare Parts A and B, Part D coverage is not provided under traditional Medicare. Instead, beneficiaries must affirmatively enroll in one of many hundreds of Part D plans offered by private companies.<sup>22</sup>

Part D is where you hear about the doughnut hole—another area that is ripe for confusion. "The way the doughnut works, that's not logical," Evans said. "We're all used to as things go up, eventually the plans pays for it. But the way the doughnut was designed, you have this gap. It's a political design to fit the cost."

## Sample Comparison of Premium and IG Costs in Original Medicare (With a Medigap and a Part D Plan) vs. a Medicare Advantage HMO With Part D

The sample figures below are based on 2008 rates and were obtained from [www.Medicare.gov](http://www.Medicare.gov) through a plan search. Intentionally simplified, this chart only compares premium and IG costs and does not account for the doughnut hole or other copays and coinsurance. For the MA example (on the right), three plan examples are given with covered out-of-pocket expenses ranging from zero to 20 percent. Further, a \$5,000 monthly cost is assumed for IG treatment. For specific fees on actual plans, please visit [www.Medicare.gov](http://www.Medicare.gov). Once there, enter your IG brand for more-exact estimated monthly costs.

Original Medicare, Medigap, & Part D (monthly)		MA HMO with Part D (monthly)		
		20%	10%	0%**
Part A & B	\$96	HMO \$100 Part B \$96	HMO \$100 Part B \$96	HMO \$100 Part B \$96
Supplemental (Medigap)	\$175	N/A	N/A	N/A
Part D	\$25	N/A	N/A	N/A
IG Costs*	\$0	\$1,000	\$500	\$0
<b>Premiums and IG</b>	<b>\$296</b>	<b>\$1,196</b>	<b>\$696</b>	<b>\$196</b>

\* Medigap A-J should cover the 20 percent gap that Medicare A and B do not cover; plans K and L pick up 50 percent to 75 percent of the 20 percent gap respectively. This chart assumes 20 percent gap coverage.

\*\* An MA plan that charges 0 percent out of pocket is hard to find.

practices with fines, suspensions of enrollment or revocation of the ability to sell PFFS plans.<sup>14</sup>

The insurance industry has also agreed that stricter marketing guidelines are advisable. However, some question whether the proposed guidelines go far enough, as they do not limit “the commissions that agents get for selling private Medicare plans, which underlie the drive to sign up customers and are fueling Medicare marketing abuses, several critics charge.”<sup>15</sup>

Though a good sign that both Medicare and the insurance industry recognize a need for change, there’s still no guarantee that it will be effected anytime soon. Given that, the onus largely falls on the consumer to avoid a bad plan choice. For those looking for plans, one theme emerges loud and clear: Buyer beware! And, when doing your shopping, it might not hurt to keep this article with you. ■

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# The Littlest Things

By Cheryl L. Haggard

**A**t a recent appointment with Caleb’s ear, nose and throat physician, we were anticipating yet another surgical intervention for Caleb’s chronic nosebleeds.

“So, what brings you here today?” Dr. Mann asks cheerfully.

“Caleb’s nose keeps bleeding,” I answer with customary concern.

“Yeah,” Caleb pipes in. “Just running around at recess or bouncing a ball makes my nose bleed. It’s embarrassing!”

“And frustrating for me,” I chime in. “I’m the one who’s about to take stock in stain remover.”

As Dr. Mann performs his customary look-see at Caleb, I brace myself for the inevitable.

“So Caleb,” Dr. Mann says, interrupting my thoughts. “Show me how you spray steroids up your nose.”

Caleb giggles, then mimes his nightly routine, what we call “kissing your nose.” Then he shakes his head, closes his eyes and says, “Bleccccch!”



Thanks to a miniature family of “bug goobers” (microscopic germs such as streptococcus pneumonia) that have taken up residence in Caleb’s maxillaries, our son has had to endure years of unrelenting upper respiratory infections.

By the age of 10, Caleb had already bravely undergone four sinus surgeries.

And despite how much fun we have with human discharge during his routine sinus washes (you wouldn’t believe the entertainment value in watching to see if Caleb’s string of goo can make it from one end of the basin to the other), we know that sometimes the only solution to the source of his infections is very big surgery. Surgery that is, of course, a very big pain. It means missed school, work and life in general. It means no Friday Night Football. Worse, though, to me, it means no bunco—one of the few chances I have to enjoy female camaraderie.

“So, what’s the verdict?” I ask.

“Caleb’s missing the mark when he’s spraying his nose. He’s irritated some of his mucous membranes.”

My mind wanders to the prospect of surgery No. 5.

“Oftentimes we have to go in and cauterize the tissues that have been damaged.”

‘And there it is,’ I think, wallowing in my pity-pot, not noticing as Dr. Mann fiddles with two wooden examination sticks and a thick rubber band.

Caleb spies the simple medical tools and begins drooling.

“Cool! Rubber bands!”

“Caleb and rubber bands don’t get along,” I tell Dr. Mann, referring to Caleb’s accurate launching of said item at a pretty girl during kindergarten, which led to a Haggard household ban on the fun office product.

“But these, along with spraying his sinuses correctly, will keep him from needing another surgery.”

That’s all I need to hear. The moratorium is over.

Finishing the brilliant bloody nose dam, which resembles eyebrow tweezers, Dr. Mann places it on Caleb’s face. Inciting laughter, Caleb models his new plug.

As we say our goodbyes, hoping to not see Dr. Mann until a year or more from now, I think about his simple solution to our very big problem. All it took was a rubber band and two sticks to avert the havoc that would be wreaked by another sinus procedure. Funny how sometimes it’s the littlest things that can pack an extraordinarily large punch in our lives.

Now that I think about it, I wonder what other burdens, other than medical, might be lifted with a rubber band and two sticks. For example, for overspending, I can put the rubber band around our checkbook and smack my hand with the sticks! My husband loves that idea! Or perhaps they’ll come in handy for the occasional moral temptation. Ever aware of the pitfall of gossip at bunco night (a group of women and gossip? I know, I know—you’ve never heard of such a connection!), I decide to take the wooden examination sticks and thick rubber band to the next bunco night.

As I pull out the device, I ask my girlfriends what they think. Everybody likes the idea just fine. Whether it’s righteousness that sways the group, or the vision of a slingshotted snack headed their way, it’s hard to say. But as I said, sometimes it’s the littlest things that can have the biggest punch! ■

# Advanced Directives: An Essential Part of Your Wardrobe

By Jim Trageser

Too many of us don't have one at all.

Not only should we have one, it may not do us (or our families) much good if we don't carry it with us.

Donna Beatty, an attorney practicing in Spokane, Wash., says people should realize that an advanced directive—popularly known as a living will—is one of the necessities of modern living. Without one, should you suffer serious, life-threatening injury or illness, decisions about providing or withholding care will be made by others—people who may not be familiar with your wishes regarding what kind of care you'd want to receive or not receive.

Who should have an advanced directive?

"Everybody. Except maybe children. You never, ever know," she said. "A directive instructs the hospital, 'I want palliative care,' 'I want all life-saving measures,' or 'I don't want any, just give me fluids.'"

Beatty—who admitted that she doesn't currently have a living will (the person designated as her proxy in her previous advanced directive recently died)—offered the public spectacle surrounding the late Terri Schiavo as an example of what can happen when one doesn't have an advanced directive. Schiavo suffered serious brain damage after collapsing in 1990. When her doctors offered little prognosis for recovery, her husband petitioned a court to have her feeding tube removed—saying she had told him she would not want to exist in a vegetative state.

However, her parents, other family and friends cited her Catholic faith in arguing to the courts that Schiavo would never have wanted to give up any chance at recovery, no matter how remote.

Long story short, Beatty said: Had Schiavo prepared an advanced directive, her wishes about the issue would have been clearly known, sparing her family and friends



the agony of trying to decide what was right for her. (The courts eventually sided with her husband, and Schiavo died in 2005 shortly after the feeding tube was removed.)

While preparing a living will can be uncomfortable, Beatty said we're all going to die someday—whether we're prepared for it or not. "Everybody should think about that—as gruesome as it is."

Along with the advanced directive, Beatty recommended also having a document known as a durable power of attorney—to appoint a proxy to make decisions on your healthcare should you become unable to do so (if, for instance, you undergo surgery and are under anesthesia).

"An advanced directive is basically instructions to the healthcare provider with the contingency that if I'm unable to make healthcare decisions on my own, then so-and-so would be able to do that," Beatty said. "A durable power of attorney is separate from an advanced directive. It could give the person who's given the powers the ability to handle financial issues, insurance issues, those kinds of things."

Preparing these documents doesn't have to be expensive. Most popular will-preparation packages (such as Kiplinger's WILLpower software or Quicken® WillMaker) include forms for filing a living will and power of attorney, and range in price from about \$20 to \$50. Beatty said there are also websites where you can purchase and download the forms to create your own living will.

"Some states—Washington is one of them, Idaho is one of them—allow you to fill out a form and have it on file with the state, so if emergency personnel come to your house, they could access it. It's a very limited advanced directive—it's a form you fill out basically. It's mostly if you choose not to have life-saving measures taken, so they would understand you would not want resuscitation."

Once you have created your advanced directive and durable power of attorney (or had an attorney in your state draft them for you), you should keep one copy with your regular doctor, another with your legal documents (such as your will), and a third with the person designated as your proxy. (Also, keep a copy in your wallet or purse.)

In addition to what kind of treatment you want to receive if you have a life-threatening medical condition, Beatty pointed out that you can also use an advanced directive to lay out your wishes regarding organ donation.

"It could be expressed there, and it is a good idea," she said, adding that "it also has to go through the state stuff—the driver's license. At least your wishes could be expressed, so the doctors would know to keep you on life support until your organs could be harvested." She added that in many states, even if you have expressed your desire to donate your organs or body upon death, your family may have to sign off on the donation.

People with various immunological diseases are still able to donate their healthy organs to those in need of a transplant. Only people with HIV and cancer are prohibited from donating their organs, and there is a tremendous backlog for most major organs—hearts, lungs, kidneys and livers.

Beatty pointed out that while laws about advanced directives and power of attorney vary by state, the Constitution also requires states to recognize legal documents drafted in the other states; just as you don't need to get a new driver's license for each state you travel through, so you don't need to worry about your living will or power of attorney being valid if something should happen while you're traveling, assuming you have it with you.

Children are a special case, Beatty said, because parents or legal guardians will ultimately make any life-or-death decisions regarding minors.

But Beatty recommended that parents of children with serious medical conditions should discuss with the children what kind of treatment they'd want to receive should things take a bad turn. She does not advocate writing those wishes out, though, because the parents are still

going to have to make that decision on the spot—just having talked through it with the child will provide all the preparation a family will need in such a difficult time.

People with some immune deficiencies are, obviously, more susceptible to infection—and if they are in a life-threatening medical condition, their susceptibility is greater.

But Dr. Terry Harville, medical director of the Special Immunology Laboratory, Histocompatibility Laboratory, and Immunogenetics and Transplantation Laboratory (as well as a specialist in pediatric immunology and rheumatology for the University of Arkansas for Medical Sciences), cautioned against erring on the side of giving up too quickly when preparing one's advanced directive.

*Without one, should you suffer serious, life-threatening injury or illness, decisions about providing or withholding care will be made by others—people who may not be familiar with your wishes regarding what kind of care you'd want to receive or not receive.*

"In general, how 'aggressive in treatment' with potentially likely fatality depends on several factors: age and otherwise relative health of the patient," Harville wrote in an e-mail. "A young, otherwise very healthy child deserves the nth degree of treatment, because they have a greater potential for good recovery. An elderly person with extensive heart and lung disease may not be able to recover due to those complicating factors, not merely that they have an immunodeficiency.

"Perhaps the 'biggest' issue in advanced directives is 'mechanical support.' This generally relates to having endotracheal intubation and ventilatory support. Again, the

young with healthy hearts and lungs are more likely to respond and be weaned from the support back to breathing on their own. However, if someone has extremely injured lungs (e.g., bronchiectasis), they may not be able to be weaned from the ventilator, even if an acute lung infection could be treated.

"We currently have antibiotics or immunoglobulin to treat most of the infections. A person with an immunodeficiency may not be able to mount an appropriate response to an infection, but we may have therapy that could help. It is therefore difficult to identify any particular infection for which there is no hope of recovery.

"Therefore, advanced directives for someone with an immunodeficiency may not truly be different from someone with an otherwise intact immune system." ■

# A Force to Be Reckoned With

By Ever Fecske



Brynn (left) and Ever

**M**y sister Brynn is the strongest person I know. She is far wiser than her 19 years, and although she is wise, she is still empathetic and emotional. She possesses a perfect blend of strength and love. Besides my mom, Brynn is the other woman in my life who provides incredible stability.

I have been ill all of my life in one way or another. In the last three years, I've dealt with COVID, interstitial lung disease, and both IVIG and prednisone treatments. Through it all, my sister has been there. She was there when so many others weren't. It's common to think that "sure, she is your family," but she has proven to be so much more than that. She is my best friend.

There are times when I feel guilty about the attention I receive from family members due to my illness. I also wonder if the attention ever causes Brynn to resent me. For this issue, I decided to ask her questions about our relationship.

**Ever:** How has being my sibling affected your perception on life? Do you find that sometimes your take on things is different from your friends who do not have a similar situation? What lessons about life have you learned from observing me?

**Brynn:** Being your sibling has made me see how small things that so many of us see as a crisis or a dilemma truly have simple answers and are unimportant in comparison to what others are dealing with. You have been through so much and have never rendered the woe-is-me act like so many people would do, including myself, if

put in your shoes. Through your experiences I have been able to separate the significant moments in life from the superficial. So when I put on a pair of shorts and think my thighs look fat, I have learned not to sulk but to remember that things could be a whole lot worse.

**Ever:** OK, this one might be tough but you can be honest—have you ever found yourself jealous or resentful of any extra attention I may have received because of my condition? If so, how did you deal with these emotions?

**Brynn:** I have always known that any extra attention you received was necessary. What you deal with and have dealt with in the past is not something that you can go through alone, and it requires a second pair of eyes and ears. It was definitely hard at times when Mom would have to go with you every day, and I indisputably got frustrated at times and voiced it loud and clear, but it has never been an emotion caused by jealousy or resentment.

**Ever:** What is the greatest thing that siblings can do for each other?

**Brynn:** The greatest things siblings can do for each other is to be there for one another, to listen to each other's problems no matter how simply they can be solved, to share outrageous stories and ideas without judgment, and most of all, to love them no matter what.

**Ever:** I totally agree. What is the greatest thing we have done for each other?

**Brynn:** We have provided each other with an outlet, we can vent openly to one another, which is awesome. Our relationship is like having a best friend who can't get rid of you no matter how hard they try. We can fight one day, or even one hour, and then the next we're fine, and we're laughing and having fun. It's comforting to know that I have that.

She is so right! She is absolutely my unconditional outlet, and I try my hardest to be the same for her. I like to think of our sisterhood as a force to be reckoned with. There have been times where people have been unpleasant to me because I look different than I did in high school, and Brynn has stepped right in and put them in their place. She will say something like, "You don't know her! You don't know what she has been through! Get a life!"

How priceless is she? I love her more than anything, and my appreciation is endless. ■



# Let's Talk!

By Shirley German Vulpe, EdD

If your life depends on immune globulin, this column is for you! It is an opportunity to network and share our experiences, because it behooves us to learn as much as possible about all of the ramifications of our illnesses, and this column allows us to learn from one another. If you have a story to share, please email us at [editor@IGLiving.com](mailto:editor@IGLiving.com).

For this column, I interviewed 58-year-old Mitch Fishman, who has been diagnosed with Dysschwannian sensory motor neuropathy, an autoimmune peripheral nerve and nerve root disorder; sarcoidosis, an inflammatory disease that can affect almost any organ in the body; Alport syndrome, an inherited kidney disease; and chronic anemia.

**Shirley:** Can you tell me about your diagnostic process?

**Mitch:** Sure, the Alport syndrome I inherited. It was diagnosed when I was about 30, but the others were discovered because I pushed my doctors to investigate. In January of 2007, after two unsuccessful laminectomies, I had my back fused at the lumbosacral area with six rods. My doctor told me that a side effect of the surgery may be numb feet. I thought, me never, but then yes, indeed, I did have numbness. The orthopedic surgeon said, "Live with it. It is nothing." I still wondered, and I also had a chronic cough and was tired. I consulted family, friends and professionals at the pain clinic and a knowledgeable pharmacist. I was advised to see a pulmonologist, who ordered blood tests and a CAT scan of my lungs. This revealed a mass that was diagnosed as sarcoidosis. Sarcoidosis can also cause neuropathy. I started steroid treatments, and my cough went away. Anemia was also discovered, and B-12 shots twice a week were ordered. However, I felt we still were not at the bottom of things.

My feet were exceedingly painful and felt like they were coming out of my shoes. I could not walk or drive. I pushed to be seen by a neurologist. I was finally referred to one outside of my HMO. He diagnosed the Dysschwannian neuropathy and recommended that I receive IVIG.

**Shirley:** Have you had any problems receiving or paying for the IVIG?

**Mitch:** None at all. My HMO immediately referred me to a nurse infusion clinic. Everything has gone wonderfully. I receive IVIG twice a week.

**Shirley:** Has it helped?

**Mitch:** Definitely, I can now walk two to three blocks and can drive for about 45 minutes. I am able to work a little and can drive my 15-year-old daughter to school and other activities. The pain is less, and my quality of life is much better.

**Shirley:** How about the other conditions?

**Mitch:** I still have chronic fatigue and have to rest a lot, but that is mostly because of the Alport syndrome. I also wear a hearing aid and had to have eye surgery because of the Alport syndrome. My chronic cough is under control with my puffers.

**Shirley:** Have you received any community support?

**Mitch:** Yes, my wife and daughter are immensely supportive. The pharmacist and the pain clinic professionals I mentioned earlier helped me a lot. Certainly the nursing agency and the nurses who help me with my infusions have been wonderful. I have learned

a great deal from them, and they have been incredibly helpful.

**Shirley:** What was the worst advice you were ever given?

**Mitch:** Just "live with it," by my orthopedic surgeon.

**Shirley:** What was the best advice?

**Mitch:** You can get some comfort. Keep looking.

**Shirley:** Have you any final message for those who read this column?

**Mitch:** Sure do. Take control of your situation and be DEMANDING with your MDs. It is your problem. You cannot be passive. Be persistent, you must get everything done for yourself that you can! ■

## Resources

1. Alport syndrome is an inherited disease that always affects the kidneys and may affect hearing and vision. [www.kidney.org](http://www.kidney.org)
2. Chronic Immune Dysschwannian/Dysneuronal polyneuropathy is a rare neurological disorder. An autoimmune peripheral nerve and/or nerve root disorder, it usually responds to IVIG treatment. [www.ncbi.nlm.nih.gov/pubmed/15088499](http://www.ncbi.nlm.nih.gov/pubmed/15088499)
3. Sarcoidosis is an inflammatory disease that can affect almost any organ in the body. However, typically the lungs are affected. [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org)



# Managing Prescription Costs

By Jim Trageser

**P**rescription costs are different from many other medical costs: Coming in smaller increments, they can sneak up on you. But for those of us on long-term prescriptions, the cost of drugs can run into the thousands of dollars over the course of a year—rivaling the cost of a visit to the emergency room.

Fortunately, many prescription costs can be managed, and doing so is easier than one might think.

The two quickest ways to help control what you pay for prescription drugs are to comparison shop among pharmacies and to ask your doctor for a generic version of a prescribed drug.

Shopping around for a prescription drug is a concept that still feels strange to many of us. Traditionally, your doctor writes you the prescription, and you then take it to the neighborhood pharmacy.

And, of course, you pay whatever the pharmacy charges.

But the whole universe of prescription drugs has changed over the last few decades. New miracle drugs that both prolong life and improve our standard of living

have come with a price—often steep. Research and development costs of complex new treatments, along with rising legal liability for drugs with unforeseen side effects, have caused pharmaceutical companies to seek to recoup their investments through higher prices on the drugs that receive government approval and reach local pharmacy shelves.

To encourage pharmaceutical companies to continue investing in yet more new drugs (which does benefit us all), Congress has set patent protection at 20 years from the time a new drug is developed in the United States. Until that patent expires, only the company that invented the drug can sell it. And in the United States, there are no government-imposed price controls. Some new cancer drugs are extremely expensive, running into the thousands of dollars per dose.

Once the patent on a drug expires, however, other companies are free to sell bioequivalent generic versions. (They still need to prove to the government that their formula of the drug is indeed bioequivalent to the original—

meaning its effect on the body is the same, with the same efficacy and risks.)

Because there is open competition among generic versions of the same drug (and because the manufacturers of generic drugs don't have the years of research and development to make up), the prices on generic drugs are generally only a fraction of the original cost of the brand-name version.

At the same time, the increasingly tough competition among retail chains has led Wal-Mart, Kmart, Target and Costco to slash the prices they charge for many generic prescription drugs.

Responding to Wal-Mart's decision in 2006 to lower prices on many generic drugs to only \$4 for a month's supply, and \$10 for three months' worth, Safeway announced in early June that it would match that price in its stores in the eastern United States, following Target's decision to also match Wal-Mart's prices. And in late June, Kmart announced it would offer \$5 pricing on one-month supplies of more than 500 generic prescription drugs ([www.tinyurl.com/6pfj8j](http://www.tinyurl.com/6pfj8j)). The membership store Costco offers one-month supplies of many generics for just a little over \$5, with similar savings for 90-day supplies as well.

Longs Drugs, a drugstore chain in the western United States, offers generic pricing similar to Costco's and will even deliver prescriptions at no additional charge in some areas. (All prices are accurate as of early September.)

But not everyone is using these pharmacies. The June issue of *Consumer Reports*® magazine contained the results of a survey of pharmaceutical prices that showed a range of prices from pharmacy to pharmacy. (Consumers can search the Consumer Reports Health.org website for prices among brand names and their generic equivalents at [www.tinyurl.com/662g2s](http://www.tinyurl.com/662g2s).)

So while the unaware consumer might be paying more than ever (admittedly for drugs that offer relief previous generations never dreamt of), the more savvy have ample opportunities to purchase their prescription drugs at inflation-adjusted prices our grandparents would envy.

For instance, according to the *Consumer Reports* study, Bayer's brand-name Cipro antibiotic costs about \$400 for 90 250 mg tablets. (Prices at stores surveyed ranged from \$389.94 to \$406.57.)

On the other hand, the generic ciprofloxacin costs \$4 for 14 250 mg tablets at Wal-Mart (as of its most recent price list, found at [www.walmart.com](http://www.walmart.com)), and \$5 for 20 of the same tabs at Kmart ([www.kmart.com](http://www.kmart.com)). Costco ([www.costco.com](http://www.costco.com)) lists a price of \$11.95 for 30 of the 500 mg tabs.

Another common drug, the generic asthma treatment albuterol, is included in Kmart's \$5 program in 2 mg tablets (90 quantity), \$4 for the same package at Wal-Mart (listed as a one-month supply), while Costco lists the inhaler at \$18.

Many of the large retail chains list their prices for various prescriptions on their websites, making comparison shopping easier than ever. (The above prices were found using the stores' own websites, plus the *Consumer Reports* survey.)

In addition to comparison shopping for generic drugs, be sure to check with your employer to see if you have a prescription drug plan as part of your benefits package. Using a prescription plan can offer dramatic savings on newer drugs for which generic versions are not yet available.

For those who are self-employed or whose employer doesn't offer medical benefits, some local government agencies, such as Loudoun County, Va., ([www.tinyurl.com/5vlz5c](http://www.tinyurl.com/5vlz5c)), have drug discount cards—often offering up to a 20 percent lower price at participating pharmacies. (The discount plans work similarly to a private insurance plan, in which the government agency negotiates a discount in exchange for sending their clients to the participating stores—a sort of volume discount.)

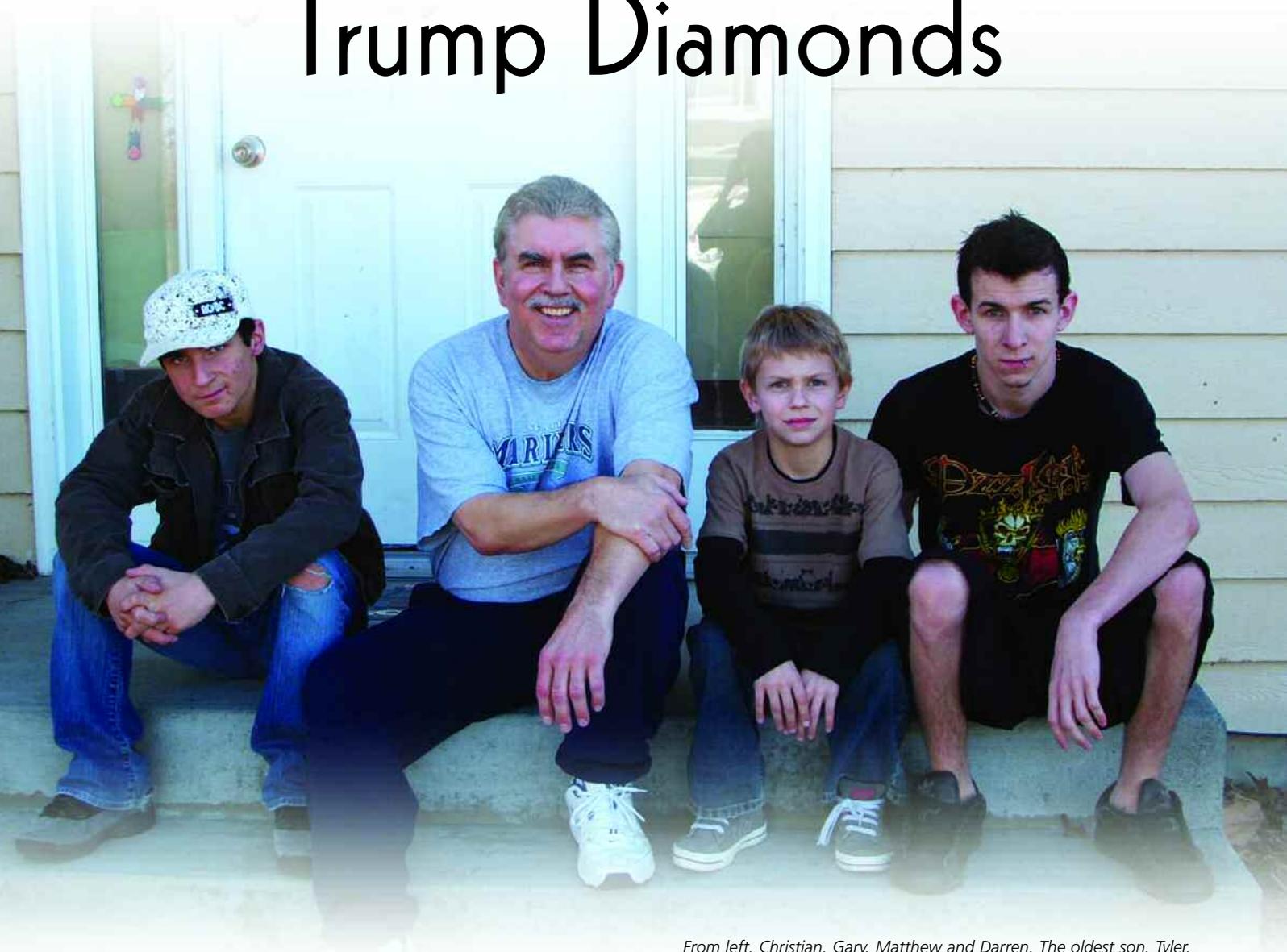
The program is overseen by the National Association of Counties (NACo), which contracts with Caremark to negotiate the bulk discounts from retail outlets. NACo maintains a list of counties participating in the drug discount program ([www.tinyurl.com/2gdsoj](http://www.tinyurl.com/2gdsoj)).

Another way to save money is to purchase prescription drugs via mail order. Medco, which handles prescription benefits for many health insurance carriers (such as Blue Cross and Blue Shield), offers a mail-order service in which plan members can get up to three months of prescriptions filled at a significant discount. Medco ([medcohealth.com](http://medcohealth.com)) also provides mail order to Medicare enrollees, and many if not most prescription benefit plans offer similar savings for those who order in bulk by mail.

For a small annual membership fee, Walgreens is offering a prescription savings club where you can buy three-month supplies of many generic drugs for \$12.99. Target has a new membership program where for every 10 prescriptions filled at a Target pharmacy, you get a credit for 10 percent off for your next shopping trip.

As more and more of us find ourselves on treatment plans that include long-term prescriptions, exploring ways to bring down costs promotes our medical and financial health. ■

# Trump Diamonds



*From left, Christian, Gary, Matthew and Darren. The oldest son, Tyler, is not pictured. The youngest, Matthew, is from a later marriage.*

By Mark T. Haggard

**D**iamonds are created when coal is exposed to prolonged periods of intense pressure. In the same vein, beauty in people is often revealed during dark times. Few situations are darker than the events that Gary Trump experienced in 1993. But during that time, diamonds began to form, their emergent sparkling hinted at through fortuitous circumstances as well as the kindness of others. Even now, some 15 years later, Gary's faith and resolve—the ultimate priceless gems—still shine brightly.

"The first six months of 1993 were hell," Gary recalls.

At the time Gary and his wife, Tracee, lived in Richland, Wash., with their two young boys. Thirty-six-year-old Tracee was late into her pregnancy with their third child when she came down with a fever just before her delivery. She was diagnosed with viral encephalitis, an infection of the brain.

Tracee was transferred to the University of Washington Medical Center in Seattle, where a series of tests determined

that the encephalitis was the result of common variable immune deficiency (CVID). Over the next three weeks, 24 hours a day, Tracee was administered massive doses of intravenous immune globulin (IVIG) into her spinal fluid.

During this time, Gary lived in the hospital room with his wife.

Two-and-a-half months later, the fever broke and Tracee was released from the hospital, but she would be disabled for the rest of her life. Against this backdrop, the diamonds began to reveal themselves: The Trumps were never billed by the University of Washington Medical Center; Gary never missed a paycheck from his job at the Hanford Nuclear Reservation; and, for an entire month, church members brought the Trumps dinner every night.

Gary also received help from members of his own family, including his parents, who lived in nearby Hermiston, Ore. The greatest sacrifice came from his wife's family.

"Tracee's mother is my hero," Gary said, high praise for any mother-in-law. "She moved up here from Mount Shasta, and has never gone back."

Shortly after Tracee came home, newborn son Christian came down with viral pneumonia. He was airlifted to the medical center in Seattle, and once again Gary found himself living in a hospital. And, once again, diamonds were revealed. People visited almost daily: Gary's sister, his sister-in-law, his parents. He received regular phone calls, and, when he was stressed, the nurses took care of him, encouraging him to get out of the room to take a walk and relax.

Thankfully, Christian beat the pneumonia two weeks later.

In 1997, darkness fell again when Tracee lost her battle with CVID.

Following Tracee's death, Gary took his family for grief counseling. He also kept the boys busy with sports and church. He told them they could talk about their feelings

anytime they wanted. They didn't say much, but their mother was clearly still on their minds.

Now, more than a decade later, two of Gary's boys, Darren and Christian, are fighting their own battles with CVID. Both started IVIG therapy at age 5. Now in their teens, both receive subcutaneous immune globulin (SCIG or subQ). Gary acknowledged that keeping adolescents on their medicine is challenging. "All I can do is remind them and encourage them," he says.

But often, reminding and encouraging are not enough. Teenage boys are teenage boys. They think of themselves as indestructible: They play with fire; they drive too fast; and the Trump boys forget to take their medication.

This past year, Darren graduated from high school and moved out of the house. Without his father's reminders, Darren missed treatments and became ill. Antibiotics and a return to SCIG therapy restored his health, but he has had to move back home.

And in the back of Gary's mind is the fear that he might lose his kids the same way that he lost Tracee. And yet his resolve is clear: "I'm not going to let anyone else in this family suffer and die like Tracee."

Still, Gary knows that when the boys feel healthy, they don't think about their need for treatment. Although Christian and Darren still have pictures

of Tracee in their room, according to Gary, "the memory of their mom doesn't change them. It doesn't convince them that they need their medicine."

But he is quick to add, "I have faith that they will eventually realize how lucky they are, and that they will both live long and productive lives."

Like their father, these young men have been exposed to prolonged periods of intense pressure. Guided by their family's courage, they are already transforming into diamonds—Trump diamonds—who will shine for others during dark times. ■

*“ I have faith that they will eventually realize how lucky they are, and that they will both live long and productive lives. ”*

# Raising Neuropathy Awareness

By Cheryl Brooks

The Neuropathy Action Foundation (NAF) held its second annual Neuropathy Action Awareness Day on June 26 at the UCSF Mission Bay Conference Center in San Francisco.

NAF President Dominick Spatafora, who's preparing for a conference in November, dubbed the gathering a success.

"This event helped the NAF empower neuropathy patients and increase neuropathy public awareness," Spatafora said. "Neuropathy patients and those who love them have the inherent ability to be passionate and persuasive advocates."

Empowerment is crucial, Spatafora continued, for patient advocacy—both for oneself and for others.

"Empowering yourself means that you should understand neuropathy and know how to navigate the healthcare system in your state," Spatafora said. "Once you are educated, you should get involved and participate in the policies that affect your condition."

Because the NAF believes that patients should not have to pay to learn about their disease, neuropathy patients attended the daytime seminars and luncheon free of charge.

The conference attracted more than 250 attendees, exhibitors, corporate sponsors and speakers from across the country, including the 17th surgeon general of the United States, Richard H. Carmona, MD, MPH, FACS, and Jennifer Holliday, Grammy and Tony Award-winning singer and actress.

Featured speakers included Patrick M. Schmidt, CEO of FFF Enterprises, Inc., and IG Living's publisher, and Michelle Vogel, a representative of The Alliance for Plasma Therapies, who co-presented "IVIg and the Importance of Blood/Plasma."

IG Living advisory board member Todd Levine, MD, and David Saperstein, MD, outlined the basics with "Neuropathy 101 for the General Public."

Aware of the importance of advocacy, Dr. Levine offered advice in a post-conference interview for patients who don't feel there's a real level of interest from their doctors about treating their condition.

"The first step is to be evaluated by a neurologist who has some interest and/or expertise in peripheral neuropathies," Dr. Levine said.

"There's a tremendous amount being discovered monthly," Dr. Levine continued, so having a doctor who stays abreast of current research is key.

To find such a doctor, Dr. Levine advises patients to check out the university hospitals designated as neuropathy centers by The Neuropathy Association on [www.neuropathy.org](http://www.neuropathy.org). For patients who do not live near a center, local support

groups, which can also be found on the site, may be able to provide potential doctor recommendations.

Trisha Torrey, Every Patient's Advocate for the About.com Guide to Patient Empowerment, spoke about the tools patients need to navigate medical care. Torrey posted the following on her blog about the event.

- *Patients with neuropathy are as frustrated by diagnosis problems as anyone else. There are at least 100 different forms of neuropathy, and it can be caused by dozens of other problems: diabetes, injury, chemo, other toxins, even alcoholism. Unfortunately, the cause of this short-circuiting for many patients cannot ever be determined.*
- *Doctors can't agree on treatments, and patients get confused. There was a surgeon who was citing statistics on the success of several surgeries similar to carpal tunnel surgery. But a few speakers later ... two doctors were very clearly anti-surgery.*
- *For some neuropathy patients, there are some infusion-type treatments that work very well, including one called IVIG, which uses blood platelets. The problem is, insurance companies don't want to cover IVIG. Some patients who have been treated successfully with IVIG for months, even years, find insurance coverage for it suddenly dropped. An organization was founded a year ago to help patients defend their need for infusion treatments, and it has found quite a bit of success. But I find it's a shame they have to work so hard. The success of the treatment is well-documented. Patients are able to return to normal function.*

You can check out this blog at <http://patients.about.com/b/2008/06/29/neuropathy-20-million-suffer-from-a-condition-youve-never-heard-of.htm>.

On Nov. 17, patients will have another chance to join forces. NAF will co-host with Banner Good Samaritan Medical Center an Arizona Neuropathy Awareness Day, which will feature Drs. Levine and Saperstein. The event, to be held at the Orange Tree Golf Resort in Scottsdale, Ariz., will promote neuropathy awareness and benefit Banner Good Samaritan Neuroscience Peripheral Neuropathy Clinic. The majority of the proceeds will go to the clinic to help evaluate uninsured patients and to fund research. The remainder will go to the NAF for neuropathy education and patient advocacy/empowerment.

If you would like more details about this event, check out [www.neuropathyaction.org](http://www.neuropathyaction.org). ■

# Resource Directory

For a more comprehensive list of resources, visit the Resources page at [www.IGLiving.com](http://www.IGLiving.com).

## Ataxia Telangiectasia (A-T)

### Websites

- A-T Children's Project: [www.atcp.org](http://www.atcp.org)
- NINDS A-T Information Page: [www.ninds.nih.gov/disorders/a\\_t/a-t.htm](http://www.ninds.nih.gov/disorders/a_t/a-t.htm)

## Chronic Inflammatory Demyelinating Polyneuropathy (CIPD)

### Websites

- GBS/CIDP Foundation International: [www.gbs-cidp.org](http://www.gbs-cidp.org)
- National Institute of Neurological Disorders and Stroke (NINDS) Chronic Inflammatory Demyelinating Polyneuropathy (CIPD) Information Page [www.ninds.nih.gov/disorders/cidp](http://www.ninds.nih.gov/disorders/cidp)
- Neurology Muscular Dystrophy and Neuropathy Institute Illustration of a damaged myelin sheath on a nerve: [www.beverlyhillsneurology.com/cidp](http://www.beverlyhillsneurology.com/cidp)

### Online Peer Support

- The Neuropathy Association: [www.neuropathy.org](http://www.neuropathy.org)
- Barbara's CIDP/GBS Site (This is a personal website) [www.geocities.com/HotSprings/Falls/3420](http://www.geocities.com/HotSprings/Falls/3420)

## Evans Syndrome

### Websites

- Office of Rare Diseases (catalog of online resources) <http://rarediseases.info.nih.gov/GARD/Disease.aspx?PageID=4&diseaseID=6389>
- New!** • Clinical Reference from eMedicine: [www.emedicine.com/ped/topic721.htm](http://www.emedicine.com/ped/topic721.htm)

### Online Peer Support

- Evans Syndrome Research and Support Group: [www.evanssyndrome.net](http://www.evanssyndrome.net)

## Guillain-Barré Syndrome (GBS)

### Websites and Chat Rooms

- The GBS/CIDP Foundation International, [www.gbs-cidp.org](http://www.gbs-cidp.org), has 23,000 members in 160 chapters on five continents. 610-667-0131
- The GBS/CIDP Foundation International Discussion Forums provide the opportunity to talk to other GBS patients and learn more about ways to manage the illness: [www.gbs-cidp.org/forums](http://www.gbs-cidp.org/forums).
- Miller Fisher Syndrome, considered to be a variant of GBS, is explained on the National Institute of Neurological Disorders and Stroke, NINDS Miller Fisher Syndrome Information Page: [www.ninds.nih.gov/disorders/miller\\_fisher/miller\\_fisher.htm](http://www.ninds.nih.gov/disorders/miller_fisher/miller_fisher.htm).

### Online Pamphlets

- The National Institute of Neurological Disorders and Stroke has a GBS Fact Sheet at [www.ninds.nih.gov/disorders/gbs/detail\\_gbs.htm](http://www.ninds.nih.gov/disorders/gbs/detail_gbs.htm).
- The Mayo Clinic has an overview of Guillain-Barré Syndrome at [www.mayoclinic.com/health/guillain-barré-syndrome/DS00413](http://www.mayoclinic.com/health/guillain-barré-syndrome/DS00413).
- The National Institute of Neurological Disorders and Stroke has an information page about CIDP: [www.ninds.nih.gov/disorders/cidp/cidp.htm](http://www.ninds.nih.gov/disorders/cidp/cidp.htm).

### Online Peer Support

- GBS & CIDP Discussion Forum – UK Bulletin Board – For Ireland and England [www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi](http://www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi)
- GBS Support Group and Chat Room, UK [www.jsmarcussen.com/gbs/uk/chat.htm](http://www.jsmarcussen.com/gbs/uk/chat.htm)

- GBS Foundation Discussion Forums: [www.guillain-barre.com/forums](http://www.guillain-barre.com/forums)
- Yahoo Support Group Discussion Board [http://health.groups.yahoo.com/group/GBS\\_CIDP](http://health.groups.yahoo.com/group/GBS_CIDP)

### Books and Articles

- "A Handbook for Care Givers," by Helen Rummelsburg, gives an account of caring for her husband and offers helpful hints for patients and caregivers. Available at the GBS website bookstore at [www.gbsfi.com](http://www.gbsfi.com).
- "Bed Number Ten," by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.
- "Caring for a Child With GBS," by Patricia Schardt, is a short guide written by a mother of a child with CIDP. Available at the GBS website bookstore at [www.gbsfi.com](http://www.gbsfi.com).
- "No Laughing Matter," by Joseph Heller (the best-selling author of Catch-22), who teamed up with Speed Vogel, his best friend, to describe Heller's battle with and triumph over GBS.

## ITP (Idiopathic Thrombocytopenic Purpura)

### Websites

- ITP Support Association, UK: [www.itpsupport.org.uk](http://www.itpsupport.org.uk)
- Platelet Disorder Support Association: [www.pdsa.org](http://www.pdsa.org)
- National Heart, Lung and Blood Institute [www.nlm.nih.gov/health/dci/Diseases/itp/ITP\\_Whats.html](http://www.nlm.nih.gov/health/dci/Diseases/itp/ITP_Whats.html)

### Online References

- Idiopathic thrombocytopenic purpura [www.mayoclinic.com/health/idiopathic-thrombocytopenic-purpura/DS00844](http://www.mayoclinic.com/health/idiopathic-thrombocytopenic-purpura/DS00844)
- Idiopathic Thrombocytopenic Purpura: Michael A. Silverman, MD [www.emedicine.com/EMERG/topic282.htm](http://www.emedicine.com/EMERG/topic282.htm)
- Immune Thrombocytopenia: Current Understanding and Future Research, Robert S. Mocharnuk, MD [www.medscape.com/viewarticle/459249](http://www.medscape.com/viewarticle/459249)
- ITP: Idiopathic Thrombocytopenic Purpura: <http://familydoctor.org/113.xml>

## Kawasaki Disease

### Websites

- Kawasaki Disease Foundation: [www.kdfoundation.org](http://www.kdfoundation.org)  
PO Box 45 • Boxford, MA 01921  
Tel: 978-356-2070 • Fax: 978-356-2079 • Email: [info@kdfoundation.org](mailto:info@kdfoundation.org)
- Kids Health discusses Kawasaki disease [www.kidshhealth.org/parent/medical/heart/kawasaki.html](http://www.kidshhealth.org/parent/medical/heart/kawasaki.html).
- Overview from the American Heart Association focuses on how the disease affects the heart [www.americanheart.org/presenter.jhtml?identifier=4634](http://www.americanheart.org/presenter.jhtml?identifier=4634)

## Mitochondrial Disease

### Websites

- United Mitochondrial Disease Foundation promotes research and education for the diagnosis, treatment and cure of mitochondrial disorders and provides support to affected individuals and families. [www.umdf.org](http://www.umdf.org)
- The Cleveland Clinic website provides many articles when searched by the topic, "mitochondrial disease." [www.clevelandclinic.org/health](http://www.clevelandclinic.org/health)

# Resource Directory

- The National Institute of Neurological Disorders and Stroke provides an informative Mitochondrial Myopathies Information Page. [www.ninds.nih.gov/disorders/mitochondrial\\_myopathy/mitochondrial\\_myopathy.htm](http://www.ninds.nih.gov/disorders/mitochondrial_myopathy/mitochondrial_myopathy.htm)

## Multifocal Motor Neuropathy (MMN)

### Websites

- National Institute of Neurological Disorders and Strokes (NINDS) provides a Multifocal Motor Neuropathy Information Page: [www.ninds.nih.gov/disorders/multifocal\\_neuropathy/multifocal\\_neuropathy.htm](http://www.ninds.nih.gov/disorders/multifocal_neuropathy/multifocal_neuropathy.htm)
- Multifocal Motor Neuropathy Center at Johns Hopkins Department of Neurology [www.neuro.jhmi.edu/MMN/index.html](http://www.neuro.jhmi.edu/MMN/index.html)
- The Neuromuscular Center at Washington University in St. Louis, Mo. Neuromuscular Home Page [www.neuro.wustl.edu/neuromuscular](http://www.neuro.wustl.edu/neuromuscular)
- The Neuropathy Association is dedicated to helping those with conditions affecting peripheral nerves. [www.neuropathy.org](http://www.neuropathy.org)

## Multiple Sclerosis (MS)

### Websites and Chat Rooms

- The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS. [www.nationalmssociety.org/](http://www.nationalmssociety.org/)
- All About Multiple Sclerosis provides accurate and comprehensive medical information about MS written in plain English by people living with the disease and its symptoms. [www.mult-sclerosis.org/index.html](http://www.mult-sclerosis.org/index.html)
- Multiple Sclerosis Foundation works for a brighter tomorrow for those affected by MS. [www.msfacts.org](http://www.msfacts.org)
- Multiple Sclerosis Association of America seeks to enrich the quality of life for individuals with multiple sclerosis. [www.msaa.com](http://www.msaa.com)
- MSWorld's Chat and Message Board features patients helping patients. [www.msworld.org](http://www.msworld.org)

### Online Peer Support

- Friends with MS: [www.FriendsWithMS.com](http://www.FriendsWithMS.com)  
Forum: <http://health.groups.yahoo.com/group/FriendsWithMS>
- My MSViews: [www.mymviews.org](http://www.mymviews.org)  
Forum: [http://health.groups.yahoo.com/group/MSViews\\_Multiple\\_Sclerosis](http://health.groups.yahoo.com/group/MSViews_Multiple_Sclerosis)
- MS Support Group: <http://health.groups.yahoo.com/group/mscured>
- The MS Carousel—A Place to Meet With People Who Understand MS!  
<http://health.groups.yahoo.com/group/themscarousel>

## Myasthenia Gravis (MG)

### Websites and Chat Rooms

- The Myasthenia Gravis Foundation of America (MGFA) is the only national volunteer health agency dedicated solely to the fight against (MG). [www.myasthenia.org](http://www.myasthenia.org)
- Myasthenia Gravis Fact Sheet prepared by National Institute of Neurological Disorders and Strokes. [www.ninds.nih.gov/disorders/myasthenia\\_gravis/myasthenia\\_gravis.htm](http://www.ninds.nih.gov/disorders/myasthenia_gravis/myasthenia_gravis.htm)
- Mayo Clinic's overview of myasthenia gravis: [www.mayoclinic.com/health/myasthenia-gravis/DS00375](http://www.mayoclinic.com/health/myasthenia-gravis/DS00375)

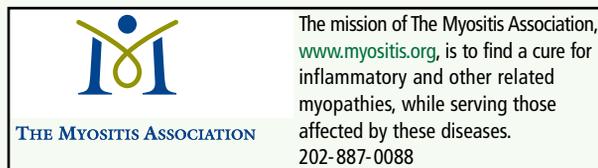
### Online Peer Support

- MGFA's Forum: <http://health.groups.yahoo.com/group/MGnet>
- Bette's Myasthenia Gravis Support: <http://health.groups.yahoo.com/group/bettesmyastheniagravisupport>

- Maddy's MG Support: <http://health.groups.yahoo.com/group/maddysmgssupport>
- Autoimmune Information Network Inc.: [www.aininc.org](http://www.aininc.org)  
PO Box 4121 • Brick, NJ 08723 • 877-246-4900 • Email: [autoimmunehelp@aol.com](mailto:autoimmunehelp@aol.com)

## Myositis

### Websites



- International Myositis Assessment and Clinical Studies Group is a coalition of healthcare providers and researchers with global approaches to improved treatments and understanding of myositis: <https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main>
- The Cure JM Foundation was created specifically to find a cure for Juvenile Myositis (JM), while also providing support and information for families affected by JM. <http://curejm.com>
- Johns Hopkins Myositis Center is a new patient treatment center that brings the expertise of rheumatologists and neurologists into a single clinic for patients with inflammatory (autoimmune) and toxic (drug induced) muscle conditions. [www.hopkinsmedicine.org/rheumatology/clinics/myositis\\_center.html](http://www.hopkinsmedicine.org/rheumatology/clinics/myositis_center.html)

### Online Peer Support

- Juvenile Myositis Family Support Network: [www.curejm.com/family\\_support/index.htm](http://www.curejm.com/family_support/index.htm)
- Myositis Association Community Forum: [www.myositis.org](http://www.myositis.org)
- Myositis Support Group: [www.myositisupportgroup.org](http://www.myositisupportgroup.org)
- Myositis Support Group UK: [www.myositis.org.uk](http://www.myositis.org.uk)
- Yahoo Myositis Support Group Discussion Board: <http://health.groups.yahoo.com/group/OurMyositis>
- The California Myositis Symposium held in 2005 was captured on DVD. It contains information about polymyositis, dermatomyositis and inclusion body myositis, including doctors' discussions and detailed slides and explanations of muscle biopsies, skin rash, and tools used to diagnose these diseases. Other presentations offer valuable lessons in maintaining a positive attitude, exercises for physical therapy and innovative tools to aid in everyday activities. The DVD is available at no charge by sending an email to Richard Gay at [rgay@socal.rr.com](mailto:rgay@socal.rr.com).

### Books and Articles

- "Coping With a Myositis Disease," by James R. Kilpatrick, is written by myositis patients telling their personal stories.
- "Inclusion-Body Myositis and Myopathies," by Valerie Askanas (Editor), Georges Serratrice (Editor) and W. King Engel (Editor), is devoted to discussing the two forms of inclusion-body myositis.
- "Living With Myositis," edited by Jenny Fenton, is an accessible, realistic and sympathetic guide to facts, feelings and future hopes.
- "Myositis—A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References," by ICON Health Publications, is a three-in-one reference book: a complete dictionary of terms relating to myositis, a list of bibliographic citations about the disorder and a guide to Internet resources.
- "Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers," an indispensable resource for families of children with myositis and their healthcare teams, is available at [www.myositis.org](http://www.myositis.org).

# Resource Directory

- "The Official Patient's Sourcebook on Inclusion Body Myositis," by James N. Parker (Editor) and Philip M. Parker (Editor), is a reference manual for self-directed patient research.

## Pemphigus and Pemphigoid

### Websites

- The International Pemphigus and Pemphigoid Foundation provides information and support to people living with the autoimmune diseases. [www.pemphigus.org](http://www.pemphigus.org)
- Information from the National Institutes of Health: [www.niams.nih.gov/hi/topics/pemphigus/pemphigus.htm](http://www.niams.nih.gov/hi/topics/pemphigus/pemphigus.htm)  
[www.nlm.nih.gov/medlineplus/ency/article/000882.htm](http://www.nlm.nih.gov/medlineplus/ency/article/000882.htm)
- Rare disease report: <http://rarediseases.about.com/od/rarediseasesp/a/pemphigus05.htm>

## Peripheral Neuropathy (PN)

### Websites



The Neuropathy Association, [www.neuropathy.org](http://www.neuropathy.org), is devoted exclusively to all types of neuropathy, which affects upwards of 20 million Americans. The Association's mission is to increase public awareness of the nature and extent of PN, facilitate information exchanges about the disease, advocate the need for early intervention and support research into the causes and treatment of neuropathies. 212-692-0662

- To learn about PN, how it is classified, the symptoms, causes and treatments, see the Peripheral Neuropathy Fact Sheet available at [www.ninds.nih.gov/disorders/peripheralneuropathy/peripheralneuropathy.htm](http://www.ninds.nih.gov/disorders/peripheralneuropathy/peripheralneuropathy.htm).
- The Neuropathy Action Foundation, at [www.neuropathyaction.org](http://www.neuropathyaction.org), educates, empowers and informs patients and physicians about neuropathy.

### Support Groups

- Click on the Member Services tab of the website, [www.neuropathy.org](http://www.neuropathy.org), for listings of support groups across the nation.

### Online Peer Support

- Calgary Neuropathy Support Group: [www.calgarypn.org](http://www.calgarypn.org)
- MSN Support Group Discussion Board: <http://groups.msn.com/PNPARTNERS>
- The Neuropathy Association Bulletin Board: [www.neuropathy.org](http://www.neuropathy.org)
- Yahoo Neuropathy Support Group Discussion Board: <http://health.groups.yahoo.com/group/neuropathy>
- Yahoo Support Group – Australia Discussion Board: <http://au.groups.yahoo.com/group/LifeWithPN>

### Books and Articles

- "If You're Having a Crummy Day, Brush Off the Crumbs!," by Mims Cushing, is a how-to book that offers more than 75 ways to help people get through the days when neuropathy (or other ailments) is particularly difficult.
- "Medifocus Guide to Peripheral Neuropathy," is a guide to current and relevant PN research, organized into categories for easy reading.
- "Numb Toes and Aching Soles," by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.
- "Numb Toes and Other Woes," by John Senneff, is the second in a series of three books. It focuses on clinical findings and treatment strategies for PN.
- "Nutrients for Neuropathy," by John Senneff, the third in the Numb Toes series, is

focused exclusively on nutrient supplementation as a means for managing PN.

- "Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop" by Dr. Norman Latov, MD, PhD, published 2007, Weill Medical College, Cornell University, provides practical information on all the neuropathies, causes and treatments.

## Primary Immune Deficiency Disease (PID)

### Websites and Chat Rooms

 <a href="http://www.primaryimmune.org">www.primaryimmune.org</a>	The Immune Deficiency Foundation (IDF), <a href="http://www.primaryimmune.org">www.primaryimmune.org</a> , is dedicated to improving the diagnosis and treatment of PID through research and education. 800-296-4433
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### Jeffrey Modell Foundation

The Jeffrey Modell Foundation, [www.info4pi.org](http://www.info4pi.org), is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for primary immunodeficiency. 212-819-0200

- The National Institute of Child Health and Human Development (NICHD), [www.nichd.nih.gov](http://www.nichd.nih.gov), is part of the National Institutes of Health. Go to the "Health Information and Media" tab on the website and do a search under "primary immunodeficiency."
- The American Academy of Allergy, Asthma & Immunology, [www.aaaai.org](http://www.aaaai.org), has a helpful Q&A section on its website, with resources and tips for those with various immune deficiencies.
- The Michigan Immunodeficiency Foundation, [www.midf.org](http://www.midf.org), seeks to improve the quality of life for Michigan residents affected by PID.
- The International Patient Organization for Primary Immunodeficiencies (IPOPI), [www.ipopi.org](http://www.ipopi.org), promotes the worldwide improvement in the care and treatment of PID patients.
- To connect to a PID message board, go to [www.info4pi.org](http://www.info4pi.org).
- To chat with peers on IDF's Forum, go to [www.primaryimmune.org/forums/forum\\_intro.htm](http://www.primaryimmune.org/forums/forum_intro.htm).
- Chat with parents of children affected by primary immune deficiency at <http://health.groups.yahoo.com/group/PedPID>.
- Chat with peers with PID at <http://health.groups.yahoo.com/group/PIDsupport>.
- A group of family and friends of patients with primary immune deficiencies maintains a nonprofit network in the New England area: [www.nepin.org](http://www.nepin.org)
- Baxter's website, [www.immunedisease.com](http://www.immunedisease.com), offers in-depth information on immunology, PID and treatment with intravenous immune globulin. Click on "European" to see SCIG information.
- Rainbow Allergy-Immunology, [www.rainbowbabies.org/immunology](http://www.rainbowbabies.org/immunology), provides comprehensive diagnostic, therapeutic and consultative services for children and adults with immunologic diseases. For patient information about subcutaneous IG therapy: [www.rainbowbabies.org/subcu](http://www.rainbowbabies.org/subcu).
- **New!** Support for those with PID in the New England area: [www.teamhope.info](http://www.teamhope.info)

### Online Pamphlets and Education

- Go to the National Institute of Allergy and Infectious Diseases site at [www.niaid.nih.gov](http://www.niaid.nih.gov) and search for "primary immune deficiency."
- "Understanding the Immune System: How It Works," by the U.S. Department of Health and Human Services, is found at [www3.niaid.nih.gov/healthscience/healthtopics/immuneSystem/PDF/theImmuneSystem.pdf](http://www3.niaid.nih.gov/healthscience/healthtopics/immuneSystem/PDF/theImmuneSystem.pdf)

# Resource Directory

- “NIAID Initiative Addresses Primary Immune Deficiency Diseases by National Institute of Allergy and Infectious Diseases” is located at <http://www3.niaid.nih.gov/news/newsreleases/2003/pirc.htm>
- The “Immunodeficiency in Pediatrics” program (PREP®) audio series is a new pediatrician education program that can be obtained by contacting the American Academy of Pediatrics at 866-843-2271 or visiting [www.prepaudio.org](http://www.prepaudio.org).

## Online Peer Support

- Chat with parents of children affected by PIDD <http://health.groups.yahoo.com/group/PedPID/>
- Chat with peers with PIDD: <http://health.groups.yahoo.com/group/PIDsupport/>
- Immune Deficiency Foundation Forum [www.primaryimmune.org/forums/forum\\_intro.htm](http://www.primaryimmune.org/forums/forum_intro.htm)
- Jeffrey Modell Foundation Message Board: [www.info4pi.org](http://www.info4pi.org)
- Rhode Island peer group <http://health.groups.yahoo.com/group/RhodeIslandPID/>

## Books and Articles

- “21st Century Complete Medical Guide to Primary Immune Deficiency, Severe Combined Immunodeficiency (SCID), Chronic Granulomatous Disease (CGD), for Patients and Physicians,” by PM Medical Health News, contains federal government clinical data and practical information for patients and physicians.

## Scleroderma

### Websites

- Johns Hopkins Medicine Scleroderma Center: [scleroderma.jhmi.edu](http://scleroderma.jhmi.edu)
- Scleroderma Research Foundation: [www.srfcure.org](http://www.srfcure.org)
- Scleroderma Foundation: [www.scleroderma.org](http://www.scleroderma.org)

### Online Peer Support

- Educating instead of medicating CureZone.com <http://curezone.com/forums/f.asp?f=404>
- International Scleroderma Network: [www.sclero.org/support/forums/a-to-z.html](http://www.sclero.org/support/forums/a-to-z.html)

## Stiff-Person Syndrome (SPS)

### Websites

- American Autoimmune Related Diseases Association Inc., [www.aarda.org](http://www.aarda.org), is the only national organization dedicated to addressing the problem of autoimmunity. 800-598-4668 [aarda@aarda.org](mailto:aarda@aarda.org)
- Autoimmune Information Network Inc., [www.aininc.org](http://www.aininc.org), helps patients and family cope with the disabling effects of autoimmune diseases. 732-262-0450 [autoimmunehelp@aol.com](mailto:autoimmunehelp@aol.com)
- National Association for Rare Disorders (NORD), [www.rarediseases.org](http://www.rarediseases.org), promote awareness of rare diseases and the need for research. 800-999-6673 [orphan@rarediseases.org](mailto:orphan@rarediseases.org)
- National Institute of Neurological Disorders and Stroke (NINDS), [www.ninds.nih.gov](http://www.ninds.nih.gov), offers treatment, diagnosis and research information for rare diseases. 800-352-9424 [braininfo@ninds.nih.gov](mailto:braininfo@ninds.nih.gov)
- Mayo Clinic — Stiff-Person Syndrome: Can it be treated? [www.mayoclinic.com/health/stiff-person-syndrome/AN01377](http://www.mayoclinic.com/health/stiff-person-syndrome/AN01377)
- Diagnosed with SPS in 1994, Debra Kemery recounts her experience and offers practical information about coping with the disease at [www.stiffman.org](http://www.stiffman.org).

### Books and Articles

- “A Flower Grows in Stone: The Diary of a Life in Progress,” a firsthand account of her struggle with Stiff-Person/Moersch Woltman Syndrome, is written by

first-time author Anisah Hassan. Available from Llumina Press, Ingram, and Baker & Taylor, [www.llumina.com](http://www.llumina.com).

## General Resources

### Product Information

- Influenza and the influenza vaccine [www.cdc.gov/flu](http://www.cdc.gov/flu) or call 800-CDC-INFO (800-232-4636)
- IVIG Carimune NF [www.carimune.com](http://www.carimune.com)
- IVIG Flebogamma [www.grifolsusa.com/pdfs/flebo\\_14Jun05.pdf](http://www.grifolsusa.com/pdfs/flebo_14Jun05.pdf)
- IVIG Gammagard Liquid [www.gammagardliquid.com](http://www.gammagardliquid.com)
- IVIG Gammagard S/D [www.immunedisease.com/US/therapies/gammagard/index.html](http://www.immunedisease.com/US/therapies/gammagard/index.html)
- IVIG Gamunex [www.gamunex.com](http://www.gamunex.com)
- IVIG Octagam [www.octapharma.com/corporate/03\\_products\\_and\\_therapeutic\\_areas/01\\_immunoglobulin\\_product\\_line/03\\_octagam.php](http://www.octapharma.com/corporate/03_products_and_therapeutic_areas/01_immunoglobulin_product_line/03_octagam.php)
- **New!** IVIG Privigen [www.privigen.com](http://www.privigen.com)
- SCIG (subcutaneous immune globulin) Vivaglobin [www.vivaglobin.com](http://www.vivaglobin.com)

### Other Organizations

- Alliance for Plasma Therapies is a unified, powerful voice of patient organizations, healthcare providers and industry to advocate for fair access to plasma therapies. [www.plasmaalliance.org](http://www.plasmaalliance.org)
- For suggestions on how to deal with the medical and emotional impact of caring for an ill child, go to [www.kidshealth.org/parent/system/ill/seriously\\_ill.html](http://www.kidshealth.org/parent/system/ill/seriously_ill.html).
- The National Committee for Quality Assurance provides free access to detailed report cards on health plans, clinical performance, member satisfaction, access to care and overall quality on its Health Plan Report Cards Online at [www.ncqa.org](http://www.ncqa.org).
- The nonprofit Patient Advocate Foundation, [www.patientadvocate.org](http://www.patientadvocate.org), seeks to assure patient access to care, maintenance of employment and financial stability. 800-532-5274

	The nonprofit Patient Services Incorporated, <a href="http://www.uneedpsi.org">www.uneedpsi.org</a> , specializes in health insurance premium, pharmacy co-payment and co-payment waiver assistance for people with chronic illnesses. 800-366-7741
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- WebMD, [www.webmd.com](http://www.webmd.com), is a handy medical reference that helps consumers take an active role in managing their health by providing objective healthcare and lifestyle information.
- For a pediatrician’s guide to your child’s health and safety, visit [www.keepkidshealthy.com](http://www.keepkidshealthy.com).
- The National Organization for Rare Diseases, at [www.rarediseases.org](http://www.rarediseases.org), provides links to numerous other organizations that have disease-specific support groups and virtual communities for patients and caregivers.
- American Autoimmune Related Diseases Association (AARDA) [www.aarda.org](http://www.aarda.org) brings national focus to autoimmunity through research, education and patient services. 800-598-4668
- Band-Aides and Blackboards, [www.lehman.cuny.edu/faculty/fleitas/bandaides](http://www.lehman.cuny.edu/faculty/fleitas/bandaides), started by a nurse working on her dissertation, focuses on children with chronic illness.
- American Chronic Pain Association (ACPA) was founded in 1980 to provide resources for people coping with chronic pain. [www.theacpa.org](http://www.theacpa.org)

### Education and Disability Resources

- Continuation of Health Coverage—Consolidated Omnibus Budget Reconciliation

- Act (COBRA): [www.dol.gov/dol/topic/health-plans/cobra.htm](http://www.dol.gov/dol/topic/health-plans/cobra.htm)
- Social Security: [www.ssa.gov/disability](http://www.ssa.gov/disability)
- California State Disability Insurance (SDI): [www.edd.ca.gov](http://www.edd.ca.gov)  
(Please note that each state has a different disability program.)
- IDEA 2004 Resources: [www.ed.gov/policy/speced/guid/idea/idea2004.html](http://www.ed.gov/policy/speced/guid/idea/idea2004.html)  
News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities.
- The National Disabilities Rights Network: [www.ndrn.org](http://www.ndrn.org). This website offers a search tool to find resources in your state to assist with school rights and advocacy.
- U.S. Department of Education Website: [www.ed.gov](http://www.ed.gov).  
This website, a U.S. federal government website, offers a parents section that has a subsection titled "My Child's Special Needs" that can be most helpful.
- U.S. Department of Health and Human Services, Office of Civil Rights, [www.hhs.gov/ocr/504.html](http://www.hhs.gov/ocr/504.html), spells out your rights under Section 504 of the Rehabilitation Act.
- Wrightslaw: [www.wrightslaw.com](http://www.wrightslaw.com). Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities.
- The Americans with Disabilities Act of 1990  
Provides protection for people with disabilities from certain types of discrimination and requires employers to provide some accommodations of the disability. For more information, visit [www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm).

## Additional Reading

- "Anatomy of an Illness," by Norman Cousins, is a best-seller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body's capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.
- "A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed," by Linda Wilmschurst and Alan W. Brue, is available on Amazon.com.
- "The Confused Consumer's Guide to Choosing a Health Care Plan: Everything You Need to Know," by Martin Gottlieb, helps consumers through the confusing maze of choosing a healthcare plan.
- "The Everyday Guide to Special Education Law," by Randy Chapman, Esq., makes the law accessible to parents so they can be more effective advocates for their children. Available at [www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15](http://www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15).
- "Living Creatively With Chronic Illness: Developing Skills for Transcending the Loss, Pain and Frustration," by Eugenia G. Wheeler, is a self-help book specifically designed to help the chronically ill, their families, friends, counselors, medical personnel and the clergy.
- "Managing Pain Before It Manages You," by Dr. Margaret A. Caudill, is a wellspring of wisdom and practical approaches that can help transform your life and your pain.
- "Not Dead Yet: A Long Strange Trip From Doctor to Patient and Back Again," by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.
- "Pride and the Daily Marathon," by Jonathan Cole, describes how Ian Waterman was suddenly struck down at work by a rare neurological illness that deprived him of all sensation below the neck, and how he reclaimed a life of full mobility.
- "Pronoia Is the Antidote for Paranoia," by Rob Brezsny, explores the best way to attract the blessings that the world is conspiring to give us.
- "When You're Ill or Incapacitated" comprises one-half the booklet it shares with "When You're the Caregiver," both written by James E. Miller, suggesting 12 things to remember or do in each role.

- "YOU the Smart Patient: An Insider's Handbook for Getting the Best Treatment," by Michael F. Roizen, MD, and Mehmet C. Oz, MD, with the Joint Commission on Accreditation of Healthcare Organizations, shows you how to tackle such healthcare decisions as picking the best doctors and hospitals for you, knowing when to get a second opinion, and more.

## IG Manufacturer Websites

- Baxter: [www.baxter.com](http://www.baxter.com)
- CSL Behring: [www.cslbehring.com](http://www.cslbehring.com)
- Grifols: [www.grifolsusa.com](http://www.grifolsusa.com)
- Octapharma: [www.octapharma.com](http://www.octapharma.com)
- Talecris: [www.talecris.com](http://www.talecris.com)

## Pump and Infusion Sets Websites

- EMED Corporation: [www.safetymedicalproducts.com](http://www.safetymedicalproducts.com)
- Graseby Marcal Medical: [www.marcalmedical.com](http://www.marcalmedical.com)
- Intra Pump Infusion Systems: [www.intrapump.com](http://www.intrapump.com)
- Repro Med Systems, Inc: [www.repro-med.com](http://www.repro-med.com)
- Norfolk Medical: [www.norfolkmedical.com](http://www.norfolkmedical.com)

## Medical Research Studies

- Check out the official website for the National Institutes of Health patient recruitment program. This site provides summaries and criteria for studies as well as the ability to search for studies being conducted for a specific disease or disorder. <http://clinicalstudies.info.nih.gov>
- This website provides a wealth of information about clinical trials and volunteer participation. It gives you the ability to specify the disorder you are interested in, the location of the study, and the medication names or research protocols. [www.centerwatch.com](http://www.centerwatch.com)
- This site has a registration form to request that you be notified about recruitment for future studies. [www.clinicaltrials.com](http://www.clinicaltrials.com)
- WebMD has a service that matches volunteers with trials. There is an online questionnaire to complete and you will be notified via email of upcoming studies that match the criteria of your questionnaire. You can also search for specific studies. [www.webmd.com](http://www.webmd.com)

## Food Allergies

- Allergic Disorders: Promoting Best Practice  
[www.theallergyreport.com/reportindex.html](http://www.theallergyreport.com/reportindex.html)
- American Partnership for Eosinophilic Disorders: [www.apfed.org](http://www.apfed.org)
- National Institutes of Health, National Institute of Allergy and Infectious Diseases (2004). Food Allergy: An Overview (NIH Publication No. 04-5518). [www.niaid.nih.gov/publications/pdf/foodallergy.pdf](http://www.niaid.nih.gov/publications/pdf/foodallergy.pdf)
- Food Allergy and Anaphylaxis Network: 800-929-4040 [www.foodallergy.org](http://www.foodallergy.org)
- World Allergy Organization: [www.worldallergy.org](http://www.worldallergy.org)
- Sicherer, S.H. (2006). "The Complete Peanut Allergy Handbook: Understanding and Managing Your Child's Food Allergies," Johns Hopkins Press.

## Reading Just for Kids

- "Germs Make Me Sick," by Melvin Berger, explains with colorful illustrations how your body fights germs.
- "Little Tree: A Story for Children With Serious Medical Illness," by Joyce C. Mills, is a comforting fable for young children facing serious life challenges.
- "My IVIG Book," written from a 3-year-old's perspective about his infusions, comes with a kit for other children to create their own personalized book. Free from Baxter at [www.immunedisease.com/US](http://www.immunedisease.com/US).
- "Our Immune System," enables children who are immune deficient and their families to explore together the immune system. Available from the Immune Deficiency Foundation at [www.primaryimmune.org](http://www.primaryimmune.org).

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*Have something to add to these pages? Please send your suggestions for additions to the IG Living Resource Directory to [editor@IGLiving.com](mailto:editor@IGLiving.com). In this case, more is indeed better!*



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