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IMMUNE GLOBULIN COMMUNITY
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April-May 2009

Lunchtime Safety

Tips for Kids Who Bring Lunch to School

Minimizing Infusion Anxiety

U.S. $3.00

Chronic Conditions and Employment Law — Page 36

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IMMUNE GLOBULIN COMMUNITY

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

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Features

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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Subscriptions to *IG Living* are free, and readers may subscribe at www.IGLiving.com or by calling (800) 843-7477 x1362.

Departments

Join an IGL Readers Group or Teleforum

We hear from many, many patient and family member readers who would like to connect with others to share their experiences living with chronic diseases, or maybe just to share a cup of coffee with folks who understand. *IG Living* can help you connect with others in two ways.

First, we can help you determine if there's a patient organization support group in your area or help you start an IGL Readers Group. To join a group or start one in your area, visit www.IGLiving.com and click on IGL Readers Groups.

Second, we can add you to our email invitation list for our IGL Readers Group teleforums. Every month, *IG Living* will send email invitations to readers who let us know they are interested in participating in hosted toll-free teleforums to discuss topics relevant to the IG community. Each moderated, hour-long call—there will be two each month—will be filled on a first-come, first-served basis and will be limited to 15 readers.

To let us know that you want to receive the teleforum email invitations, please email kmcfalls@IGLiving.com or call (888) 433-3888 x1349.

FDA History 101

In 1937, streptococcal infections were treated with tablets (or powdered) sulfanilamide. At the request of a salesman from Tennessee, the drugmaker's chief chemist experimented and found that sulfanilamide dissolved in diethylene glycol. The new liquid formula was not tested for safety, as the law at the time did not require such. Given this, the poisonous nature of diethylene glycol—a chemical normally used as antifreeze—was overlooked.

As reports of death began emerging—in total, more than 100 people died—the Food and Drug Administration (FDA) assigned nearly all of its 239 chemists and inspectors to the daunting task of recovering the 633 shipments of the product that had been sent across the country. Working together, federal, state and local officials recovered 234 gallons of the 240 gallons produced. The 25 federal seizures that recovered the drug were legal due to the charge of misbranding, as being called an elixir was incorrect due to the product's lack of alcohol. If the product had been called a solution, no violation of law would have occurred, and the FDA would have had no legal authority to recover the drug.[1]

According to the FDA website, "the Elixir experience did more than hasten enactment of the 1938 Federal Food, Drug, and Cosmetic Act. The New Drug section, added to prevent such tragedies, gave the United States a new system of drug control which provided superior protection while stimulating medical research and progress. And 25 years later, it saved the nation from an even greater drug tragedy—a thalidomide disaster—like that in Germany and England."[2]

What fascinates me most about this story is how diligently officials worked in an era without the Internet to retrieve 97 percent of the hazardous product. (In one establishment alone, 20,000 sales slips were checked to track the product's sale.) Today, thankfully, given current technology and regulations, it seems impossible that this kind of situation could repeat itself in the United States. Take, for example, the fact that MedWatch, the FDA's adverse event reporting program, "automatically routes Internet reports of critical drug reactions to FDA safety evaluators in seconds."[3] And that's no small accomplishment, given that pre-market testing cannot always discover the side effects of a new drug before it enters the marketplace.[4]

For the system to work most effectively, however, consumers must know about it. And while consumers can file reports with their healthcare practitioners (and obviously should alert providers to all reactions to any product), they can also report events themselves. (Note: Consumers should also report adverse reactions to a product's manufacturer.)

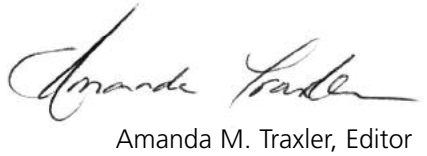
When it comes to biologics, which immune globulin (IG) is classified as, the FDA defines adverse experience as an "event occurring in the course of the use of a biological product in professional practice; an adverse event occurring from overdose of the product whether accidental or intentional; an adverse event occurring from abuse of the product; an adverse event occurring from withdrawal of the product; and any failure of expected pharmacological action."[5] Further, consumers can report events "that may be symptomatically and pathophysiologically related to an event listed in the labeling, but different from the event because of greater severity or specificity."[6]

While it is my sincerest hope that none of you should ever need to report an adverse reaction to *any* medicine you take, if the situation arises, you know what to do. To report an event online, go to www.accessdata.fda.gov/scripts/medwatch/medwatch-online.htm.

Switching Hats

My role at *IG Living* is changing. Starting next issue, a new editor will be at the helm. But I'm not going far, as I still will be writing for the magazine. I look forward to meeting more of you. This community is full of amazing stories, and I can't wait to help tell them.

As usual, enjoy this issue. And please send feedback to editor@IGLiving.com.



Amanda M. Traxler, Editor

[1] The 1937 Elixir Sulfanilamide Incident, www.fda.gov/oc/history/elixir.html
[2] Ibid.
[3] Automation Brings Public Safety, U.S. Food and Drug Administration, www.boozallen.com/media/file/100763.pdf
[4] Ibid.
[5] FDA website, www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfcfr/CFRSearch.cfm? fr=600.80.
[6] Ibid.

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. Your confidential information will not be used for any purpose but communicating with you about your questions.

Kurt: Does anyone reimburse for travel expenses?

Kris: While it is not unusual for Medicaid plans to help with the cost of transportation for medical care, it is not common to see private insurance companies or Medicare pay for transportation. I checked your state's Medicaid website and found medical travel expenses may be covered, but do require preapproval.

For future reference, Angel Flight is a charitable organization that arranges free flights for those who are financially distressed, or who are in a time-critical, non-emergency situation due to their medical condition. You can access them at www.angelflight.com.

Keep in mind you may also be able to deduct your medical travel-related expenses from your taxes. To check if your expenses qualify, visit www.irs.gov/publications/p502/ar02.html#en_US_publink100014890.

In addition, some travel-related expenses for medical care can be reimbursed under a flexible spending account (FSA) or a health savings account (HSA). For details on qualified expenses, speak with your plan administrator or go to www.irs.gov/pub/irs-pdf/p502.pdf.

Leah: What are the risks of contracting a blood-borne disease from multiple-donor intravenous immune globulin (IVIG)?

Kris: The concerns you have regarding IVIG are common. Because IVIG is made from pooled human plasma, the risk of it transmitting disease cannot be reduced to zero. However, there has never been a reported case of HIV transmitted through IVIG. Before we had the viral inactivation processes that are now used, there were some cases of hepatitis transmission reported in the mid-1990s. Since then, the process of manufacturing IVIG has improved, resulting in no recorded cases of hepatitis transmitted in IVIG.[1] The Food and Drug Administration (FDA) guidelines surrounding plasma donation and fractionation are quite strict. All manufacturers that sell IVIG in the United States must follow the same stringent guidelines for plasma donations and manufacturing. For more detailed information regarding your particular product, see the package insert. And it's always wise to voice any concerns surrounding medications to your personal physician and/or pharmacist.

Leta: What are the risks for having thrombosis after an infusion in an "under-the-skin" port for someone with a neuropathy?

Kris: In previous editions of *IG Living*, we have addressed the issue of ports mainly for patients with a primary immune deficiency disease (PIDD). In those cases, many immunologists are dead-set against ports because they consider the risk of infection too high. In addition, because PIDD patients now have the option of infusing subcutaneously, many physicians prefer patients try that method first. Given that your case and neurological disease are different, I asked neurologist Scott Carlson, MD, from the Rockwood Clinic in Spokane, Wash., to comment. ➢

[1] J Am Pharm Assoc 42(3):449-459, 2002

Dr. Carlson: The risk of systemic thrombosis should not be any different using an infusion port versus usual intravenous (IV) infusion. The risk of thrombosis in general is very low but still an important side effect to know about. A review article by Brannagan et al in *Neurology* (1996:47:674-677) suggested that only one patient in 88 receiving IVIG over time had a venous thrombosis, and that patient was bedridden. The recently published ICE trial for CIDP did not contain any thrombotic cases in the 117 patients randomized in the trial. The risk of stroke is very low, but published incidence is hard to find. There might be a small risk that the infusion port itself could clot, and good port flushing and management are important.

Jake: If I take family leave, can my employer require medical records?

Kris: According to the U.S. Department of Labor website, www.dol.gov/elaws/esa/fmla/faq.asp, you do not have to provide medical records. The employer may, however, request that for any leave taken due to a serious health condition, you provide a medical certification confirming that a serious health condition exists.

Please keep in mind that there are other conditions to qualify for the Family and Medical Leave Act (FMLA). To make sure your condition or circumstances apply, you can go to www.dol.gov/esa/whd/fmla/index.htm or call 1-866-4-USWAGE.

Vince: Are there any side effects for a 65-year-old woman (my mom) who has been getting immune globulin (IG) infusions for just over a year if she decides to just stop? Also, what does it mean when a doctor tells you that your immune system rating is just a few points below average?

Kris: It is never a good idea to change or stop taking any medication without consulting the prescribing physician. If the patient has questions about the diagnosis or treatment, sometimes getting a second opinion from an experienced immunologist can help. [A good website to find a doctor is www.aaaai.org.] It would be helpful to take copies of her lab work to the appointment if she decides to seek a second opinion. I posed your questions to Dr. Terry Harville, MD, PhD, Medical Director, Special Immunology Laboratory, University of Arkansas for Medical Sciences. He had some informative thoughts.

Dr. Harville: Regarding the first question, there are no "withdrawal" symptoms. If IVIG is not needed, there will be no repercussions. If IVIG therapy is providing benefit, then within three to six months of therapy, the antibody levels will fall and recurrent infections may return.

About the second question, this can be more difficult to define. It depends on the "mean" or "average" value, and some measure of how far below average "normal" exists. For example, the average adult American male has a height of 5 feet 11 inches. Since the average is found by taking all the heights and dividing by the total number, we know that all adult American men will not have a height of 5 feet 11 inches, but those in the "middle" will be close to this height. It turns out that the values that are considered to be normal for height begin at 5 feet 4 inches and go up to 6 feet 2 inches. So the average height of an adult American male falls between 5 feet 4 inches and 6 feet 2 inches. Anyone who falls within this range is average, though he may be on the short side, or the tall side. To someone who is 6 feet 2 inches, a man who is 5 foot 4 may seem short. However, both are average. While a 5-foot-4-inch-tall man is still average, a 5-feet-3-inch-tall man is below average.

So are these "few points below average" still in the range of average? It depends on the test utilized, on what part of immunity is tested, the age of the subject, and other factors.

Further, as an example: When a patient has slightly low IgG levels and recurrent pneumonias, perhaps an immunodeficiency is truly present. By comparison, another person actually has lower IgG levels but is never ill; an immunodeficiency may not be present.

The point is that all the factors have to be considered. Slightly lower-than-average values in the face of recurrent documented infections are significant for the possibility of immunodeficiency. Lower-than-average values without infections may not be significant.

The Child Within

By Ever Fecske

A circle. I remember twirling in a circle when I was 5 years old and watching my pink party dress float up and thinking I was the most beautiful girl in the world, and not just because my dad said so, but because at that moment, my world was complete. At 5, a pink party dress, white ruffled socks and black patent leather Mary Janes that would "tap" when I walked was everything. Who knew that 19 years later I would still remember that dress and the life that was so full and wonder why? Why, although I have been through some of the most challenging experiences anyone could dream of, do I still want to put on that party dress and twirl around?

Then I realize that for most of us (and I wish I could say it's like this for all of us—because it should be), childhood is a time of having all our needs met. And, if we're really lucky, our needs are met in such a way that we are provided lifelong memories filled with comfort and laughter. In that regard, I consider myself lucky.

I do not, however, usually consider myself lucky considering all the medical procedures—usually surgeries or other new treatments—that I often undergo. However, there are a few simple things that make the experiences bearable, sometimes even enjoyable. After, I have a brand-new pair of pajamas ready for me. And as soon as I can eat, my mom knows that I love steaming-hot macaroni and cheese. And even though I am a grown woman, my mom will braid my hair so I don't have to worry about it being done. I'll watch a movie, do a cross-stitch, read a book or play solitaire. It's these little things that keep me from feeling down or sorry for myself.

The fact is, the feeling that I am being taken care of brings me not just comfort, but also consistency. When going through something that is invasive to my body, faith that everything is going to be taken care of when I get home allows me to heal without stress or worry. In some ways, and I'm not embarrassed to admit it, it's like being a child again.

And then I think, why should I be embarrassed? Children often naturally display many admirable traits. For example, they are completely open-minded and free with the love they give. And then there's their innocence. And their ability to keep hope alive. And how they find joy in small things. When thinking about these things, it occurs to me that maybe keeping a childlike perspective is the best way to live and love. For all of us—even those without chronic conditions.

We all have moments of weakness, whether it is physical or emotional, and the support and recognition we receive from loved ones usually helps us feel stronger. I make it a priority to recognize those who bring me comfort. Often it's family and friends. Sometimes it's strangers. And other times, it's a 5-year-old I still know well, even after all these years. Dancing and twirling, she is still quite the maker of circles—as well as hope. For that, I thank her.

Birds, Bees and Butterfly Needles

By Cheryl L. Haggard

Our 7-year-old daughter, Molly, and 9-year-old son, Caleb, have common variable immune deficiency (CVID), and both have been on immune globulin (IG) since they were babies. Caleb does quite well receiving the lifesaving medicine via his port, and we're blessed that he hasn't (knock on wood) reacted to his gamma. Molly, on the other hand, had terrible side effects. We recently decided to switch her to subcutaneous immune globulin (SCIG) infusions, and she hasn't had a migraine (knock on wood) yet.

In a lot of ways, SCIG has made our lives easier. No more crying, puking or headaching. And that's just for

my husband, Mark, and me! Molly's SCIG infusions have been like slicing a hot knife through butter. However, during one recent infusion, a familiar shrill yowl interrupted our newly discovered infusion Nirvana.

"What's wrong, Molly?" I asked.

"My belly button is on fire, Momma! Heeeelp!" (Insert glass-shattering shrieks here.)

"I'm coming with some ice. Hang on, Sweets," I cooed.

I gathered up an icepack as fast as I could and hurried to our bedroom, where Molly likes to receive her infusion in comfort (i.e., in a king bed with a 32-inch TV that she does not have to share).

"It burns! It burns, Momma!" Molly whimpered. "Put the ice on my belly button!"

I secured the icepack on her stomach, where tiny SCIG butterfly needles were affixed, and wiped her tears in hopes that the burning would subside.

"Do you feel better, Sweetie?" I asked.

The look on Molly's face told me the fire was not out. I was desperate to ease Molly's pain. And as unpleasant as it was for me to invoke memories of birthing Molly without drugs, I looked deep into my precious daughter's hazel eyes and began Lamaze breathing.

"Hee hee hoo. Hee hee hoo. Molly, look at my nose and breathe with me. Hee hee hoo."

Huffing and puffing, Molly and I blew away the ebb and tide of the relentless waves of burning.

After about five minutes of gasping and panting, Molly's discomfort became tolerable (or she was too dizzy to tell otherwise).

"Feeling better, Hon?" I asked while brushing her silky blond bangs away from her eyes. She nodded and relaxed her head on my pillow, her eyes peacefully closed.

"You know," I began, interrupting tranquillity, "that's the way Momma breathed when I had you and your brothers. They call it Lamaze."

Molly's eyes widened and she began to panic. Tossing pillows around, she kicked her legs out from under the covers as if she was frantically looking for something.

"Molly, stop it!" I shouted. "You are going to pull your needles out!"

"Where is it, Momma?" Molly cried. "Where is it?"

Mark came into the room and demanded, "What is going on?"

I grabbed Molly and strong-armed her into lying back on my pillow. "Are you looking for Chocolate Moose (a beloved stuffed animal) or your blankie?" I asked while checking her SCIG sites.

"My baby! My baby! Where is she? What happened to her?" Molly wailed, placing her face in her hands.

Mark and I locked eyes in confusion as a familiar maternal instinct sent shivers up my spine.

"I mean, my belly button hurt really bad," Molly continued, "then we started to 'hee hee hoo.' Isn't a baby supposed to pop out now? Isn't this how babies are made?"

Mark glanced my way and asked, "Where's the calendar I got you for Christmas?"

"The one titled, 'Why Do Men Have Nipples'?"

"Yeah, that one. The answer to Molly's question must be in there," Mark chided, making his way toward the couch to avoid a lose-lose situation.

Three grape popsicles later, Molly's 7-year-old hormones finally calmed down, and I was able to convince her that human babies are not the result of an SCIG infusion. What babies are the result of I decided to gloss over as I considered whether a post-infusion talk was in order.

With her infusion finally complete, we began the tender task of removing her needles. After I carefully pulled back the Tegaderm™ and gently exposed the plastic "wings" of the butterfly needle, I noticed a perfect outline of a butterfly left on Molly's soft skin.

"Look, Molly! There's a butterfly next to your belly button!"

"There sure is, Momma. Can I color her in so she won't fly away just yet? Then can I color some bees, and some birds and you can draw a great big tree, and…"

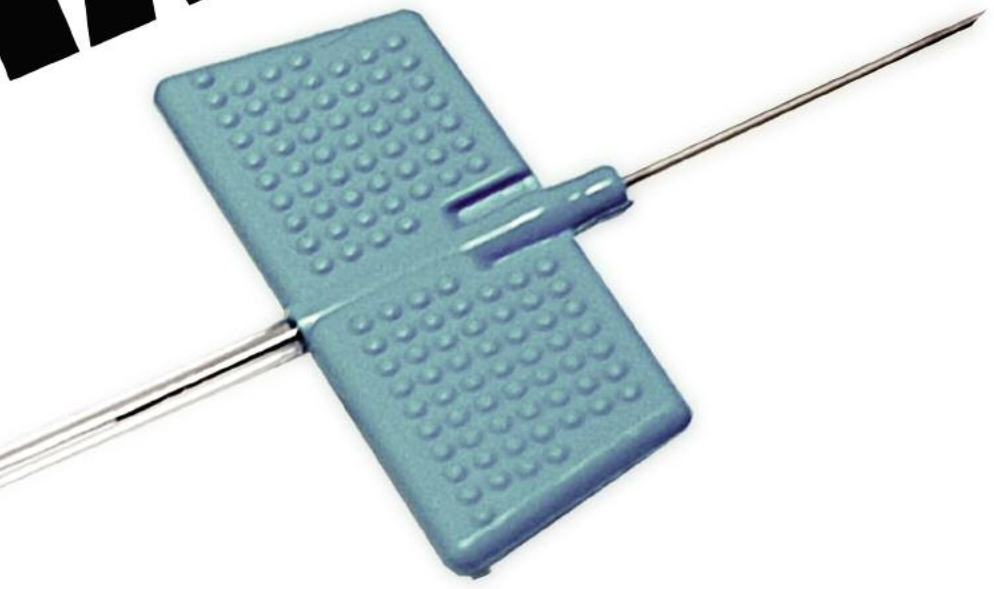
Thinking I wasn't quite ready for my own "butterfly" to grow up so quickly, and wondering what her bath water was going to look like, I interrupted her, "Let's just stick with the butterflies for now."

As Molly agreed, I thought to myself, *there's plenty of time for the birds and the bees*.

Minimizing Infusion An

By Amanda M. Traxler and Kris McFalls

Anxiety



Jim Potter has never liked needles. According to the Eugene, Ore., resident, who has hypogammaglobulinemia, others usually comment that there would be something wrong with him if he did.

That's why every three weeks, when the time comes for his intravenous immune globulin (IVIG) infusion, Potter says that he tries to not think about it.

"It's just something that has to happen," Potter said. "You just turn your head and let it happen."

His aversion puts Potter in good company, as "a dislike or mild fear of needles is very common."[1]

For some, though, the fear of needles may be much more severe. Up to 10 percent of the population may experience needle phobia, a condition that is neither confined to children nor emotion-driven, and which can be "more rigorously defined by objective clinical findings in addition to subjective symptoms."[2]

For others, especially when it comes to the immune globulin (IG) community, anxiety and fear around infusion time can develop for reasons that aren't directly related to a fear of needles. Some individuals simply do not have veins that are easily accessible. Though an adult can at least rationally come to terms with the need for repeated pokes, it's understandable that someone who may not be initially bothered by needles could become anxious if difficult-to-access veins make infusion time uncomfortable or even painful. And for a child, who may not be old enough to comprehend the situation, those circumstances can be extremely challenging. Along these lines, recurring side effects with IG treatments, such as headaches after an infusion, can also contribute to unease developing around infusion time in general, and needles in particular.

Given the range of circumstances and reasons that can be associated with an aversion to needles, the following survey of solutions can make infusion time as comfortable as possible for everyone involved. ➢

Needle Phobia

According to its clinical definition, "the etiology of needle phobia is rooted in an inherited vasovagal [relating to the vagus nerve and blood vessel dilation and heart rate] reflex that causes shock with needle puncture. With repeated needle exposure, those with an inherited vasovagal shock reflex tend to develop a fear of needles. Unlike most other phobias, in which exposure to the feared object excites tachycardia [rapid heartbeat], victims of needle phobia typically experience a temporary anticipatory tachycardia and hypertension [high blood pressure], which on needle insertion turns into bradycardia [slow heartbeat] and hypotension [low blood pressure]."[3]

Clinically, needle phobia presents physically as syncope (fainting), near-syncope, lightheadedness, or vertigo upon needle exposure, along with other autonomic symptoms, such as pallor; nausea; cardiovascular depression with a drop in blood pressure or pulse or both (with or without an initial rise in blood pressure or pulse or both); electrocardiogram anomalies of virtually any type; and rises in any combination of several stress hormones (antidiuretic hormone, human growth hormone, dopamine, catecholamines, corticosteroids, renin, endothelin, and beta-endorphin).[4]

> *"... I was so unbelievably frightened by needles, if I saw someone getting a shot on the news when they were talking about the flu, I had to leave the room."*

From a layperson's perspective, Garret Moore, a resident of Lakeland, Fla., who has primary immune deficiency disease (PIDD), appeared to have many of the symptoms of needle phobia, including sweating, shaking, lightheadedness, paleness and queasiness.

"In the beginning, I was so unbelievably frightened by needles, if I saw someone getting a shot on the news when they were talking about the flu, I had to leave the room."

Eventually, with the help of a supportive nurse, Moore has become used to needles and infusions. One of the things he knows well, however, is that tensing up only made things worse.

"Heather [Moore's nurse] would always tell me to calm down and breathe," Moore said, "or it's going to make it a lot harder."

According to Teresa Gettman, a registered nurse for the Seattle Children's Hospital Research Foundation, fear and anxiety do make infusions more difficult.

"Basically, hormones come into play and they're [patients] in the fight-or-flight response," Gettman said. "All of their blood rushes to their heart and chest, so their veins go absolutely flat, which makes them very hard to access."

And, Gettman continued, veins can seem to disappear quickly.

"I've seen a teenage boy where from across the room you could literally see his veins, and as soon as he knew what I was doing, you could literally see them shrinking," Gettman said. "His veins tightened, and they were gone, just absolutely gone. And if they're totally flat, there's just no way you can get into them."

Dealing With a Phobia

When Moore was diagnosed with PIDD, one of the first things he felt was relief.

"I had been constantly sick," Moore said, "and it was making it difficult for me to do the things I wanted to do. So when they actually diagnosed it and I knew I was going to begin treatments to get better, it was a huge relief."

Then Moore learned that needles would be part of his treatment.

"When I found out I was going to have to get IVs," Moore said, "I figured I've got to get a hold on this and figure out what to do."

Seeking help, Moore enlisted a key figure, his nurse.

"You know that you're going to have to do it, and it's going to be with you your entire life, so you should just try to get as comfortable as you possibly can, realize that you're going to have to work with your nurse," Moore said. "When I told Heather, she automatically wanted to help me, so just being honest and talking to your nurse is probably the best thing."

Even before the first infusion, Moore worked with his nurse to ease his fright.

"Heather started off by having me help her set up everything and put all the equipment out. Then we worked on getting comfortable with needles. She just let me hold the needle and get comfortable with knowing it's not going to hurt me, and I'm going to be OK. Then she let me get comfortable watching people get IVs."

According to Moore, repeating the above steps helped him become comfortable with the procedure. And when it came to his first infusion, Moore used another tool to help himself cope.

"I had every single possible spot that could get an IV covered in EMLA, like four or five spots. It completely numbs wherever you put it," Moore said of the topical anesthetic that contains lidocaine and prilocaine to numb the skin.

Gettman concurs: "And as an adult, if you're really afraid, there's no reason you shouldn't have any numbing cream."

Over time, Moore has become much less anxious about infusions. Though he admits that he's always going to be nervous, "because needles are needles," the trust he's developed with his nurse is key.

"I know if I wasn't with Heather, I'd be a lot more nervous, but you just get comfortable with your nurse," Moore says. "Heather's never had to stick me more than once."

Clearly, the confidence Moore has in his nurse's skill is crucial to alleviating his anxiety.

"A nurse's skill level will help establish trust. ...With each successful event, the patient won't even think about the IV," Gettman says.

According to Gettman, not all homecare nurses are equally skilled. That means that finding a good one is the responsibility of the patient, who may need to do some interviewing.

"I would ask them what their IV experience is, especially their most recent experience," Gettman said. "They may have 10 years' experience, but it may have been five years since they're started an IV because they've been out being a mom or doing something else with their career."

Those who receive infusions at a clinic, though, may not have a choice of nurses. Such is the case with Potter.

"I go to an infusion center," Potter said. "The last treatment I had, it took three times to get the IV in. After the second one, the nurse got someone else to come in and do it. It was kind of a comedy of errors that day."

Normally, though, Potter finds he is able to trust the healthcare professional on hand.

"I just turn my head and put all my trust and confidence into the healthcare professional who is putting the straw into my vein. There is a fair amount of discomfort, sometimes it hurts worse than others, but I know it's something I need to do."

And even Moore has successfully received an infusion without his usual nurse.

"I had to get an IV [while I was traveling] in Georgia one time without Heather," Moore said, remembering an unexpected illness that sent him to a hospital while traveling. "I was completely fine, it just took time to get me comfortable with needles."

> *"...There is a fair amount of discomfort, sometimes it hurts worse than others, but I know it's something I need to do."*

Infusion Difficulties

Though Potter never liked needles, he is an example of a patient whose discomfort grew over the course of receiving infusions. While many who switch to subcutaneous IG infusions prefer this method for its ease and convenience, such was not the case with Potter. In fact, Potter's decision to return to intravenous infusions may be more related to his initial lack of comfort with needles rather than anything about subcutaneous infusions per se. After giving it a try, it became clear that intravenous infusions suited him better. With this method, someone else was doing the heavy lifting.

"I decided to go back to doing the IV infusions at the hospital and let somebody else put the needle in me," Potter said.

He admits he never exactly got the hang of subcutaneous infusions.

"It was a four-site infusion with four 9-milliliter needles that I had to poke into myself. At first, it was a little difficult to do, and then it got a little easier."

Unfortunately, Potter seemed to have a susceptibility for hitting nerves during his infusions.

"It seemed as though I was hitting a nerve at least one out of the four times I was putting a needle in my body," Potter said. "I'd pull it out and then I'd have to work up the courage to put it back in again, and I knew that if I hit another nerve, it was going to hurt again."

This led to more apprehension about needles, which increased the amount of time his infusions took altogether.

"Doing the home infusions, it took two to three hours for me to do it at home, and it was once a week. ➢

And I started thinking, you know, it takes me about two to three hours to go to the hospital, and that's once every three weeks."

Finally, the camel's back broke.

"There was one time, and that was when I guess I knew that I needed to stop doing it. It took me 30 to 45 minutes just to get the needle in. And I thought, 'You know, I just can't do it anymore.' "

For Potter, the time factor, as well as hitting nerves fairly regularly, led him to switch back to intravenous infusions.

"All I have to do is just show up and sit in a chair," Potter relates, "and I get to watch cable TV, which I don't have at home. And it also gets me out of work a couple hours early, so I actually look forward to it."

Not that he's a fan of needles.

"I just kinda grin and bear it."

Tips for Children

When it comes to children who may not be old enough to verbalize a fear of needles, an earlier piece of advice warrants repeating: Find a good infusion nurse—especially one who has pediatric experience.

"I would also ask about their pediatric experience," Gettman said, "because when we're teaching someone to start IVs who's only ever done adults, they're terrified of kids. And even though they may be a good IV starter, you still have to have a good, positive attitude. If you're afraid yourself, you're not going to be a success."

> *"Don't tell the kid it's not going to hurt unless you absolutely know it's not."*

Even with a good infusion nurse, however, infusion time can be extremely difficult for children. Just ask Jeanette Weaver, of Kirkland, Wash., whose daughter, Grace, used to experience tremendous distress during infusions. Her daughter's suffering motivated Weaver to find help. According to Weaver, her research led her to virtual reality glasses, which studies show can help during procedures such as infusions. For her daughter, these glasses have been extraordinarily effective.

"They [the glasses] have made it possible for her to access without sedation," Weaver reports. "The first time we used them, it was incredible. She went from kicking and screaming and being held down by three adults to lying sedately and only saying 'ow' when she accessed. They are a coping tool."

For some children who are out of control but who are too young to understand instructions (about 1 to 2 years old), Gettman suggests bundling.

"For one child who was doing that [kicking and screaming] recently, as soon as I bundled her, she immediately stopped," Gettman said. "It was almost like she felt totally out of control, she was so anxious, but when I wrapped her up, it gave her some semblance of control."

Gettman usually considers bundling a last-resort option. In the scenario above, Gettman said that she asked the mom if anyone had tried bundling the child before. When the mom responded yes, saying that it had helped, Gettman decided to try that.

"I couldn't believe the difference with her."

For older children, however, rational communication trumps bundling.

"I do not want to bundle an 8-year-old," Gettman says, "so if they're screaming and fighting, usually I will have everyone leave. Usually that panics the child and they'll say 'I want my mom and dad.' And I say, 'No, we have to talk first.' Then I ask them, 'How many pokes do you want? Five? 10? Because you have to have at least one and there is no way I am going to get an IV in with you acting that way.'"

After conveying to a child that she will get help from as many nurses as needed, but that she is not going to let parents watch a struggle, Gettman says that the children usually let Gettman put an IV in about 99.5 percent of the time.

Gettman also advises the following for making infusion time easier for children:

- Always tell the child the truth. "Don't tell the kid it's not going to hurt unless you absolutely know it's not."
- List each step of the procedure with a child before it happens: "I usually break it up into individual steps. For example, I say, 'I'm going to wash your hands,' and then I wash their hands. Telling them beforehand what is coming next builds a short-term trust, especially if you've never met this child before. When it comes to the point where 'Now you have to have a little poke,' then I do it. And I don't usually dwell on that part until I'm ready to do it, so that way they don't have any

anxiety buildup. And that way when I say that I'm done, they also know I'm done."

- Try the "lights off" trick: "As soon as I get the IV in, I have the lights turned off. Sometimes if a child is really out of control and the lights go off, all of a sudden they'll stop mid-scream and look around. Then they can hear me when I say I'm done." The idea imparted to the child is that nothing bad is done with lights off. "I had some developmentally delayed kids who have remembered that," Gettman says. "Once I forgot to do that and the boy looked at me and said, 'Light off.'"

Improving Vein Access

No matter a patient's age, sometimes veins are difficult to access. Gettman gives the following advice to help with this issue.

- Warm the infusion site. For those who do home infusions, take a super hot bath just before the appointment. For those who go to a clinic, Gettman advises wearing gloves along with heat packs used for skiing (for both hands, too). According to Gettman: "I don't want anybody overly hot, but I want them to feel almost sweaty warm, so that way when the person goes to try to put the IV in, when they touch their hand, their hand is warm."
- Wear loose, comfortable clothing.
- Drink lots of water before the infusion.
- Make yourself laugh. According to Gettman: "It's hard to be anxious when you're laughing."
- Think of something that makes you angry. While this tip may seem odd at first (and perhaps should only be considered by those who are not watching their blood pressure), Gettman points out that "usually it is easier to have someone feel angry than to think of the ocean or try to laugh." Gettman relayed a story of a time when she used this tactic on a patient: "I tried talking to him about things that would make him angry. I asked him about school, etc. His brother was listening. And just before I was about to put in the IV, when I was cleaning the area, his brother grabbed something from him. …He would've jumped off the bed to chase his brother around the room except that I taped his arm so well down to the board. His vein popped up, so I put the IV in really quick. And his brother said: 'Did you get it?' I said, 'Yes.' The patient turned around and asked, 'You put the IV in when I wasn't looking?' He was mad, but the parents just laughed. It was very dramatic, the difference in his veins."
- Say "whoosh." Surprisingly, this can help relax the body. According to Gettman, this can work for patients who tighten their hands so an IV can be put in. About one patient, Gettman says: "His veins are so tight, the needle practically bounces off of it, so it doesn't actually go in, but the 'whooshing' makes his body relax so the needle can go in."

MAKE INFUSION TIME EASIER

- Use the power of positive thinking: Try not to think of infusions as a horrendous experience. This idea can be particularly important at the time of a diagnosis.
- Use a numbing cream such as EMLA.
- Use coping tools such as listening to music, virtual reality glasses or watching TV.
- Drink plenty of water before your infusions.
- Heat the infusion site by taking a bath or using heat packs to warm the area.

While infusions probably don't top anyone's list of favorite things to do, patients can take several steps to make infusion time easier. No matter the issue, whether it be a needle phobia or difficult-to-access veins, the above strategies can be immensely helpful. For many individuals, keeping the focus where it belongs—on staying healthy—may be the ultimate advice.

"I overthought everything," Moore said. "If I really just thought, 'Hey, I'm doing this to feel better,' then I would have been fine. It was actually thinking about the needles that was freaking me out." ◪

[1] Hamilton, J. "Needle Phobia, A Neglected Diagnosis," Journal of Family Practice, August 1995.
[2] Ibid.
[3] Ibid.
[4] Ibid.

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Lunchtime Safety

Tips for Kids Who Bring Lunch to School

By Jessica Schulman, PhD, MPH, RD

Though this article focuses on children's school lunches, its guidelines pertain to anyone concerned about maintaining the food safety of a packed lunch.

The alarm has gone off, they've finished breakfast and somehow your kids are dressed and ready for school. But they need one more thing from you—their lunches. And, because you think of yourself as a responsible, caring parent, you naturally want those lunches to be tasty, nutritionally balanced and safe. Easy, right?

In fact, sending children to school with a lunch that meets all of these criteria is not simple at all. You understand that proper nutrition is critical for a child's health, growth, psychological development and school performance, but eating well while keeping food safe is not always easy in a school setting—and it can be a significant challenge for those who live with certain chronic diseases. What can parents and caregivers do to ensure that their children have a healthy and safe lunch when the bell rings? This article offers some tips. ➢

Food Safety First

From the time your little ones grab their lunches on the way out the door to the time they open those lunches some four hours later, a lot can happen to the food you have so lovingly prepared. No matter how carefully you clean your kitchen, food products carry microbes and bacteria. The Partnership for Food Safety Education points out that those microbes and bacteria reproduce best in food that is sitting in the "danger zone," i.e., between 40° F and 140° F (www.fightbac.org). As a general rule, the site cautions that food sitting at room temperature for more than two hours (and less than one hour in warmer weather) should not be consumed.

Your child's classroom is a potential danger zone, and the foods you send to school, if not refrigerated, may sit at room temperature for a lot longer than two hours. What can you do to make sure the foods you prepared are still safe to eat at noon?

1 Include frozen foods (or a frozen gel pack) to keep lunches cool.

- Freeze finger fruits: strawberries, grapes, banana slices, mandarin oranges, pineapples, papaya and mango.
- Freeze dairy: traditional yogurt cups such as Yoplait Kids™ or tubes such as Stonyfield Farm's Squeezers™ (Organic Portable Lowfat Yogurt). Watch for brands that have lower sugar and are fortified with vitamin D.
- Freeze healthy box drinks: Look for calcium and vitamin D fortified juice, soy milk and rice milk. These tend not to perish at room temperature.
- Separate perishables: Keep meats and animal byproducts away from the rest of the meal. Purchase small packets of creamy food or salad toppings (e.g., ranch dressing, mayonnaise, soft cheeses, etc.) that may be frozen or keep them cold. This may involve putting deli meat in a separate containing over a cold pack or asking school administration if the lunch may be placed in a refrigerator at or below 40° F.

2 Start with cold foods cold and hot foods hot.

- Check your home refrigerator temperature. It should be between 35°F and 40°F. The colder the food is kept, the fewer opportunities microbes will have to gather. (Note: If you store medicine such as immune globulin [IG] in the same location, follow the product-insert instructions. Some IG products must be stored at 36°F to 46°F). If you plan on sending leftovers for lunch, place a serving of the food into the refrigerator immediately after cooking. Avoid letting it sit out on the table and then wrapping it up. Do not send children to school with leftover foods that have been sitting out at a restaurant.
- Start off as hot as possible. Fill a thermal container with boiling water and let it stand a few minutes. Then, empty the container and pour in piping hot soup, stew or pasta, etc. Soups or dishes that are put in an insulated container should bubble for at least two minutes before they are packed.

3 Keep surfaces clean.

- Make sure the lunch box and containers are as clean as possible before placing foods inside.
- Follow instructions about how to care for your containers.
- Paper bags and disposable containers may be a safer alternative for those who have little time for meticulous cleaning and food preparation.

4 **Wash your hands well before preparing any food and remind children to wash their hands before digging into lunch.**

5 **Choose foods that will not support microbial growth.**

- Go vegetarian. Animal products and deli meats tend to have higher levels of microbes even before you make it home from the supermarket. Time spent in a lunch box at temperatures higher than the fridge (above 60° F) will allow these little buggers to flourish. In just two hours, food is considered a safety hazard. What can you do? Start with a product that tends to be lower in microbes from the get-go. Most major supermarkets sell vegan deli slices that mimic bologna, roast beef and turkey. My exceptionally finicky second-grader (seriously, not even hot dogs or frozen pizza!) will not eat any deli meats except bologna by Yves® or Smart Deli®. With time and patience, eventually, you will find the right offerings for your child.
- You can pack these deli slices up on a whole grain bun with mustard and ketchup. Send the dressing or mayonnaise on the side (try using small single-use packets). If your child wants cheese on the sandwich, consider wrapping it separately and placing it against the frozen gel pack.
- Vegetarian versions of "franks and beans" (Lightlife Smart Dogs® or Tofu Pups®, Yves Veggie Weiners® or Tofu Weiners®) can be served from an insulated container. See above for food-safety information.
- Legumes or beans are an excellent source of nutrients and fiber. Try hummus or another bean spread. And sneak in some thinly sliced or shredded tomatoes, cucumbers or carrots.
- The old standby, PB&J. Peanut butter and jelly sandwiches can be a healthy choice for kids. Try using peanut or other nut-butter varieties that are pasteurized, not hydrogenated, and do not add sugar. Add fresh bananas, apples or a fruit spread. Aim for whole-wheat bread. (WARNING: Check with school officials! Due to the risks of those living with peanut allergies, peanut butter is not allowed in some grade levels or is banned altogether. If it is not allowed, save the PB&J for weekend trips or outings away from schoolmates.)
- Toss in dried foods: Look for "no sugar added" or "organic" products such as dried mangoes, apricots and pitted prunes, among others. Many supermarkets offer interesting varieties of banana chips, Bing cherries, dried white peaches, Bartlett pears and orange-flavored cranberries. Dried fruits are loaded with vitamins A and C and antioxidants (potential health-promoting compounds).

Note: Fresh-cut fruits or vegetables are considered perishable, as are meat and animal byproducts. Keep them cold and throw them away if they are not consumed by lunchtime.

6 **Choose the best possible container.**

- According to the Partnership for Food Safety Education (www.fightbac.org/content/view/78/10), insulated soft-sided lunch totes are good for keeping food cold, but metal or plastic lunch boxes and paper bags can also be used.
- Try double-layering paper bags to help insulate the food. A frozen gel pack must be packed with perishable food in any type of lunch box or bag. Look for carriers from reputable suppliers that are certified as lead-free.
- Limit exposure to bisphenol A (BPA). Researchers from the National Toxicology Program at the National Institutes of Health suggest that BPA is widely available in food and drink packaging and may pose health risks. BPA can leach into food from plastics (e.g., polycarbonate tableware, food-storage containers, water and baby bottles) and epoxy resins that coat metal products (e.g., food cans, bottle tops, dental sealants and water-supply pipes). Containers that contain BPA usually have a #7 on the bottom. When ➢

possible, opt for glass, porcelain, stainless steel or BPA-free containers. According to the company SC Johnson, BPA is not used in its plastic products (i.e., Ziploc® brand bags or Saran™ brand wraps).

Ask for Assistance

Trying to supervise meals at school does not necessarily require super powers. Fortunately, schools are usually willing to help, provided that parents communicate their needs and desires clearly and effectively.

- Learn about reasonable accommodations or special guidelines at the school. Some districts have general guidelines about what foods can be brought to school. However, each school has unique protections and policies for food concerns. Shawna, former PTA president, explains that "every school is different in the way that they enforce certain rules about what to bring or won't let you bring to school." She says, "If the child has a special nutrition need, the parent should contact leadership at the school and see what they are willing to do to help. … it really just depends on the school's administration."
- Young children may need assistance opening containers, packets or smearing sauce over foods. Parents ought to talk with the teacher to ensure that reasonable assistance or encouragement is being offered to their children.
- Children with disabilities or special circumstances (e.g., life-threatening food allergies) may establish a 504 Plan or an Individualized Education Plan (IEP) to guarantee that the child receives appropriate accommodations. It is crucial that proper nutrition is addressed for children with special medical needs. In addition, it is not uncommon for IVIG treatment, or gamma interferon (used to treat chronic granulomatous disease), to cause mild side effects that inhibit appetite. For suggestions on what you might want to include in a 504 or IEP plan, see the sidebar, "Examples of Nutrition-Related Requests for School Personnel." (Refer to the Immune Deficiency Foundation's publication, "A Guide for School Personnel" at www.primaryimmune.org/publications/school_guide.pdf)
- Amanda has three elementary-age children who live with a primary immune deficiency disease (PIDD). An ongoing concern was making sure the kids had access to foods they would eat (such as deli turkey) but that necessitated a refrigerator. The school staff was willing to place a small one in the classroom; it will follow the children to their grade classroom.

Examples of Nutrition-Related Requests for School Personnel[1]

- Staff will present instructions to the class on hand-washing procedures.
- Staff will encourage students to wipe down tables and clean hands before eating.
- Student will be allowed to carry or have easy access to waterless hand soap or hand sanitizer.
- Staff will assist student with opening his food containers and setting up the lunch as needed.
- Staff will encourage students to eat healthy foods that parents have sent to school.
- Student will go to designated staff when frequent meals or snacks are needed due to nutritional issues.
- Student will be allowed bathroom privileges as needed. He should never be denied access.
- Student should be allowed to carry a water bottle and drink from it as needed.
- Student will be encouraged to wipe the section of the table she is eating on prior to eating.
- Student will have access to a clean and secure refrigerator for lunch meals.
- Student will have a place to keep any meats or dairy products at or below 40° F.

Make It Fun!

Kids (and adults) respond well to foods that are appealing and colorful. Use this to your advantage!

- Cut sandwiches into novel shapes. Make pocket sandwiches with pita bread. And place sandwich fixings on a whole wheat mini bagel or tortilla.

[1] "Where to Find BPA-Free Products," U.S. News and World Reports, www.usnews.com/blogs/on-medicine/2008/5/2/where-to-find-bpa-free-products.html, May 2, 2008.

- Try multigrain rice salads or high-protein quinoa (pronounced "keen-wa").
- Use rainbow or character pastas.
- Sometimes, if you want to make certain your child eats right, it's safer and easier to have a "backwards" day. For breakfast, serve what would otherwise be a healthy balanced lunch (maybe last night's dinner) and for school lunch, pack up pancakes or a bagel with cream cheese (on the side, frozen or next to a frozen gel pack) with fruit and yogurt.
- Plenty of shelf-stable products are fun to eat and also pack easily, such as unsweetened applesauce, fruit cups in light syrup or fruit bowls, or pretzels (Newmans Own® brand offers a protein-enriched version). If a lunch is balanced, don't worry about a small sweetened yogurt or a granola bar. Children who live with certain chronic health problems may need the extra energy for healing and growth.

Involve Your Child

As your children begin to take more responsibility for their morning routine, let them participate in preparing their lunches as well. If their lunches are selected, rather than imposed, they are more likely to eat them even when you are not watching.

- Let your child pick out a favorite lunch box and thermos.
- Involve your child in developing the shopping list, grocery shopping or packing the lunch.
- If your child dislikes a particular food (such as soy milk or fortified juice), involve them in selecting a different flavor. Choose a few different options and have a taste-off. Make trying new foods a positive experience. Even if they do not like the food, return to it periodically.
- Try changing the texture of the food. For example, the child may not like cooked vegetables but may be willing to eat pureed tomato sauce with blended veggies (shredded or smooth consistency) mixed in. Consider investing in an emersion blender.
- Let your children know that you're thinking of them with small notes offering love and encouragement.

Those with immune deficiencies or gastrointestinal absorption conditions, among other chronic illnesses, should discuss the best nutrition plan with their physician or nutrition specialist. Even with the best-made lunch, it may be necessary to include a certain type of supplemental tablet, food or drink. ■

This article is for informational purposes only. Individuals with medical conditions should consult their physician to determine what eating pattern is appropriate for them. The writer is a registered dietitian, holds a doctorate in health behavior and is an author of the book "Nutrition in Sickness and in Health."

Resources

Food Safety: Home for the Holidays, *IG Living*, Dec-Jan 2007.
www.igliving.com/web_files/igl_D-J07_34-37.pdf

Partnership for Food Safety Education, BAC!® to School: Quick Tips to Packing a Safe Lunch,
www.fightbac.org/content/view/78/10

The U.S. Department of Agriculture (USDA) Meat and Poultry Hotline at 888-MPHotline (888)674-6854. TTY number for hearing impaired (800)256-7072.

Center for Food Safety & Applied Nutrition
www.cfsan.fda.gov

Full of Life

By Amanda M. Traxler

Only one question seemed to faze Parker Robb, whose easy-going and confident nature belies the angst oft associated with adolescence.

When asked his least favorite subject, the Boyds, Md., 10th-grader paused a moment before answering: "That's a hard one. There's too many."

Then, as if last year's electoral noise still buzzed in his ears, the 16-year-old found his answer: "Probably government…I've never been a big fan of government."

In that regard, Parker probably resembles most of his fellow countrymen. But in many other ways, Parker is in a class unto himself.

Born with SCIDS (severe combined immune deficiency syndrome), Parker had only about 15 percent of an immune system naturally. Before he was 4, toddler Parker underwent four haplo transplants to try to establish an immune system. None of them took. At 12, he tried gene therapy, which also didn't work. Today, though, due to a successful bone-marrow transplant when he was 15, Parker's immune-system levels are near-normal. With doctors saying that his bones still have room to grow, Parker soon will begin taking human growth hormone. Just over 4 feet, Parker weighs about 70 pounds.

Beyond his medical history, several other attributes set Parker apart: a gift for photography that has both schoolmates and parents wondering when they can purchase his photos; a social ease uncommon for many adults, let alone a teen; and, perhaps most surprisingly, a tendency to honestly forget that he has a rare health condition.

According to Parker: "People would come up to me and nicely ask, 'What's wrong with you?' And I'd say, 'What do you mean?' I'd have to think about it, and then I'd be like, 'Oh yeah.'"

Neil Robb, Parker's father, says that Parker has never been embarrassed about revealing his condition.

"He would just tell people 'I don't have an immune system,'" Neil said.

Though his diagnosis was clearly a defining factor in his life, it was not a constricting one.

"My parents have always given me a normal life," Parker said. "They protected me in the usual sense, but they haven't overly protected me. I've always gone to public school."

That fact, which may surprise some, was due to the parental decision to raise Parker like any other child.

"Every family approaches this a little differently. Our approach was to have Parker lead as normal a life as ➢

possible and not to be in a state of denial about his condition. But if he wasn't sick, we didn't dwell on it. I was not a germ fanatic with him. … He went outside and played with the kids during the daytime."

Naturally, Parker still occasionally was ill.

"About every three to four months I'd have to take him into the hospital and we'd check in for a day or two."

Generally, though, public school—which Parker's doctor supported—was smooth sailing, save for the time when Parker switched schools after moving in the third grade. As usual, Neil met with school nurses beforehand, telling them "everything usually goes fine."

Working close by, Neil assured nurses that he'd retrieve his son pronto if Parker had one of his occasional fevers.

"Three hours later he was lying on the nurse's floor, bundled up as tight as he could be, just shaking," Neil recalls. "I had him on antibiotics right away, but it didn't quite go as well as it could have. But I told them this was really unusual, and for the rest of the time, everything went really well."

To make things easier at school, Neil stayed plugged into Parker's school life by meeting with teachers before the year began and maintaining weekly contact thereafter.

"I would try to go into the classroom at least once a week and help out for an hour or two," Neil said.

Likely appreciative of his efforts, the nurses and teachers, according to Neil, "have been great."

One middle school teacher in particular had a telling influence on Parker's life.

"This teacher…when she saw me, she said that's going to be a good actor," Parker said.

When she asked him one day to explain to his class what he's gone through, Parker agreed.

"Some people were crying, I was crying," Parker said. "Everybody was asking me questions, so it just formed a really good bond between all of us."

Though he describes himself as thoughtful and nice, Parker's favorite role was playing the boss character in "The Pajama Game."

"I got to yell at people," Parker said, adding that "my dad says I should always be a boss when I grow up."

Not ruling anything out, Parker's pretty sure of one thing that will be a part of his future: photography.

"I work [as a photographer] for the newspaper at my school," Parker said. "I'm getting to be so known that the parents are calling me up asking me

to come to soccer games to take pictures of their kids."

And if the measure of an artist is whether work has been sold, then Parker already qualifies. After receiving a digital camera as a gift while in the hospital for a transplant procedure, Parker would later sell his first photos from his hospital bed.

"Later in the transplant, I got permission to go out for a day or two," Parker said. "Actually, those were some of my best pictures."

Not that the transplant was akin to an artist's retreat.

"That was probably the roughest time I had," Parker said.

According to Parker, the chemotherapy was the worst.

"I've known people who've gone through chemo but I've never understood how hard it was," Parker said. "The way me and my dad describe it is that 'it's the closest to dying you can get without dying.' "

These days, however, the trials and tribulations of the transplant are fodder for laughter.

"Me and my family joke about it now," Parker said. "They tell me stories of what happened certain days and I'm like, 'No, I didn't do that. I didn't yell at you,' and they're like 'Yes you did,' because I was so crazy because it was so hard."

Already past this medically traumatic time, Parker also doesn't dwell needlessly on the future.

"I don't worry too much," Parker said. "I've never been that kind of person. I sort of think about now."

And yet, Parker still does think about one thing on the minds of many high school students: college. When the time comes, Parker hopes to attend Maryland to study journalism. "I've always liked writing, but I didn't really like long writing. So newspapers seem perfect for me," Parker said.

Parker acknowledges that writing for papers is more technical than he'd expected.

"I didn't really think about structure," Parker said.

With a couple of years till college, Parker has plenty of time to learn all of the rules. Including those about a story's ending, which many advise should be a payoff for the reader.

Parker's spirit—exuberant and full of life—makes that task easy for the story at hand.

"When he gets ready for school at 6:30 in the morning," Neil says, "he's downstairs dancing and singing literally almost every morning."

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 you'd like to share, please email it to us at editor@igliving.com.

In this column of the "Let's Talk!" series, I interviewed 64-year-old Lance Abair. Lance is a jazz musician who has chronic inflammatory demyelinating polyneuropathy (CIDP), a neurological disorder characterized by progressive muscle weakness and sensory impairment. In CIDP, the immune system attacks the insulation around the nerves (myelin sheath) of peripheral (arms and legs) muscles. The damage decreases the nerves' ability to conduct the electricity needed to provide appropriate sensation and movement for peripheral muscles. The disease is difficult to diagnose and can begin in many ways. Tingling, numbness, muscle weakness and difficulty with normal activities involving arms and legs (walking, curling hair) are typical symptoms.

I met Lance while we waited in a doctor's office. As a group of us chatted to pass the time, Lance commented that he had just discovered a great magazine called *IG Living*. After I told him that I write a column for the magazine, I requested an interview with him.

Shirley | Can you tell me about your diagnostic process?

Lance: | The first symptoms appeared Nov. 8, 2007, and I was diagnosed in February 2008. I was doing production work in my home studio with a young band from Seattle called Natalie Portman's Shaved Head. Suddenly, between lunch and dinner, my left hand and forearm became numb and weak. I finished the session and thought I would be better in the morning, but I wasn't. So we called my doctor. He thought I had had a stroke so he ordered a brain scan. It was OK, so he referred me to a neurologist, who referred me to another one. They did EMGs (electromyogram) and other tests and tried a number of medications, which did not work. No one could come up with anything. Luckily I have a good friend who has a restaurant in Hollywood, Lucy's El Adobe Cafe. She said she would have a friend call me. I received a call from Dr. W. King Engel (Professor of Neurology and Pathology, Director of the Neuromuscular Center, Keck School of Medicine, University of Southern California), who made an appointment at the Good Samaritan Hospital. He ordered numerous blood tests, a spinal tap and a muscle biopsy. He diagnosed CIDP and ordered IVIG, 30 grams twice weekly, daily injections of vitamin B-12 and folic acid tablets.

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

Lance | No, but I am covered by private health insurance, first my own from work, now my wife's (I was laid off the day after I received my diagnosis). I'm worried what will happen when I have Medicare.

Shirley | Has IVIG helped?

Lance | Yes. First of all, it hasn't gotten worse. I have had a little improvement that appears to have plateaued now. It is very subtle. For example, turning on faucets and buttoning jeans is easier. I still have ups and downs and experience unexpected bouts of fatigue where I have no energy, all I want to do is sleep. Luckily I have no pain.

Shirley | How has it affected your ability to play?

Lance | I have lost the dexterity and strength in my left hand that I need to play the sax. I can play keyboard using my right hand. Fortunately, I am able to correct mistakes using computer software. My daughter, Mindi, is also a jazz musician who plays the sax and sings. She has four albums out. This all occurred after completing my first solo sax "smooth jazz" album. I co-wrote nine of the 12 songs with Matthew Hager and one with Mindi. Unfortunately, now that I can't play anymore, we can't come out with the album, as I can't promote it. It is just sitting there and I am trying to come to terms with it. The keyboard is an outlet, but I find my inspiration is impaired as a result of the CIDP. Also, the further away from the sax I get, the less I am inspired. I have played since 1959 and have always thought of myself as a sax player. My brain still fingers all the notes, but my fingers don't work. It is weird. If I don't get better, I don't know what I will do next.

Shirley | That must be very difficult to handle.

Lance | Yes, I'm trying and still wondering if this is really happening to me. I would have great difficulty if I thought it was just a cosmic accident. Luckily I am a religious person. I believe things happen for a reason, things will work out. I have to exercise patience and make the most of it. I feel useless and miss the creativity, but I focus on the fact that I have the rest of my body and my brain and a wonderful family.

Shirley | Have you any favorite jazz musicians?

Lance | Other than my daughter? Oh, I have so many of them. Too many to mention, but the first that come to mind for sax are Cannonball Adderley and Paul Desmond. On keyboard, Oscar Peterson and Bill Evans.

Shirley | Have you received any support?

Lance | Yes! My wife. I married my dream girl and still feel that way after 41 years. She gives me my daily shots. My daughter, as I mentioned. My doctor and all the staff at the neuromuscular clinic are positive and helpful. I have great faith in them. I have also done some research on the computer. I found *IG Living* magazine to be quite an eye opener. It helped to realize I'm not the only one. It is good to read about others with similar problems.

Shirley | What was the worst advice you were ever given?

Lance | None intentionally. Most people are completely unaware of CIDP. The most difficulty I had was finding a consistent nurse to administer my IVIG. Fortunately, I have found one now.

Shirley | What was the best advice?

Lance | From Lucy's restaurant. Lucy is a wonderful, caring woman who has a fantastic Mexican restaurant that is an old Hollywood hangout. In fact. Mindi's first hit song is called Lucy's. Lucy connected me with Dr. Engel.

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

Lance | Everyone is different. For me, I found getting the magazine very helpful and would give it to anyone I know with this condition. Find a good doctor and find out about your disease. Do what you can to not let it get you down. Try to not be too stressed. Faith in God has helped me. I would also be interested in meeting any other musician who has this or similar problems. ■

Resources

1. NINDS Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Information Page, www.ninds.nih.gov/disorders/cidp/cidp.htm

2. Mindi Abair, mindiabair.com

Subcutaneous Immunoglobulin Infusion: A New Therapeutic Option in Chronic Inflammatory Demyelinating Polyneuropathy

By De-Hyung Lee, MD, Ralf A. Linker, MD, Walter Paulus, MD, Christiane Schneider-Gold, MD, Andrew Chan, MD, and Ralf Gold, MD

Chronic inflammatory demyelinating polyneuropathy (CIDP), a chronic inflammatory disease of the peripheral nervous system (PNS), is clinically characterized by hypo- or areflexia and progressive or relapsing motor or sensory dysfunction developing over weeks.[1] In the last two decades, clinical trials (class I evidence) have revealed the therapeutic efficacy of prednisolone, plasma exchange, and, in particular, intravenous immunoglobulins (IVIG),[9-11,17,18] although these studies were focused on treatment of acute deteriorations. IVIG short-term therapy is based on clinical trials recommending the periodic administration of 0.4 g IVIG per kilogram body weight every 4 weeks.[13] The immunomodulatory and anti-inflammatory actions of IVIG are complex and involve the modulation of expression and function of Fc receptors as well as an influence on complement activation and the cytokine network. Moreover, IVIG may contain anti-idiotypic antibodies and lead to an inhibition of maturation and altered function of dendritic cells as well as a modulation of T- and B-cell activation, differentiation and effector function.[19]

The side effects of long-term steroid treatment, the high costs and shortage of IVIG,[2] and the potential risks of plasma exchange as invasive therapy and the need for frequent hospitalizations underscore the need to develop innovative therapeutic regimens for the treatment of autoimmune diseases of the PNS. In genetic disorders such as primary (PID) and secondary antibody deficiencies, immunoglobulins have been administered for more than 25 years[6-8] and have been proven to be safe, without long-term side effects.[16] An alternative approach, the subcutaneous administration of immunoglobulins (SCIG) via a small portable pump, has been initiated for these disorders.[3,4,23,30] This regimen is well established for children with PID and SCIG results in well-balanced IGG plasma levels while lowering peak concentrations in comparison to IVIG.[31] Further data from these studies speak for reduced side effects and significant cost savings with SCIG.[29] In particular, application of SCIG with a small portable pump at home can significantly improve quality of life by reducing the frequency of hospitalizations. Therefore, we explored the use of SCIG in CIDP in this preliminary, unblinded study.

Case Report: Patient 1

A 73-year-old woman had a 13-year history of definite CIDP confirmed by sural nerve biopsy and typical electrophysiological findings. Clinical examination at onset of disease revealed severely disturbed proprioception with gait ataxia. Motor nerve conduction velocities were between 35–37 m/s in the median nerve and sensory nerve action potentials were absent (Table 1).

Initially, treatment with corticosteroids led to an improved gait and corticosteroids were gradually tapered followed by clinical stabilization for six years. Nine years after disease onset she experienced a relapse with progressive sensory loss and mild to moderate distally pronounced tetraparesis requiring bilateral assistance for ambulation. Oral corticosteroids were resumed but resulted in long-term side effects (osteopenia and Cushing's syndrome) and only temporary clinical benefit. Thus, therapy with intravenous cyclophosphamide pulses (600 mg/m2) was initiated.

Initially, treatment led to improvement of symptoms and the patient was able to walk without assistance. Due to severe side effects including diarrhea, hair loss, stomatitis, and hematologic changes, however, cyclophosphamide therapy had to be stopped after six cycles. Subsequently,

Table 1. Clinical and electrophysiological findings of patient 1 and patient 2 on treatment with SCIG.

Days after treatment	ISS	MRC	ODSS	CMAP (mV)	NCV (m/s)	DML (ms)
Patient 1						
-183	5	20.5	7	3.1	42	5.6
-75	8	23.5	4	-	-	-
7	8	23.5	4	3.7	41	6.1
138	8	24.5	4	3.6	45	6.6
206	8	24	5	-	-	-
Patient 2						
-28	4	28	4	3.5	34.9	5.2
0	6	28	4	4.3	35.0	5.1
77	7	29	3	4.0	34.9	5.1

Clinical measures include the sensory sum score[24] for sensory deficits (ISS), the Medical Research Council sum score (MRC) for weakness,[15] and the overall disability sum score[15] to assess overall disability (ODSS). As a representative paraclinical measure, motor conduction studies of the right tibial nerve including assessment of amplitude of the compound muscle action potential (CMAP), nerve conduction velocity (NCV), and distal motor latency (m/s) are shown. Day 0 indicates initiation of SCIG treatment; days preceded by a minus symbol indicate days prior to treatment.

proprioception and tetraparesis deteriorated progressively and led to increasing impairment of mobility until the patient was chairbound. Two months after discontinuation of cyclophosphamide, therapy with IVIG was started and has continued for the last 18 months, with 60 g IVIG per month (two infusions of 30 g each, equaling 0.4 g/kg). Several attempts to lower IVIG dosing or to extend infusion intervals failed due to rapidly worsening tetraparesis three weeks later. Monthly IVIG administration led to a temporary, fluctuating stabilization. Central venous access was required to continue therapy. Meanwhile, additional immunosuppressive therapy with azathioprine had to be stopped after 17 months due to hepatotoxicity. Alternative immunosuppressive therapy with mycophenolate mofetil (1,500 mg per day) was well tolerated but did not stop progression of the disease and the patient was referred to our outpatient clinic for advice.

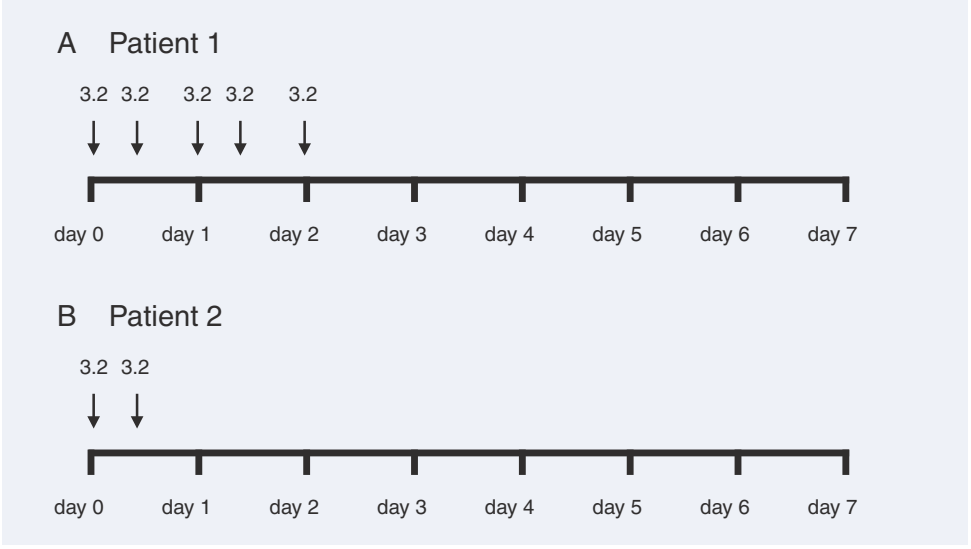
After obtaining informed consent, we initiated a treatment with SCIG following the previous IVIG regimen. To that end, a polyvalent immunoglobulin (Vivaglobin 160 mg/ml; Behring-Aventis, Marburg, Germany) and a portable, programmable pump (CRONO super PID; Mantsch-OMT, Minden, Germany) designed for a maximal syringe capacity of 20 ml were used. After being built-up gradually, the patient received a weekly SCIG dose of 16 g in a total volume of 100 ml infused over 10 h. The weekly dosage was divided into five equal doses administered over the course of three subsequent days, with each dosing containing 3.2 g SCIG in a volume of 20 ml (Fig. 1A). Due to subcutaneous swelling, the maximum dosage per day was limited to 6.4 g. Besides mild local skin reactions, treatment was well tolerated, without additional side effects. On therapy with SCIG for more than eight months, the patient has maintained her ability to walk with assistance (Table 1). Arm function also stabilized; hand-held vigorimetry revealed stable grip strength of the right hand, with 30 kPa at the beginning of subcutaneous therapy and 30 kPa on day 138. This clinical stability was well reflected by the electrophysiological findings (Table 1).

Case Study: Patient 2

A 53-year-old man presented to another department with a five-year history of sensory symptoms; examination revealed impaired proprioception. A diagnosis of CIDP was established by typical findings in the cerebrospinal fluid with elevated total protein level and by a slowing of motor conduction velocities. Initiation of IVIG therapy (40 g/day over five days) led to complete remission of sensory symptoms. As maintenance therapy, immunosuppression with azathioprine was started. However, this regimen ➢

did not stop disease progression and his sensory symptoms worsened. Thus, treatment was switched to mycophenolate mofetil (1,500 mg per day), yet tingling, paresthesias, and atrophy of the distal leg and arm muscles developed. On examination at our outpatient clinic, he presented with moderate hypesthesia and pallhypesthesia in all four limbs as well as a distally pronounced, atrophic tetraparesis. At that time he was found to have slowed motor conduction velocities and compound muscle action potentials of decreased amplitude (Table 1). Informed consent was obtained and the patient was started on combination therapy with mycophenolate mofetil and SCIG. The dose of SCIG was built up gradually until he was receiving a weekly SCIG dose of 6.4 g in a total volume of 40 ml (FIG. 1B), all applied on one day (corresponding to a monthly SCIG dose of 25.6 g). Besides mild local skin swelling, side effects were not observed. On continued treatment for over two years, sensory as well as motor symptoms have remained clinically stable, a finding confirmed electrophysiologically. (Table 1)

Figure 1. Application scheme of SCIG for patient 1 (A) and patient 2 (B). Arrows indicate infusion of single SCIG doses each containing 3.2 g IG in a volume of 20 ml.



Discussion

The first experiences with subcutaneous administration via battery-powered syringe pumps were gained in the late 1970s, when Berger and colleagues introduced a pump for slow, subcutaneous administration of larger IG amounts.[8] Since then, subcutaneous administration of IG has emerged as an alternative administration route both in children and adults for several indications and now should be considered for treatment of certain neuromuscular disorders.

The clinical efficacy of IVIG is well established in different inflammatory diseases of the PNS including multifocal motor neuropathy, Guillain–Barré syndrome, and CIDP.[13] We have demonstrated a sustained effect of SCIG in CIDP in a 1:1 dose ratio compared to IVIG. The clinical stabilization of both of our patients suggests an equivalent efficacy of SCIG and IVIG. This observation is further corroborated by another case report describing effective treatment with SCIG in a patient with multifocal motor neuropathy.[22]

Interestingly, the frequency of subcutaneous administration did not influence therapeutic efficacy in the present cases. Both patients remained clinically stable either with weekly pulses (patient 2) or more continuous application (patient 1). Although one study in panhypogammaglobulinemia reported inadequate efficacy of intramuscular IG compared to IVIG,[12] further systematic data on application intervals, especially in neuromuscular diseases, are not available.

In the present cases both patients received mycophenolate mofetil as a concomitant immunosuppressive therapy. Several recent studies have suggested that mycophenolate mofetil monotherapy may be beneficial in patients with various neuromuscular disorders, including myasthenia gravis, myositis, and CIDP, and other reports have demonstrated the efficacy of combined treatment with mycophe-

nolate mofetil and IVIG.[14,25,27,28] Further systematic clinical studies are needed to better define efficacy, combination therapy, optimal dosage, and application intervals of SCIG in neuromuscular diseases.

In our patients, SCIG treatment did not result in severe adverse effects. Apart from subcutaneous swelling, skin reactions or systemic side effects were not observed. In an observational study, 1,500 subcutaneous infusions were clinically followed: none of the patients displayed significant allergic reactions,[5] thus confirming the tolerability of this approach.[20,26] In patients with PID, SCIG was even reported to decrease systemic side effects compared to IVIG or intramuscular administration.[21,32]

Further advantages of SCIG include increased patient autonomy and parenteral application without the need for venous access. The easy and independent handling of infusions reduced hospitalizations, especially in the first patient. Thus, treatment with SCIG contributes to maintenance of an independent life, and patients with PID report an improved quality of life.[21] Limitations comprise a restricted volume that can be administered in one infusion, thus sometimes necessitating repetitive dosing to reach equivalence with intravenously applied dosages.

Finally, pharmacoeconomic aspects are important. In this regard, IVIG therapy represents a particularly costly regimen, sometimes limiting its clinical use. In the present cases, switching therapy from IVIG to SCIG reduced medication costs for immunoglobulin by 50% (e.g., in patient 1 from €60,000 to 30,000 using equivalent dosages). Thus, subcutaneous application may be not only safe and effective, but may reduce treatment costs in patients with chronic neuromuscular diseases.

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Chicks Dig Scars

By Mark T. Haggard

It was the relaxing end to a long day at work. It was our ritual: 4-year-old Calvin and 2-year-old Caleb would climb into the shower with me, and we would wash ourselves before going to bed. Calvin, though, was beginning to feel his aggressive boy nature, climbing all over his dear old dad. One moment became a life-changer.

As I prepared to rinse off, I didn't notice that Calvin had climbed up on the edge of the bathtub and was about to go Hulk Hogan on me. Before I could issue any kind of warning, he jumped, slipped off of my lathered shoulder, and fell back into the wall, careening through the soap dish, and on to the floor of the shower. Clear streams of water turned pink then red as blood flowed down the drain. I immediately got Caleb out of the shower and called for my wife.

First-aid mode overtook all my thoughts as I assessed the situation. The porcelain soap dish had been reduced to a jagged shelf of stone jutting from the shower wall

and my son lay in a heap with a 24-inch cut running down his back to the top of his buttocks. "Direct pressure," I recalled, grabbing a towel and pressing it to the laceration. I called for my wife again.

"Why are you letting Caleb run through the house stark naked and dripping wet?" my wife asked, entering the bathroom. Then she saw the blood.

I expected that she would freak out. She didn't. Apparently watching our son undergo a sweat chloride test for cystic fibrosis had prepared her for anything.

"Get me some clothes," I demanded, still pressing on Calvin's back.

"What happened?"

"I'll tell you later. Get me some clothes."

After getting dressed, I backed the car out of the driveway preparing to run Calvin to the ER. Hearing the words "emergency room," Caleb emerged from behind the front door, still stark naked, holding his stuffed dogs. He couldn't fathom a trip to the hospital that didn't involve him.

Because Calvin has a stronger immune system than his brother, he didn't undergo the many trips to pediatricians, emergency rooms, ENTs, allergists and immunologists that Caleb did. This trip to the ER, with Calvin's back split open like a baked potato, was a new experience for both of them.

Four hours and 27 stitches later, Calvin and I returned home. "I don't like this," Calvin lamented. I tried to compose the most fatherly response I could; all I could muster was "Hey, Big Boy, chicks dig scars."

Two weeks later, I took Caleb to the hospital for his IVIG. Normally the sight of a needle prompted a wrestling match during which I would have to grapple Caleb into a submission hold while our nurses poked around for a good vein. This time he looked at me with confidence in his eyes and put his hands up. "It's all right," he said. "Chicks dig scars."

I sighed and rubbed my forehead. Until that moment, I had not realized how my brief, off-the-cuff comments influence my boys' psyche, nor did I realize how closely they listened. Whether we are aware of it or not, whether we like it or not, how we respond to our children's immune deficiencies goes a long way in determining how they will respond.

Six weeks after the soap-dish incident, Calvin's pediatrician was removing the stitches in his back. "You know," he said, "you can have plastic surgery to hide that scar."

"That's OK, Doc," Calvin replied, shaking his head, "Leave it how it is; chicks dig scars." ■

GET TO WORK

Chronic Conditions and Employment Law

By Jennifer C. Jaff, Esq.

When you have a chronic immune or autoimmune condition, and you work or want to work, are you worried about your employer finding out, or, even worse, do you feel you've been discriminated against? Should you tell your employer about your illness, and if so, when, how, and to what extent does the law protect you from retaliation? This article will try to answer these questions.

There are two federal laws you need to know a little bit about before we can begin to sketch answers.

Americans With Disabilities Act

First, the Americans with Disabilities Act (ADA)[1] prohibits discrimination in employment, as well as other settings. The ADA applies to employers with 15 or more employees, although some states have laws that protect employees of smaller businesses.

To be protected by the ADA, you have to meet a series of fairly technical requirements. First and foremost, you must be a person with a disability, have a history of disability, or be perceived to have a disability. "Disability" is defined as a substantial limitation on a major life activity. From its inception, the ADA has defined "major life activity" to include things like seeing, hearing, walking, sleeping—the things everybody does on a daily basis. However, the ADA Amendments of 2008[2] added a new category of major life activities called "major bodily functions," and this new category expressly includes the immune system. So as of Jan. 1, 2009—the effective date of the 2008 Amendments—there can be no question that a chronic

immune deficiency constitutes a "disability," at least as long as it "substantially limits" the immune system. The 2008 Amendments direct the courts to interpret "substantially limits" more broadly than they have been doing, so although there are not yet reported court decisions clarifying this, it is fair to conclude that a patient with a chronic immune or autoimmune condition is "disabled" for purposes of the ADA.

Once you have jumped through that hoop, in order to avail yourself of the protections of the ADA, you also have to show that you are a "qualified individual" with a disability. A "qualified individual" is an individual who can perform the "essential functions of a job" with or without reasonable accommodation. The "essential functions" of a job are the fundamental duties of the position. A function may be essential because the position exists solely to perform that function, or because of the limited number of employees among whom the job function can be distributed, or because the function is so highly specialized that the person is hired due to her expertise in performing that function. Generally, if you have a written job description, the functions listed on it are considered essential.

For example, if there are 10 clerical employees who answer telephones and the call volume is such that all 10 are not needed, answering telephones may not be considered to be an essential function of the job. However, if you are the only receptionist answering phones, then answering telephones is an essential function.

This step of the analysis, while perhaps somewhat dry and technical, is one of the ADA's biggest problems for chronically ill patients. For most jobs, attendance is an essential function, so if you can't make it to work reliably, you can't perform the essential functions of the job, and, thus, you may not be a "qualified individual" even if you have a disability.

However, if you could perform the essential functions of the job *with* reasonable accommodation, you would be a "qualified individual." Thus, if you can't make it to work reliably every day, but you can perform the essential functions of your job from home—in other words, if attendance is not an essential function—then you are a qualified individual with a disability.

And if you are a qualified individual with a disability, then you are entitled to the protections of the ADA. Those protections range from having the right to bring a complaint and, ultimately, a lawsuit against an employer who violates the ADA, to asking for reasonable accommodations.

Reasonable accommodations are modifications or adjustments to a job or workplace that will enable an otherwise qualified applicant or employee with a disability to perform the essential functions of a job. Accommodations may include modifications that would enable an employee with a disability to enjoy equal benefits and privileges of employment, and can be anything from a handicapped parking spot to reallocation of nonessential job functions. An employer generally is not required to provide accommodation unless it knows of the disability, and even then, it is not required to provide the accommodation the employee requests. What is required is that the employer and employee engage in an "interactive process" to identify an appropriate accommodation. You aren't necessarily going to get the accommodation you ask for; if there is another reasonable accommodation that addresses your concern with less of a burden on the employer, then you have to consider such alternatives.

An employer can refuse to grant accommodation if doing so would constitute undue hardship, which is action requiring significant difficulty or expense.

To be protected by the ADA, you have to meet a series of fairly technical requirements.

The Family and Medical Leave Act

The other federal law that provides a framework within which we can consider the practical realities of working with a chronic immune disorder is the Family and Medical Leave Act (FMLA).[3] The FMLA requires all employers with 50 or more employees to grant eligible employees—those who have been employed for at least 12 months or 1,250 hours during the previous 12 months—up to a total of 12 workweeks of unpaid leave during a 12-month period for one or more of the following reasons: ➢

- The birth and care of the employee's newborn child;
- Placement with the employee of a child for adoption or foster care;
- To care for an immediate family member (spouse, child, or parent) with a serious health condition; or
- To take medical leave when the employee is unable to work due to a serious health condition.

As you can see, the FMLA does not require that you show that you are disabled; it requires only a serious health condition. Thus, whereas under the ADA an employer may gather enough medical information about your illness in order to properly fashion an accommodation, the FMLA requires only a doctor's note that establishes that you have a serious health condition.

FMLA leave needn't be taken all at once; intermittent use of the 12 weeks of leave is permitted. Thus, if you need infusions or have doctor visits, you can use the FMLA leave for those absences. The employer can require a periodic doctor's note or other update of your use of FMLA leave. During FMLA leave, your health insurance benefits must be continued. Your employer can't use FMLA leave as a reason for a negative performance evaluation; for example, the employer can't comment on absenteeism in an annual review when absences were taken under the FMLA.

Practical Realities

Both reasonable accommodation and FMLA leave are triggered by a written request from the employee to the employer. In my opinion, these are the only reasons to disclose your illness to an employer. An employer may not ask whether you have a chronic health condition in an interview, although she may ask whether you can perform the essential functions of your job. You have no obligation whatsoever to tell an employer that you have a chronic immune deficiency before you are hired, and after you are hired, the only good reason for this disclosure is if you need FMLA leave or reasonable accommodation.

The one obvious exception is the post-hiring physical exam. An applicant cannot be required to take and pass a physical exam before getting an offer of employment. However, an employer can make a job offer contingent on passing a physical exam. If a person is not hired because a post-offer medical examination reveals a disability, the reason for not hiring must be job-related and consistent with business necessity. In addition, the employer must show that there was no reasonable accommodation that would have made the job practicable for the employee, or that any such accommodation would pose an undue hardship to the employer.

When to tell your employer that you have a chronic immune disorder is a delicate question that goes beyond legality.

When to tell your employer that you have a chronic immune disorder is a delicate question that goes beyond legality. The answer I've given is strictly legal; you have no obligation to tell unless and until you need to because you are applying for reasonable accommodation or FMLA leave. As a practical matter, though, if you have to go for periodic infusions, or if you wear a visible pump, or even if you just go to the doctor fairly often, there may come a time at which you feel you need to be candid with your supervisor. Although I do not have an immune disorder, I do have two serious chronic illnesses. My ethic has always been to wait until my employer knows I'm a workaholic and then tell, so my employer doesn't worry that it will mean my productivity is lower than that of others. But to some extent, this is a personal decision that involves the dynamic of the employer-employee relationship, not one that can be dictated by law.

Of course, if you tell and then lose your job or a promotion, you will feel that telling was a mistake. Patients often believe that adverse employment action has been taken against them due to their illness. However, it is extremely difficult to prove discriminatory intent on the part of an employer. If your supervisor is making negative comments about your need to go for infusions regularly, for example, you should keep notes not only of what was said and who said it, but also who heard it said so that you have a record of witnesses. If you meet with supervisors to discuss reasonable accommodations, you can either take notes or ask for permission to tape-record the meeting (but do not

tape-record without permission since each state's law differs on the legality of use of covert tape recordings). To bring a successful case of employment discrimination based on disability, you need to prove not only that there was adverse action taken against you, and that you have a disability, but also that the adverse action was taken because of your disability. That takes proof of more than coincidence.

Court Decisions

There are very few reported court decisions involving immune disorders other than HIV/AIDS. In one such case, an employee with asthma and common variable immune deficiency (CVID) sued after being identified as a person with a disability by her employer, and being invited to seek accommodations.[4] The employee claimed that she had requested air quality testing on several occasions, and asked to be placed in a private office rather than a cubicle to reduce the risk of infection, but was ignored. She later asked permission to work from home, a request that was made after she initiated her complaint of discrimination, which was denied.

In this case involving the pre-2008 Amendments ADA, the court found that, since CVID affected only the work environment, and did not otherwise substantially limit the employee, she was not a qualified individual with a disability for purposes of the ADA. In addition, because she had not submitted written requests for accommodation in the form of workplace modifications prior to initiating her discrimination complaint, the court found that she had not made timely requests for reasonable accommodation and, even if she had, working from home would unduly burden the employer because the employee could not adequately be supervised from home. Thus, the employee lost her case.

Under the 2008 Amendments, it is fair to argue that, were this case heard again today, the first part of it most likely would have come out differently. The employee would be found to be substantially limited in a major life activity. However, the lessons of this and so many other cases are clearer when it comes to seeking reasonable accommodation, and the same lessons apply to the FMLA: First, make any and all requests in writing, even if the law or your employer says you don't have to; second, keep notes or other recordings of any and all conversations you have with an employer or supervisor regarding your illness; and third, allow your employer to respond fully before you even think about bringing a complaint of discrimination.

My Best Advice

So should you tell your employer you have a chronic immune disorder? Not unless you have a really good reason for doing so, such as the need for reasonable accommodation or FMLA leave. If you have to tell your employer, how should you do so? In writing, and any discussions should be had, if possible, in front of witnesses. If you don't get the accommodation you're asking for, is that enough to bring a lawsuit? No, you have to engage in an interactive process to see if you and your employer together can come up with a solution. And if you cannot be accommodated after engaging in an interactive process, can you sue? Only if you can refute your employer's claim that any accommodation would be unduly burdensome. Can your employer fire you for being out sick due to illness? Yes, unless you request leave under the FMLA, which you can't do until you've been employed by your current employer for at least 12 months.

So should you tell your employer you have a chronic immune disorder? Not unless you have a really good reason for doing so …

Just as the decision whether a person is a "qualified individual with a disability" must be made on a case-by-case basis, so, too, must the decision of when, whether and how to tell an employer that you have a chronic illness. My best advice is that, in most cases, it simply is none of your employer's business. ■

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[1] 42 U.S.C. § 12101 et seq.
[2] Public Law 110-325.
[3] 29 U.S.C. § 2601 et seq. Again, there may be state laws that apply to employers with fewer employees.
[4] Henderson v. New York Life, Inc., 991 F. Supp. 527 (N.D. Tex. 1997).

On a Mission

Author Aims to Help Jump-start Research

By Catherine Billey

Most memoirists don't experience bodily harm while writing a book.

With Anisah Hassan, such was not the case.

"I think I ended up in the hospital three times during the writing of the book," Hassan said.

The book, "A Flower Grows in Stone: The Diary of a Life in Progress," chronicles Hassan's experience with stiff-person syndrome (SPS), a condition whose hallmark symptoms—potentially dangerous episodes of muscle spasms and rigidity—can be triggered by emotional stimuli. And as any writer will tell you, recounting one's life means re-experiencing its every emotion, whether happy or sad, moment by moment.

"I was cooking a meal and I was singing, and I was thinking of the chapter I was in the middle of," Hassan said. "Something struck me about what I was writing. I remember falling and hitting my head, and I tried to hold on to my office chair, which was the wrong thing to do because it had wheels. I propelled myself real hard into the wall. The impact was so hard that I fell backwards and then I heard another bang on the floor. I went into a full-body spasm."

But to Hassan, who would complete her memoir in 2007 over the course of about four months, three hospital stays were worth it. That's because Hassan's desire to write the book was rooted in more than just the desire to share her story.

Rather, she wrote the book to help raise money to restart clinical studies on her condition.

"I wanted to contribute to the research on it, because they have stopped doing research," Hassan said. "I'm not informed enough to write this book in a clinical manner, but I do know what I've lived through. So I can tell the world pieces of my life, and that'll be my contribution, that partial proceeds will go to the research fund. And so that's how the book came about. I'm using the ability I have to write to let the whole world know that 'Hey, we're here and we're suffering, and we need your help.'"

According to Hassan, SPS is considered a rare disease, a classification that does not bode well for research funding. In the United States, about 300 to 350 people have been diagnosed with the condition, though Hassan suspects that many more have it without realizing it.

"When it's not a disease such as cancer or cystic fibrosis, something that everyone knows about and that a lot of people have, they call them rare diseases," Hassan said. "There are over 6,000 rare diseases."

And there's also an organization for these conditions: National Organization for Rare Disorders (NORD). Partial proceeds from sales of Hassan's book go to this organization, which administers grants for research. According to Mary Dunkle, vice president of communications for NORD, $35,000 needs to be raised to restart studies on SPS. As of early 2009, the fund had approximately $14,400. Once the monetary goal is reached, requests for proposals will be sent to researchers. After the proposals are returned, the NORD medical advisory committee will review them and decide what grant to administer. If a study has promising results, the hope is that it can be sent to the FDA for larger studies.

"For rare diseases," Dunkle said, "these grants usually offer at least something where otherwise they would have nothing."

Living With SPS

Though Hassan is doing all that she can to contribute to raising awareness and funds, the disorder stymies her ability to do more.

"What I'm doing is very minute," Hassan said. "There's

so much more I could do if I didn't have the physical or psychological manifestations; there's so much more that I'm capable of."

For example, due to her condition, Hassan has turned down offers to speak about her disorder.

"I've been invited to travel to speak and do book signings," Hassan said, "but my anxiety and phobia won't allow it."

Sadly, anxiety and phobia are often major elements in the lives of those with SPS.

According to one website: "Startle may lead to very uncomfortable and prolonged spasms. The symptoms worsen significantly with stress or anxiety, and the worsening of symptoms causes anxiety, often causing a disturbing self-perpetuating cycle."

Hassan knows this cycle all too well.

"With this disease comes many phobias," Hassan said. "I've been diagnosed with anxiety disorder and panic disorder. That's equally as bad as the disease itself. It really puts a halt on my life. It paralyzes me."

According to Hassan, the everyday nature of many of the condition's triggers, such as cold weather, emotional stimuli and stress, means that one can experience an episode of muscle spasms and rigidity nearly anywhere.

For Hassan, one episode occurred at her niece's graduation, where Hassan's excitement precipitated a full-body spasm.

"I ruined the whole thing," Hassan said. "I was so excited for her that I had a full-body spasm and an ambulance had to be called."

Though how individuals manifest stiff-person syndrome varies greatly, according to Hassan, her spasms are violent.

"Sometimes the rigidity starts first, and then the full-body spasm," Hassan said. "Once the rigidity starts, my heart pounds, and that starts the anxiety attack. My body will be as hard as stone, to the point where they can't even stick you with a needle, it's too hard, the muscles are too rigid. At that point, once the muscles get rigid, and all that pain kicks in, everything goes haywire, and that's when my spasms begin. And they are quite violent. It takes at least three to four people to aid and assist me so that I won't hit my head and I won't hurt myself. With the rigidity of the muscles being so strong, and the muscle spasms being so hard, you can tear ligaments and break bones. Even if you don't hit the floor, you can still break bones."

Due to the unpredictability of these episodes, Hassan's life is limited.

"Once you've hit the floor enough times, these phobias will come," Hassan said. "It will play a cruel trick on you, and you will never want to do that activity again."

For Hassan, that now includes attending another graduation.

Raising Awareness

Today, Hassan receives medical care at a center for advanced medicine that is also a teaching hospital, where part of her treatment protocol is immune globulin (IG). As a patient, she is also raising awareness—something that she feels is lacking.

"When I go to the emergency room, they've never heard of stiff-person syndrome," Hassan said. "They have to go on the Internet. And I have to tell them, but they're not going to take my word, the patient."

Though Hassan is glad to cooperate with the medical students, she admits that sometimes this is tiring.

"I have to be cooperative," Hassan said, "because I want them to know all that they can. The only problem is sometimes you don't feel too well, and you wish that they would come in all together, but they come in groups, so you've got to deal with it."

For Hassan, raising medical awareness is particularly important, as it took 14 years for her to receive her true diagnosis, which was in 2006. For years, Hassan thought she had multiple sclerosis (MS).

"My troubles began when I was 22," Hassan said. "I was immediately diagnosed with MS. I was treated for MS for six years with injections and steroids."

After MS was ruled out, doctors thought it was Parkinson's disease, and then rigid-spine syndrome. When the correct diagnosis was found, Hassan was relieved. At least initially.

"When I first got the diagnosis, I was elated until I got home," Hassan said.

Hassan's elation faded, she said, when she realized how little they knew about her condition.

"I know more about MS than I do about stiff-person syndrome," Hassan said.

In terms of her treatment, Hassan's doctor is open with her about all her options.

"He's always honest with me," Hassan said. "He says that so little is known about this, and that we could try this, or we could try that, and he leaves it up to me. He doesn't consider me a patient who's noncompliant."

He's also understanding about her frustrations.

"My doctor just told me last month, 'Anisah, if you ➢

About Stiff-Person Syndrome

Stiff-person syndrome (SPS) is a rare neurological disorder with features of an autoimmune disease. SPS is characterized by fluctuating muscle rigidity in the trunk and limbs and a heightened sensitivity to stimuli such as noise, touch and emotional distress, which can set off muscle spasms. Abnormal postures, often hunched over and stiffened, are characteristic of the disorder. People with SPS can be too disabled to walk or move, or they are afraid to leave the house because street noises, such as the sound of a horn, can trigger spasms and falls. SPS affects twice as many women as men. It is frequently associated with other autoimmune diseases such as diabetes, thyroiditis, vitiligo (a skin disorder causing a lack of pigment), and pernicious anemia. Scientists don't yet understand what causes SPS, but research indicates that it is the result of an autoimmune response gone awry in the brain and spinal cord. The disorder is often misdiagnosed as Parkinson's disease, multiple sclerosis, fibromyalgia, psychosomatic illness, or anxiety and phobia. A definitive diagnosis can be made with a blood test that measures the level of glutamic acid decarboxylase (GAD) antibodies in the blood. People with SPS have elevated levels of GAD, an antibody that works against an enzyme involved in the synthesis of an important neurotransmitter in the brain.

Early Stages

- Stiff-person syndrome usually begins insidiously in the axial muscles, and, if the patient is referred at an early stage, little objective findings may be found at the initial presentation.
- In the initial stage of the disease, the patient has an exaggerated upright posture and may report back discomfort or stiffness or pain in the entire back, which is worse with tension or stress.
- Patients may report disturbed sleep because, although the stiffness is relieved with sleep, when the patient transitions from rapid eye movement (REM) to stage 1 or 2 sleep they may lose the relief from the spasms, which may awaken them.
- In some patients in the early stages, brief episodes of rather dramatic severe worsening that resolve spontaneously within hours or days may occur.
- Unfortunately, because of the subtle findings and apparent strong psychological components in the early stages, the patients are labeled as psychogenic, and effective treatment is often delayed.

Later Stages

- Later in the disease, proximal limb muscles also begin to be involved, particularly when the patient is stimulated, surprised, angered, upset or frightened. This sort of stimulus may evoke painful severe spasms in the proximal arm and leg muscles that resolve slowly. The patient begins to move very slowly because rapid movement induces severe spasms. Even the distal extremities may become involved when moved rapidly.
- Exaggerated lumbar lordosis is present combined with contraction of abdominal muscles.
- Not surprisingly, depression has been noted as a comorbidity at this stage. The patient's quality of life is affected severely at this point, making it difficult or impossible to drive, work or have a satisfying social life.

don't want to smile, then don't. It's OK,'" Hassan said. "I'm getting to the point where I'm a little tired of it. No one understands it. My family doesn't understand it, my friends don't, so I'm alienated from a lot of activities that I used to do with my friends."

Despite the difficulties of living with the condition, Hassan works to stay positive.

"I have things that uplift me. I have a love for beauty," Hassan said.

A music connoisseur, Hassan loves all kinds of music, including country, jazz and big band.

Spirituality also plays a role in Hassan's outlook.

"My faith in God is the number one thing that lifts me," Hassan said, "I have an outstanding relationship with God. Based upon my teachings and what I know, if I didn't have a relationship with God, I wouldn't be able to smile."

The hope that research can begin anew on her condition also sustains Hassan. To that end, Hassan has done her part.

"When I see it [her book] in a bookstore, I look and I smile like I haven't seen this book before," Hassan said. "It's exciting to know that word is getting out and hopefully help is on the way."

"A Flower Grows in Stone" can be ordered online at www.llumina.com/store/aflowergrowsinstone.htm. For more information about NORD, check out www.rarediseases.org.

References

1. National Institute of Neurological Disorders and Stroke, www.ninds.nih.gov/disorders/stiffperson/stiffperson.htm.
2. eMedicine, http://emedicine.medscape.com/article/1172135-overview.

Resource Directory

For a more comprehensive list of resources, visit the Resources page at www.IGLiving.com.

Ataxia Telangiectasia (A-T)

Websites

- A-T Children's Project: www.atcp.org
- NINDS A-T Information Page: www.ninds.nih.gov/disorders/a_t/a-t.htm

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Websites

- GBS/CIDP Foundation International: www.gbs-cidp.org
- National Institute of Neurological Disorders and Stroke (NINDS) Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Information Page www.ninds.nih.gov/disorders/cidp

Online Peer Support

- The Neuropathy Association: www.neuropathy.org
- Barbara's CIDP/GBS Site (This is a personal website) 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
- Clinical Reference from eMedicine: www.emedicine.com/ped/topic721.htm

Online Peer Support

- Evans Syndrome Research and Support Group: www.evanssyndrome.net

Guillain-Barré Syndrome (GBS)

Websites and Chat Rooms

- The GBS/CIDP Foundation International, www.gbs-cidp.org, has 23,000 members in 160 chapters on five continents. (610) 667-0131
- 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.

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.
- The Mayo Clinic has an overview of Guillain-Barré Syndrome at www.mayoclinic.com/health/guillain-barre-syndrome/DS00413.
- The National Institute of Neurological Disorders and Stroke has an information page about CIDP: 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
- GBS Support Group and Chat Room, UK www.jsmarcussen.com/gbs/uk/chat.htm
- GBS Foundation Discussion Forums: www.guillain-barre.com/forums
- Yahoo Support Group Discussion Board http://health.groups.yahoo.com/group/GBS_CIDP
- 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.

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.
- "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.
- "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
- Platelet Disorder Support Association: www.pdsa.org
- National Heart, Lung and Blood Institute www.nhlbi.nih.gov/health/dci/Diseases/Itp/ITP_WhatIs.html

Online References

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

Kawasaki Disease

Websites

- Kawasaki Disease Foundation: www.kdfoundation.org PO Box 45 • Boxford, MA 01921 Tel: (978) 356-2070 • Fax: (978) 356-2079 • Email: info@kdfoundation.org
- Kids Health discusses Kawasaki disease www.kidshealth.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

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
- The Cleveland Clinic website provides many articles when searched by the topic, "mitochondrial disease." www.clevelandclinic.org/health

- 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

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
- Multifocal Motor Neuropathy Center at Johns Hopkins Department of Neurology 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
- The Neuropathy Association is dedicated to helping those with conditions affecting peripheral nerves. 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/
- 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
- Multiple Sclerosis Foundation works for a brighter tomorrow for those affected by MS. www.msfacts.org
- Multiple Sclerosis Association of America seeks to enrich the quality of life for individuals with multiple sclerosis. www.msaa.com
- MSWorld's Chat and Message Board features patients helping patients. www.msworld.org

Online Peer Support

- Friends with MS: www.FriendsWithMS.com
  Forum: http://health.groups.yahoo.com/group/FriendsWithMS
- My MSViews: www.mymsviews.org
  Forum: 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
- Myasthenia Gravis Fact Sheet prepared by National Institute of Neurological Disorders and Strokes. www.ninds.nih.gov/disorders/myasthenia_gravis/myasthenia_gravis.htm
- Mayo Clinic's overview of myasthenia gravis: www.mayoclinic.com/health/myasthenia-gravis/DS00375

Online Peer Support

- MGFA's Forum: http://health.groups.yahoo.com/group/MGnet
- Maddy's MG Support: http://health.groups.yahoo.com/group/maddysmgsupport
- Autoimmune Information Network Inc.: www.aininc.org
  PO Box 4121 • Brick, NJ 08723 • (877) 246-4900 • Email: autoimmunehelp@aol.com

Myositis

Websites

THE MYOSITIS ASSOCIATION

The mission of The Myositis Association, www.myositis.org, is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases.
(202) 887-0088

- 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

Online Peer Support

- Juvenile Myositis Family Support Network: www.curejm.com/family_support/index.htm
- Myositis Association Community Forum: www.myositis.org
- Myositis Support Group: www.myositissupportgroup.org
- Myositis Support Group UK: 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.

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.

- "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
- Information from the National Institutes of Health: www.niams.nih.gov/hi/topics/pemphigus/pemphigus.htm 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, 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.
- The Neuropathy Action Foundation, at 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, for listings of support groups across the nation.

Online Peer Support

- Calgary Neuropathy Support Group: www.calgarypners.org
- MSN Support Group Discussion Board: http://groups.msn.com/PNPARTNERS
- The Neuropathy Association Bulletin Board: 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 (PIDD)

Websites and Chat Rooms

The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is dedicated to improving the diagnosis and treatment of PIDD through research and education. (800) 296-4433

Jeffrey Modell Foundation

The Jeffrey Modell Foundation, 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, 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, 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, seeks to improve the quality of life for Michigan residents affected by PIDD.
- The International Patient Organization for Primary Immunodeficiencies (IPOPI), www.ipopi.org, promotes the worldwide improvement in the care and treatment of PIDD patients.
- To connect to a PIDD message board, go to www.info4pi.org.
- To chat with peers on IDF's Forum, go to 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 PIDD 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
- Baxter's website, www.immunedisease.com, offers in-depth information on immunology, PIDD and treatment with intravenous immune globulin. Click on "European" to see SCIG information.
- Rainbow Allergy-Immunology, 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.
- Support for those with PIDD in the New England area: www.teamhope.info

Online Pamphlets and Education

- Go to the National Institute of Allergy and Infectious Diseases site at 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

- "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.

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
- Jeffrey Modell Foundation Message Board: www.info4pi.org
- Rhode Island peer group: rhodeislandpidd@yahoogroups.com

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: http://scleroderma.jhmi.edu
- Scleroderma Research Foundation: www.srfcure.org
- Scleroderma Foundation: 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

Stiff-Person Syndrome (SPS)

Websites

- American Autoimmune Related Diseases Association Inc., www.aarda.org, is the only national organization dedicated to addressing the problem of autoimmunity. (800) 598-4668 aarda@aarda.org
- Autoimmune Information Network Inc., www.aininc.org, helps patients and family cope with the disabling effects of autoimmune diseases. (732) 262-0450 autoimmunehelp@aol.com
- National Association for Rare Disorders (NORD), www.rarediseases.org, promote awareness of rare diseases and the need for research. (800) 999-6673 orphan@rarediseases.org
- National Institute of Neurological Disorders and Stroke (NINDS), www.ninds.nih.gov, offers treatment, diagnosis and research information for rare diseases. (800) 352-9424 braininfo@ninds.nih.gov
- Mayo Clinic — Stiff-Person Syndrome: Can it be treated? 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.

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.

General Resources

Product Information

- Influenza and the influenza vaccine www.cdc.gov/flu or call (800) CDC-INFO: (800) 232-4636
- IVIG Carimune NF www.carimune.com
- IVIG Flebogamma www.grifolsusa.com/pdfs/flebo_14Jun05.pdf
- IVIG Gammagard Liquid www.gammagardliquid.com
- IVIG Gammagard S/D www.immunedisease.com
- IVIG Gamunex www.gamunex.com
- IVIG Octagam www.octapharma.com/corporate/03_products_and_therapeutic_areas/01_immunoglobulin_product_line/03_octagam.php
- IVIG Privigen www.privigen.com
- SCIG (subcutaneous immune globulin) Vivaglobin 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
- 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.
- 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.
- The nonprofit Patient Advocate Foundation, www.patientadvocate.org, seeks to assure patient access to care, maintenance of employment and financial stability. (800) 532-5274

PSI

The nonprofit Patient Services Incorporated, www.uneedpsi.org, specializes in health insurance premium, pharmacy co-payment and co-payment waiver assistance for people with chronic illnesses. (800) 366-7741

- WebMD, 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.
- The National Organization for Rare Diseases, at 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 brings national focus to autoimmunity through research, education and patient services. (800) 598-4668
- Band-Aides and Blackboards, www.lehman.cuny.edu/faculty/jfleitas/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

Education and Disability Resources

- Continuation of Health Coverage—Consolidated Omnibus Budget Reconciliation Act (COBRA): www.dol.gov/dol/topic/health-plans/cobra.htm

- Social Security: www.ssa.gov/disability
- California State Disability Insurance (SDI): www.edd.ca.gov
  (Please note that each state has a different disability program.)
- IDEA 2004 Resources: http://idea.ed.gov/explore/home
  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. 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.
  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/office/news/2008/discrimdisab.html, spells out your rights under Section 504 of the Rehabilitation Act.
- Wrightslaw: 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.ada.gov.

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 Wilmshurst 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.
- "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
- CSL Behring: www.cslbehring.com
- Grifols: www.grifolsusa.com
- Octapharma: www.octapharma.com
- Talecris: www.talecris.com

Pump and Infusion Sets Websites

- EMED Corporation: www.safetymedicalproducts.com
- Graseby Marcal Medical: www.marcalmedical.com
- Intra Pump Infusion Systems: www.intrapump.com
- Repro Med Systems, Inc: www.rmsmedicalproducts.com
- Norfolk Medical: www.norfolkmedical.com

Medical Research Studies

- On the official website for the National Institutes of Health patient recruitment program, you'll find summaries and criteria for studies as well as be able 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
- This site has a registration form to request that you be notified about recruitment for future studies. 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

Food Allergies

- Allergic Disorders: Promoting Best Practice: www.aaaai.org
- American Partnership for Eosinophilic Disorders: 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
- Food Allergy and Anaphylaxis Network: (800) 929-4040 www.foodallergy.org
- World Allergy Organization: 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.
- "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.

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

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