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IMMUNE GLOBULIN COMMUNITY

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December-January 2009



Inspiring Spirals

Unexpected Gifts
Received Along the Way

**Celiac Disease and
the Gluten-Free Diet**

A community service from FFF Enterprises, Inc.

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

A community service from FFF Enterprises, Inc.

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About *IG Living*

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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.

Community Spirit



If I could quantify anything, it would be how the following intangibles affect the human body: hope, inspiration, and human connection. For that matter, I'd love to see evidence of how the three work together, as it seems obvious that they do. This magazine, as well as the community it serves, is testimony of it.

Let's face it, we humans aren't much good alone. We need each other. And while I can't claim to understand the issues that those living with chronic diseases face, I do know, from being fortunate enough to meet a few of you, that the spirit in this community is astounding. It's an honor and joy to be a part of it, and very often humbling. But above all, it's inspiring.

To that end, the idea for our feature "Inspiring Spirals" was born. We can't control the DNA "spirals" we're born with, or how they may be affected by the environment or random events. An example that comes to mind is of a woman I met whose health changed profoundly after she was bitten by a black widow—the defense her immune system launched against the spider bite led to a host of autoimmune conditions she will have for the rest of her life.

What we can control is our reaction to what we've been given. We can control our attitudes. And on those days when we're not perfect beacons of sprightly light (what a burden that would be!), we can decide that, yes, tomorrow is another day.

I'm not writing this because I am a wellspring of wisdom who has the human condition down pat. I'm writing this because this is what many of you continually show me through your stories, your attitudes and your gumption.

A lot of you—whether you know it or not—regularly pass on tremendous gifts to other IG community members. To name a few: laughter, support, validation. To name a few more: hope, faith, encouragement. You even give each other a gift that isn't always obvious but which is equally precious: space to grieve, complain or just have a bad day.

One of my favorites of those words is hope. Being the word nerd that I am, I looked up its history. According to the Online Etymology Dictionary at www.etymonline.com, its roots reach back into German, with some suggesting a connection to a verb that means "leaping in expectation." Now, don't worry, I'm not trying to change your exercise regimen. Rather, I'm just trying to convey a visual about how I see many of you: courageous and spirited. In my mind, the phrase "inspiring spirals" applies to each and every one of you.

A force much bigger than any of us is responsible for the "spirals" we receive, molecules that are sometimes likened to recipes, codes or blueprints. To go with the recipe metaphor, it's almost like someone out there is compiling an enormous cookbook—each of us our own little dish that together comprise this smorgasbord of humanity.

Being an editor, I'd like nothing more than to compile a "recipe book" of the IG community, a sort of culinary who's who. I can almost see it, and I bet you can too. Like that other classic cookbook, I probably don't need to convince any of you that the word joy would appear in its title as well.

I hope you enjoy this issue. ■

Amanda M. Traxler, Editor

As always, please send feedback to editor@IGLiving.com.



Let's Talk!

By Shirley German Vulpe, EdD

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

For this column, I interviewed Duane Chally, 55, who was diagnosed about four years ago with ocular cicatricial pemphigoid (OCP), a rare, chronic autoimmune disease that affects the conjunctiva of the eye (a mucous membrane lining the outside of the eyeball). Untreated, OCP leads to progressive scarring and shrinkage of the conjunctiva and opacification of the cornea. Symptoms include red eyes, discomfort, itching, discharge and ingrowing eyelashes, and oral mucous membranes are sometimes involved. Left untreated, the condition can lead to scarring, corneal damage and sometimes blindness. Diagnosis is confirmed by biopsy, and treatment may require systemic immunosuppression.

Shirley: Can you tell me about your diagnostic process?

Duane: I developed symptoms in '98-'99. I had unexplained blisters that were itchy. I also had blisters on my gums. My doctor referred me to a dermatologist. He didn't know what it was but I also had red eyes so he referred me to an allergist. He couldn't figure it out either so he sent me to an ophthalmologist. He was stumped also. Then I got lucky. The ophthalmologist I was seeing went away and a young partner saw me. He was fascinated and said there had to be something that was being missed. I went back to the regular guy, but every time I went, the young doctor asked more questions. Eventually I was transferred to him. One day, he said he had an idea. After

inconclusive eye and skin biopsies, he sent me to other doctors. The diagnosis, cicatricial pemphigoid, was by majority opinion. My ophthalmologist follows me; however, a rheumatologist prescribes my IVIG. He has also become my advocate. Coordination of my treatment is difficult. As a truck driver, I need my infusions at night and on weekends.

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

Duane: Many. My rheumatologist originally arranged for treatments at the hospital on Friday or Saturday nights. Then that fell through. I had complications with my insurance. Then my doctor found a pharmaceutical company that would supply my IVIG and a nurse who would come to my home on the weekend. That worked until recently. Now, my insurance company told me that I'd have to buy my medicine from a company they contract with and that my copayment would increase. I have private insurance as I am self-employed, and I'm very concerned about this, as I can't afford a higher copay and I'm worried about scheduling treatment. Recently I've been working with a caseworker. My new pharmacy is working out except I don't know how much I will have to pay.

Shirley: Have you had any other treatments?

Duane: I was started on steroids right away. Later the IVIG was introduced.

Shirley: Has IG helped?

Duane: Definitely. As soon as the

IVIG was started, my eyes cleared up. However, that only lasted three weeks. Then another doctor added Cytoxan to suppress the immune system. It helped but I stopped it when my blood count got too low. I now get 100 grams of IVIG every other week and have been in complete remission for one and a half years.

Shirley: Describe your support system.

Duane: My wife reminds me when it is time for my treatments. My children are supportive but 700 miles away. My church group also. Professionals have helped a lot. The ophthalmologist with his appetite for a challenge who persisted until he solved my medical mystery. The rheumatologist who found a way for me to get treatment without missing work. The pharmaceutical company who supplied my medication and a nurse willing to meet my schedule.

Shirley: What was the best advice you've received?

Duane: The best advice, definitely, was to get Kris McFalls as an advocate. She is a huge help.

Shirley: Have you any final message for readers?

Duane: Yes, no matter what anyone says, there probably is an answer to your problem. Keep going until you find the right MD. ■

Resources

Ocular cicatricial pemphigoid:
www.merck.com/mmpe



A Small Percentage

By Cheryl L. Haggard

I'm honored to be raising children with a chronic condition; it's giving me a one-upmanship regarding the human body. Some of my buddies with healthy children tell me all the time, "I'd rather have you as my pediatrician, Cheryl."

"Naw," I demur. "The hours stink, and you do nothing but deal with sick kids all day. You couldn't pay me enough for all that nonsense!"

Then I ponder: I'm already doing that!

It's true. Raising kids with PID, I know more about the human body than I ever thought I would. But that's because we Haggards have a special way of approaching things. Our doctor once told us that, as a family, we do things big. Or rather, small. His words, something along the lines of: "If the books say it has a small percentage of



You see, Molly spent the first few days postpartum screaming her head off. I'm talking shatter-the-glass, get-your-earplugs, "will-drinking-a-whole-bottle-of-cooking-sherry-help-numb-me-of-her-inconsolable-yodeling?" screaming. I even asked my pharmacist brother if there was a drug for my life. (There wasn't.)

We ruled out colic due in part to the fact that her chronic gas ranked higher on the reek-o-meter than dear old Grandpa's or even the dog's. And while Mark and I thought that we had the horrid noises babies make under control (having dealt with Molly's older brothers' serious infections from day one), we soon learned otherwise.

But during one routine diaper change, I was the one who made a pretty horrid noise. After fighting with Molly's diaper tape and fiddling with the volume on a well-placed radio on her changing table (used to drown out her attempts at becoming our new American Idol), I looked down and saw fresh blood spots in the folds of her diapers.

My heart sank, as did my knees.

"Mark, can you please come here?" I cried.

"Where are you, Hon?" his response echoed from the garage.

"In Molly's room. Please bring me the phone, I have to call Dr. Ned right away!"

Mark entered nervously and handed me the phone.

"Oh my gosh! What's wrong with her?" Mark asked after peering at Molly's diaper.

"Mark, I know we've dealt with a lot of creepy stuff with the boys, and I don't know if you will believe me on this one, but..."

My mind skipped at least 13 years ahead.

"I think she started her period!"

Mark wrinkled his nose and commented, "Sure does explain all the screaming."

Yes, I did give him a piece of my mind that edged close to ending his ability to produce offspring. Then I called Dr. Ned, who assured us that Molly did *not* have mature female plumbing. Turns out, what happened to Molly occurs in a small percentage of female babies. Nothing serious, it was due to all the female hormones hanging around because of childbirth.

Once the scare was over, we couldn't stop laughing. And a few days later, we even managed to soothe Molly with a slick new pacifier. Finally, quiet returned. Like any medical student knee-deep in books, I was grateful. Especially given that all my medical lessons were being learned on the front lines. ■

happening, your family is that small percentage."

Oh, the lessons I have learned. One with Molly made me think I was on my way to earning an honorary medical degree. But first, let me back up a bit and tell you about Molly the infant.

Both sides of the family were looking forward to Molly: the first female to be born on either side in decades. With dozens of male relatives happily awaiting our little bundle of sugar and spice, we were all surprised when it turned out that, ahem, she wasn't very nice!

Now, my two boys were pretty straightforward. With them, I swore by what I call the Four B's of Babies: bottle, belch, binkie (or blankie) and bottom blows. Well, as an infant, my Molly was a little more constipating. (While I have heard of easygoing female babies, I have not experienced any.)



Inspiri

Unexpected

It's hard not to think about gifts this time of year. Even if you don't celebrate one of the traditional gift-giving holidays, our consumer society still barrages us with reminders of the practice in general. Not that it's a bad practice, of course. In fact, at *IG Living*, we think it deserves its own special section. But we're not focusing on material goods here. Because for many of us, the gifts we receive aren't always shiny new objects (not that there's anything wrong with that kind, either). In that vein, some gifts don't always come in packages that are easy to recognize. Oftentimes, it's through another lens altogether (such as hindsight or a new perspective) that we recognize the value of what we've been given.

For this issue, *IG Living* would like to share with you four stories from members of our community. If you're anything like us, these heartfelt gems will rival anything else you may receive this year.

ng Spirals

Gifts Received Along the Way



The Gift of Perspective

By Deena Marie

I'm running. I look up and see a big, beautiful blue sky randomly spotted with white puffy clouds. I'm moving so fast that every so often I can feel the weight of my body lift from the ground. I feel invincible. As the wind whips around me, I feel a smile slowly spreading across my face. I wake up and I gasp.

As I attempt to wipe away the deep sleep from my face, I realize that my face is wet; I've been crying. Frustrated with myself, I reach for a tissue. I swing my heavy legs to the side of my bed and fill my lungs with a slow measured breath. A breath that I will exhale as soon as I know my feet are firmly planted on the floor and that my legs will hold my weight. I carefully stand and release the breath in relief. My biggest triumph of the day and yet it's taken for granted by so many.

There are 400,000 Americans currently suffering from multiple sclerosis (MS). Statistics state that there are 200 people newly diagnosed every week and 2.5 million people

affected worldwide. These numbers are astounding to me. The unfortunate reality, though, is that there is no cure.

Scientists are making great strides and developments at a rapid rate. There is now medication to help slow disease progression, which is a development that gives us all hope. Ironically enough, "hope" is the motto of the National MS Society. If you donate and receive a bracelet, you'll see the word "hope" in big bold capital letters proudly stamped into it.

Recently, I visited an MS chat room. I was very skeptical about entering. I assumed that everyone in there would be complaining and depressed and I didn't want to further damage my already fragile emotional state. Boy, was I wrong. I was the one who ended up complaining. I complained about the fatigue, the pain, the emotional toll it has taken on my family, the numbness, and the red spots left on my body from my injectable medication. The support I received was phenomenal. It came from people all over the world.

When you're diagnosed, you learn what MS has done to your body already. You learn what else MS can ➤

potentially do to you. You learn how MS has affected the people you know who are already diagnosed. You learn what all the “book-raised” experts tell you. What you’re not prepared for is how much MS impacts every aspect of your own life. It affects not only your body and what you are physically capable of, it affects your state of mind, your career, your family, your friends, everything. The only people you can learn that from and get real advice on how to cope are the ones who are living with it right alongside of you. These people are more than just numbers, they aren’t just statistics. They’re real.

These individuals have shown me that there is no need to feel alone. There are others out there suffering. There are others out there afraid of taking their injectable medication. There are others who get red spots on their skin. The fact is: There are other people. I’ve connected with a community who truly understands me and exactly what I’m going through.

While in the chat room, as I’m complaining, I received a response that completely stopped me in my tracks. One woman’s reply to the mention of the residual red spots on my skin was “to think of them as little red spots of courage and hope—a reminder to not give up.” I was so taken aback that while sitting in front of my computer, I started to cry. Sobbing like a child and feverishly wiping at my face so that I could see well enough to type, I thanked this woman. I thanked her for giving me the determination to keep fighting.

What this woman had really given me was a gift. She gave me the gift of perspective. The cliché that “it could always be worse” is true. Every time I get a shot or see a bruise or a red spot on my body instead of crying or complaining, I smile. I smile because I realize I’m not alone. I smile because I realize that I’m not giving up. I smile because I still have the ability to dream.

My online support group has led me to some really amazing people and for that I am truly grateful. They don’t know it but I pray for each one of them every single night.

Three years later, I am still fighting and I am still dreaming of running. I’m dreaming of running down my neighborhood street, chasing my future children around my backyard; I’m dreaming of running the way I used to as a child. I may not be able to trust my legs now but I’ve promised myself that, as soon as I can, I’m not only going to walk, I’m going to run.



The Gift of Communication

Patricia Haynes, GSW

All the plant books tell us to talk to our plants, they like it and will grow for us, right? Well, my husband says I could talk ivy to death. Not only can I talk to plants, but I can talk to rocks, trees, kids, dogs, and other people just fine, thank you. But communicate? Now, that hasn’t always been so easy. Especially during the last few years—after a car accident marked the onset of multiple other symptoms that left me trudging from doctor to doctor trying to figure out what was wrong. I assure you, that was not a fun time. Not knowing how to effectively communicate with family members and doctors only exacerbated what was already a difficult situation.

Up until the accident, my life was full. I ran 24-7, and was pretty much on call for everyone (work, four boys, and my then-boyfriend, now-husband). After the accident I started to notice exhaustion, back pain, a lack of concentration and anxiety. Not just any old anxiety but a social anxiety, a fear of being around and speaking to people (even plants) I didn’t know.

I remember telling colleagues that it was all temporary and that I’d be back to “normal” in a day. Within a month of the accident, however, I was a walking zombie. Too tired to drive and too sore to sit, I also did not have the mental faculties to perform my job well. But I simply did not want to admit that I was ill, so I quit the demanding job, thinking I’ll just take an easier one. My doctor gave me several medications to cope. I started a bookkeeping job. I stayed three weeks.

Even then, I still couldn’t admit what was happening. I wasn’t ready to let go of the person I had been: a strong, capable, quick-to-learn woman who could raise kids, go to school, work two and three jobs and still cook, bake and sew. But I knew I needed to find out what was wrong with me. So I saw a new doctor. Determining that I had ruptured a disk in my back, he suggested I rest to see if it would heal. I followed the doctor’s advice and rested. My back got stiffer and stiffer.

My husband started taking off work to take me to the doctor, who continued to tell me that sleep was the best healer. I slept, my husband wondered, and my kids started to talk about mom getting fat and sloppy. Because I couldn’t acknowledge what was happening, and because I didn’t know what was wrong, I couldn’t communicate

with them. All I would say was “I don’t feel good, I’m going to sleep now.”

Finally, the doctor said that I needed an MRI. I soon learned that the disk had continued to bulge and was pressing the sciatic nerve down the left leg. After a year of being in bed, finally someone had told us part of the problem: I needed back surgery.

The surgery was not successful. Bone and metal shards still floating around in my back were rubbing the sciatic nerve and causing excruciating pain. After a second surgery, I became extremely ill. I couldn’t keep food down, and I had pneumonia twice. Unable to maintain any body heat, I couldn’t stay awake more than 20 minutes at a time, and I had mystery rashes and hives constantly. I began looking for other doctors.

This was an extremely difficult time for my husband and sons. My husband had never been ill, and my boys’ worst illness had been when the middle kids, twins, had their tonsils out in 10th grade. My behavior and problems were simply unacceptable to them. No one wanted to know what was wrong, except me. The extent of our communication made it clear that everyone in my family thought that mom was acting like her mother, “the hypochondriac.” Their general MO was to ignore me until I came to my senses.

Six doctors later, the truth came out. I had primary immune deficiency disease (PIDD), autoimmune illnesses and osteoarthritis. Though now I had answers, I still was not ready to deal with the implications of my illnesses. Because of this, neither was my family. For months, we were not able to communicate effectively. It was especially difficult for my husband. Baffled and hurt, he had many questions. He wondered how I had become so ill all of a sudden, and why any of it was happening in the first place.

During this time, I had to get used to my diagnoses. Angry, sad and distraught, I tried to bargain with God that I would stop doing anything that would cause problems (like sin). Then, one day, I saw things differently: Yeah, I have these things, now what am I going to do about them? At this point, I knew I had to become proactive about my care.

For the emotional shock of the diagnoses, as well as the constant pain, I began therapy. I also started attending

support groups, which have been informative and wonderful, as well as Internet chat groups, which are full of information one cannot get anywhere else. The people who work for this magazine have been some of the most important in my life. They not only directed me to doctors who stopped my own hysteria, but they gave me a new lease on life. Finding the right doctors to direct my care and to talk with me honestly and straight has been the biggest battle of all. Having professionals who helped lay the groundwork for me to become an active and vital part of my treatment was key.

Finally, I learned how to be good to myself. I took it easy.

I stopped punishing myself because I didn’t know how to tell myself or my family what I felt or needed. But most important, I finally learned how to do just that—to acknowledge to myself, and then communicate to my family, what I feel or need. With new tools in place, I reached out to my boys and asked for a few minutes to explain my illnesses. I also sent each one of them a letter with the illnesses listed and lightly defined. Because I continued to work on communicating with them, and gave them facts without excess emotion, they were able to really hear what was going on. Further,

they became able to help me when I asked (learning to ask, of course, was a new skill for me, too). My kids are proud that they can help out when things get rough or when my husband is out of town. My husband and I have learned to talk to one another about my conditions. A well-functioning unit, we now are able to coordinate and communicate.

I thought I was too well-educated, strong and capable to need anyone else to help me cope with my illnesses, but I wasn’t. By accepting this and reaching out to others, I have learned an enormous amount. And this has made all the difference in the quality of my life—which I now enjoy to the fullest. Not that I have been magically cured. I’m still ill, and I still experience pain. But I am happy and well-adjusted. Professionally and personally, the gift of communication has allowed me to bring my life back into balance. Best of all, I now regularly enjoy my two favorite activities. First on that list is playing with the grandkids. Second is making others laugh. Plants too, even if they don’t always get my jokes. ➤

“Professionally and personally, the gift of communication has allowed me to bring my life back into balance.”



The Gift of Independence

By Kris McFalls

As parents, we tend to give to our kids even at the expense of taking care of ourselves. Sometimes we forget about what we need to give ourselves. That can be especially true when it comes to having kids with common variable immune deficiency (CVID). I should know—I've got two of them.

Raising two kids with CVID has been both a challenge and a real blessing in my life. Although I wouldn't wish the disease on anyone, especially my own children, the special people and experiences it has brought into our lives are irreplaceable.

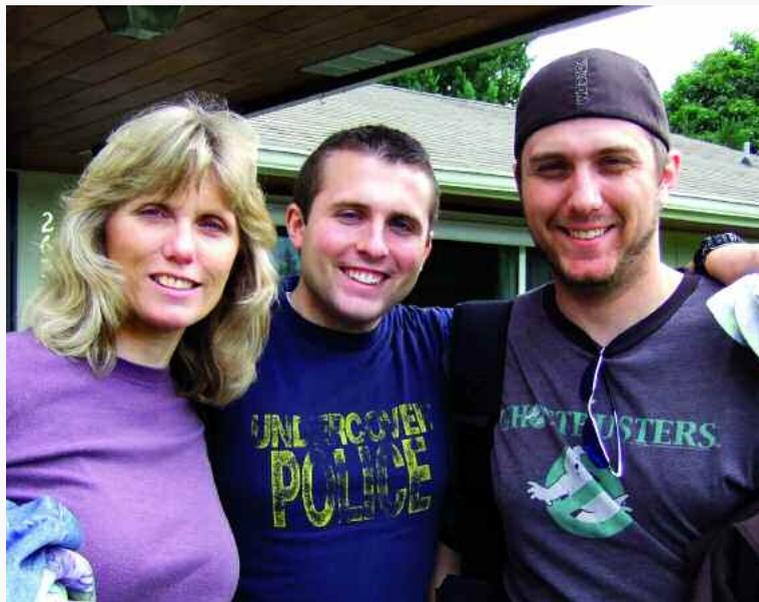
I never mourned the loss of my children's good health, to be quite frank, because they never really had it. The day of their diagnosis was more of a relief and less of a burden. I didn't at all understand what the doctor was telling me about this disease. I only heard that there was a treatment. My biggest worry at that point was the big camping trip I had planned and making sure this treatment didn't mess it up. Up until the diagnosis doctors kept telling me, he just seems sick all the time because you are a new mom. Or don't worry they will grow out of it. Well, they are 21 and 23 now and still show no signs of growing out of it. Instead, they have learned to live their lives to the fullest and not let their disease get in the way. Reaching that point, however, was a process filled with lumps, bumps and fears.

My youngest son, Keegan, required a great deal more care beyond his CVID. He had neurological impairment requiring years of speech and physical therapy. It seemed every day there was some kind of appointment for him. Konner, having only CVID, seemed so normal in my world. The challenge became making their lives feel as normal as possible, thus incorporating the disease into our lives rather than letting our lives be ruled by the disease.

Early on my kids taught me they needed control over what was happening to them and who was treating them. Keegan in Irish means "little fiery one." Aptly named, Keegan had no problems telling doctors and nurses exactly how he felt. My saving grace in the beginning was Keegan's severe speech problems; not many doctors could understand him. That was until Konner started translating. My kids taught me I needed to give them as much control as possible. That meant things like they could choose where they wanted their IV or what was on the

TV when they got their IV, but whether or not to have the IV was not a choice. To teach my kids to think of themselves as healthy, I learned never to refer to them as sick unless they had an active infection.

Thanks to Keegan's assertiveness, I even learned how to infuse both boys myself. Keegan got frustrated with the turnover of nurses and one day crossed both of his arms and told his nurse, "Nope, Mommy do it!" After overcoming the initial fear of poking my own kids, we learned to appreciate the autonomy that self-infusing brought to our lives. Our schedule no longer revolved around a nurse's schedule or business hours. We were truly fitting the IV into our lives rather than letting the IV rule our lives.



Kris McFalls with sons Keegan (left) and Konner

As the kids grew, I started to understand they were not always going to be with me and therefore they needed to learn how to care for themselves at a much younger age than most kids. In their teens, they started running the show with their doctor appointments. They kept their own lists of their medications and symptoms. The doctor would talk directly to them discussing medications and treatment plans. The doctor was their doctor, not mine, and it was their appointment, not mine. That line needed to be very clear for all involved.

When it came to chores, my kids were given no leniency. I expected them to clean their rooms just like any other parent. And just like any other teen, they ignored me.

Nonetheless my expectations for them were always high, and (aside from their rooms) they never failed to meet them. In high school both boys started making their own appointments. Thinking he had indeed grown out of his disease, Konner even made the decision to stop treatment for a while. With his doctor's approval (and under a watchful eye), Konner trialed off IVIG. After a year Konner came to appreciate the wonders of his liquid gold and never again entertained the thoughts of life without treatment.

College brought new challenges. I learned this disease was indeed my kids' disease, and they had to take it with them when they left home. Again it was Keegan who changed our path and showed us all a new direction. With memories of nurses sticking him with needles still unfaded, he announced three weeks before leaving he wanted to switch to subcutaneous infusions (SCIG). Six months later Konner made the same decision. I had adjusted to Keegan's decision but was not quite ready to adjust to Konner changing too. For me, that day meant I spent time with at least one of my sons, which I relished. I was actually enjoying IV day. I was shocked by my own feelings of loneliness and lack of control. Konner taking full control of his infusions was almost more difficult for me than the day my kids were diagnosed. All this time I had worked hard to prepare my kids to take control of their disease and live their lives to the fullest. I prepared them to be independent and to be able to care for themselves, but I had not taken the time to prepare myself. I was not ready for the life I now had. After giving my kids the gift of independence, I realized I hadn't given the same thing to myself.

After some time, though, I was able to give myself the same gift. I've learned what makes me happy, such as time with friends, church activities and multiple hobbies. By filling my life with these things, I'm able to keep smiling, move forward and appreciate the blessings life has to offer.



The Gift of Appreciation

By Jordan Scott and Amanda M. Traxler

As a shortstop, Jordan Scott, 17, likes to think ahead.

"In baseball you have to think about what you're going to do if the ball comes to you," Jordan said.

As the only child of three in his immediate family who does not have immune deficiencies—sister Julia, 20, and brother, Jonathan, 13, both have common variable immune



From top left: Jordan, Julia and Jonathan Scott with parents Jeanette and Kevin

deficiency (CVID)—such adaptability comes in handy.

"You sometimes have to be thinking about if this happens, what would I do," Jordan said.

Case in point? Unexpected hospital visits. Especially to see Julia, whose condition became apparent when she was just an infant. Often sick, Julia purportedly took her first steps in a hospital bed. Jordan's brother, who was diagnosed three years ago, still has regular doctor visits, of course, but has not been as sick comparatively.

"If they're in the hospital sick, you just can't walk in and say to them 'Oh, how's it going?'" Jordan says. "Because you know it's not going good if they're in the hospital."

Following the cue of his parents and grandparents, Jordan says he usually tried to "come to the room and maybe bring her something ... [but mostly] just hang out because nobody wants to be in the hospital, obviously, but if you have people who love you there supporting you, then at least that helps."

Not the usual middle child, Jordan knows his perspective is different from his friends'. ➤

"I've never really talked to anyone who has the same situation because normally people don't have siblings with medical problems that are serious," Jordan says. "My friends all know that my brother and sister have something, but you can't really put yourself in the situation."

As a well child, Jordan knows he's experienced situations that many won't deal with until a much later age.

"There's things I've gone through already that most people don't go through until they're a lot older, you know, as far as like loved ones being in the hospital and being extremely ill," Jordan said.

As a young boy, however, normal for Jordan meant going to the hospital—which was usually exactly where he wanted to be when his sister was sick.



From left: Jonathan, Jordan and Julia

"My sister's medical condition was a lot more serious when I was younger. It hasn't been as serious now as we've grown up," Jordan says. "She's actually gotten a little better and doesn't have to do as much. Back then ... if my sister had to go to the hospital, then I would want to go to the hospital ... because she was one of my best friends growing up, so there wasn't anything I wanted other than to be with her when she was going through stuff like that."

As he grew older, Jordan understood that not everyone spent so much time at the hospital. This is when he began to understand the gravity of the situation. With this, though,

also came the gift of appreciation.

"I definitely have come to see what's important," Jordan says. "Just seeing what my sister went through and stuff, I appreciate things, like getting to hang out with her, more than others would. Some of the things that people worry about I'm not exactly too worried about because I know there's more important things."

Not that Jordan's siblings don't know what a more-typical "normal" is like.

"Growing up, my parents tried ... to have them live a normal life, even if they have an immune deficiency."

Jordan's parents tried to make things as normal as possible for him too, which sometimes meant understanding and accommodating Jordan if ever he didn't feel up to going to the hospital.

"If there was any time that I didn't want to go to the hospital ... I would definitely tell my mom I didn't want to be here. She understood that, so she would work things out and have me go with family for a weekend so I didn't have to do it."

Along these lines, Jordan's perspective means he has some wisdom that will likely resonate in *all* families.

"Just be open with others, because if everyone is hiding their emotions and what they want to say, then everyone is going to be unhappy."

And if you think that's not bad for a 17-year-old shortstop, then just keep reading. What follows are Jordan's own words about what his brother and sister have taught him.

When I'm having a hard time, it sometimes makes me sad to know that Julia and Jonathan face the same things, but they have even more to go through with illness. I've never told them, but if I could take the pain and illness from them and let them live a normal healthy life, I would. Most of the time, I don't know what to say to them because it is so hard to imagine having to go through what they do. I love Jonathan and Julia more than anybody in the world, and seeing them hurt from an illness they have no control over hurts so much because I couldn't imagine my life without them. Knowing that they have something that can harm them and take them from me is the worst feeling ever. I know that they have both made me a better person, even though they don't know they have taught me more than anyone ever could. In so many ways, they have made me stronger than other kids. Everything I do is for them so that they can be happy and proud of me, their healthy brother. I love them. ■

Acknowledge Your Worth

By Ever Fecske

Imagine you fall down a well. You are sitting in a puddle at the bottom, and when you look up, you can see the blue sky and sunlight. You can tell the wind is blowing because leaves from the surrounding trees float down like feathers and land in the two inches of water around you. Stuck, you watch the leaves turn soggy and soggy. You wonder if you are ever going to get out, and finally, you do.

When you are finally rescued, your family and friends ask you about your experience. Were you scared? Did you try to save yourself? Were you cold? Hot? Did you get hurt on the way down? And as you sit there and recall your time in the well, you realize that you can only do your best to try to convey your experience to those around you. In your heart, you know that they may never truly understand.

At times, illness is like being stuck at the bottom of a well. Seeing no escape, it is a lonely existence. For many of us, a diagnosis leads us to question our worth as people. We view ourselves as flawed or different. The younger you are, the harder it is to be different. We so much want to be accepted by our peers, but an obscure and chronic illness makes us stand out (and not in a good way, like the high school quarterback or prom queen). Our everyday experiences are truly unique, and there are very few people who can relate.

This makes it difficult to keep life in perspective. I have so many goals and ambitions, but most of the time I don't have the energy to accomplish a shower in the morning. It is so hard to take life one minute at a time when we have always been taught to consider the future. And yet sometimes I have no choice but to live in the moment. Though necessary, there's nothing life changing about brushing my teeth or eating breakfast.

At times like this, it's stressful to think about how far away I am from my goals. I wonder if I will ever be able to have a regular job, or will I be on Social Security forever?

If I do have a job, will my boss understand the day off I need every two weeks for IVIG? All of this thinking not only makes me tired, but it also makes me feel lonely and helpless. And then I realize I'm at the bottom of the well. Counterproductive and stuck, I can't see what's going on around me.

I've realized that it's OK to ask for help to regain perspective. Someone who loves you will be more than happy to support you. When I am struggling I always call my dad, he's my go-to guy. Next thing I know he throws me a rope and helps me climb out. I am suddenly able to see again. I can see how strong I am to have survived my experiences with illness, which have shaped the person I am today—someone who then in turn tries to always support others. Because that's another thing he helped me see: how much I can help others through my strength. And though there is so much unknown, just knowing that I am loved reassures me that I will never remain stuck in the well.

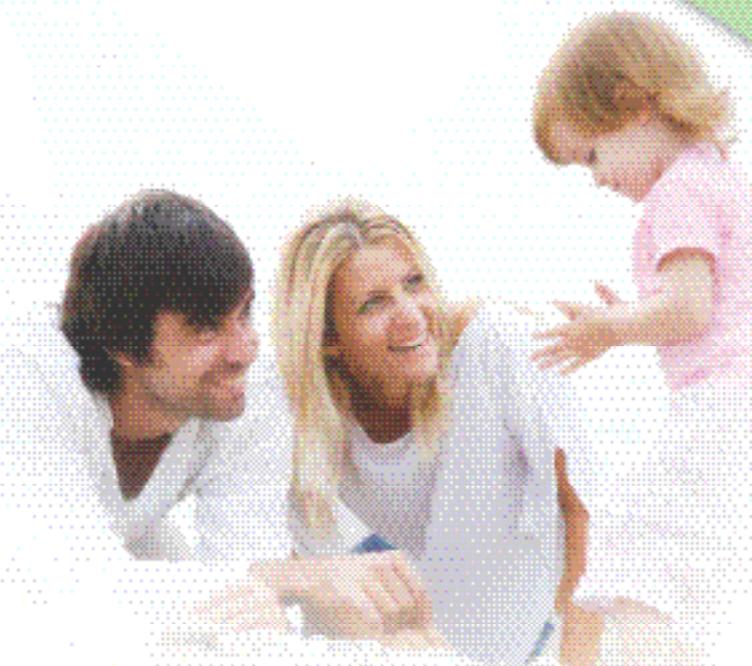
Once I am out of the darkness, I realize how sad it is that the initial reaction to illness on a social level is so negative. In my mind, our health challenges make us worth that much more. We become stronger than we ever knew we were. And though we may have moments in the well, we don't stay there. We choose to reach out and connect with others. We choose to climb. ■

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Traveling With Medication

By Carla Schick

Kris McFalls vividly remembers her son Keegan's departure two years ago for a church-sponsored mission. Keegan, like all airplane travelers, faced restrictions of no more than 50 pounds per suitcase and a two-suitcase limit with one carry-on. Unlike most airplane travelers, though, Keegan has common variable immune deficiency (CVID), which calls for packing extra gear. Some creativity was needed in getting two years' worth of clothing, equipment and medical supplies all packed up. Keegan figured out that if he put his heavy boots in his carry-on, he could get each bag down to 49.5 pounds. The only thing left was his months' supply of IG. With his carry-on full, and knowing he should not put his IG in his checked baggage, Keegan resorted to filling his pockets. According to Kris, the look of bewilderment on the transportation security agent's face when Keegan pulled out one bottle after another for hand-checking was priceless. In all, Keegan had eight bottles in various pockets of his pants and jacket.

"I had no idea his pockets could carry so much!" Kris laughingly remembers.

Even if you haven't been to the airport lately, no doubt

you're aware of the many security policies and precautions that come along with air travel. From a 3-ounce limit per container to personal security screenings, Hawaii just doesn't have the same ring to it. Hold on, Hawaii, we'll get there, let me just empty out my pockets at the security checkpoint.

For many in the PIDD and neuropathy communities, air travel is not the preferred mode of transportation. Let's face it, traveling with medications can be burdensome. From needles to quart-size plastic bags, to portable oxygen concentrators (POCs), requirements abound. Here's an overview to help keep you up-to-date.

SOPs for POCs

First, let's take a look at the standard operating procedures (SOPs) for POCs. It's important to keep in mind that not all carriers offer supplemental oxygen services. When booking your airline reservations, inquire whether:

- the airline provides oxygen services,
- such services are available on the flights you wish to take, and
- a doctor's letter (or permit to contact your doctor to verify your medical need) must be provided. ➤

The Federal Aviation Administration (FAA) has approved several POCs for in-flight use for passengers requiring oxygen: the Inogen One, AirSep Lifestyle, AirSep Freestyle, SeQual Eclipse and Respironics EverGo. These are the only POCs approved at this time. But remember, you must confirm with your airline carrier that they will allow your POC on your specific flight.



Of the many airlines currently operating, only a select few accommodate people with POCs. But good news is in sight: In May 2009, POCs must be allowed on *all* flights originating or ending in the United States. This new policy will require all airlines operating in the nation, including foreign airlines, to allow the use of approved POCs on-board and in-flight. And of course, air travel wouldn't be air travel without security; so if you're traveling with an approved POC, you will need to identify that on the POC itself when you pass through airport security. Note: All POCs that have been approved by the Transportation Security Administration (TSA) can safely be X-rayed upon request.

Three Ounces, Anyone?

Now, how about all those liquids that we have to carry? Frankly, for most of us a 3-ounce container isn't going to cut it. But have no fear—we have options, two of them,

to be exact, according to a memorandum from the TSA. First, you can place your liquids, aerosols and gels in travel-sized 3-ounce containers and then place all of them into *one* quart-sized bag. Your second option, which your doctor or pharmacist would recommend, would be to keep all liquids, aerosols and gels in their original containers. Because these items would no longer fit the 3-ounce requirement, they may not be placed in the quart-sized bag. Instead, they must be declared to the security officer. It is important to keep declared liquids separate from other property submitted for X-ray screening. Since you will very likely declare your medications and supplies to the security officer, please remember to bring supporting documentation: ID cards, letter from doctor, signed prescriptions, etc. It is also recommended, although not required, that the label on the prescription match the name on your boarding pass. If they don't match, you can expect to explain why that is so to the security officers.

For those of you wondering whether it's safe to have IG pass through the X-ray machine, here's your answer: It is generally accepted that X-rays are not strong enough to damage proteins in IVIG solutions. According to pharmacist and *IG Living* advisory board member Jim Mathews, the amount of radiation that IG would be exposed to is considered insignificant to the drug. However, Mathews says that if anyone is concerned about this, hand-checking is also an option.

"While not necessary in my estimation," Mathews said, "you can request hand-checking rather than have it go through the X-ray."

If you wish to have your medications and related supplies inspected by a security officer instead of allowing them to pass through the X-ray machine, you must ask for visual inspection *before* the screening process begins; otherwise, your medications and supplies will be X-rayed. Other important things to keep in mind:

- If you would like to take advantage of this option, have your medication and associated supplies separated from your other property in a separate pouch/bag when you

approach the security officer at the walk-through metal detector.

- Ask the security officer to visually inspect medication and then hand your medication pouch/bag to him or her.
- To prevent your medication, associated supplies or fragile medical materials from contamination or damage, the security officer may ask you to display, handle and repack your own medication and associated supplies during visual inspection. Any medication or supplies that the officer can't clear visually will be X-rayed.

To Cool or Not to Cool?

Given that temperatures change dramatically during a flight, is that safe for IG products? Well, if we throw in a little common sense, everything will be just fine. Basically, you want to avoid putting your IG product through extreme cold or extreme heat. Amy Ehlers, pharmacist-in-charge at NuFACTOR, recommends that you do not place any medication in checked baggage.

"This is especially important with IG," Ehlers said. "One is the risk of it breaking in your checked luggage as it is being handled. Another is that the temperature in the luggage compartment is not temperature-controlled, so the IG could be overheated or freeze. Also, if your luggage is lost or delayed, so is your medication."

Ehlers also recommends that when traveling with IG products, manufacturer-recommended storage guidelines should be followed.

"If the medication needs to be refrigerated, a small soft-sided cooler works best," Ehlers said. "Keep in mind that this has to fit either under the seat in front of you or in the overhead bin. Use the smallest size that will accommodate the drug and enough ice packs to keep the product cold but not frozen. Don't place the product directly on the ice packs as the IG may freeze. It can be wrapped in a washcloth or dish towel to prevent direct contact."

Note: Along these lines, gels and frozen liquids needed to cool medically related items are also permitted.

According to Mathews, most IG products can "be stored at room temperature [up to 77 degrees F] for between seven days and six months, depending on the product."

OK, so you may not be able to carry on your swords, throwing stars or otherwise pointy objects (checked baggage only, please), but at least your IG products and related supplies are set to go. Hawaii, here we come! 🗡️

Additional Tips

- Leave your medications in their original containers
- Call ahead if you need a wheelchair to take you to the boarding gate
- Keep *all* doctor-signed prescriptions handy at ALL times
- FedEx your medical supplies to your U.S. destination instead of putting them in your luggage
- Airline policies are subject to change without notice. It is recommended that you notify the airline at the time of reservation and 48 hours before flight time if you will be flying with oxygen to verify its policy

Resources

- Travelers With Disabilities and Medical Conditions: Medications
www.tsa.gov/travelers/airtravel/specialneeds/editorial_1059.shtm
- Travelers With Disabilities and Medical Conditions: Air Travel
www.tsa.gov/travelers/airtravel/specialneeds/index.shtm
- Travelers With Disabilities and Medical Conditions: Hidden Disabilities
www.tsa.gov/travelers/airtravel/specialneeds/editorial_1374.shtm
- TSA: Permitted and Prohibited Items
www.tsa.gov/travelers/airtravel/prohibited/permitted-prohibited-items.shtm
- Airline Travel With Oxygen
www.homeoxygen.org/airtrav.html
- Portable Oxygen Concentrator Information
www.homeoxygen.org/pocinfo.html
- Airline Oxygen Policy
www.homeoxygen.org/airlineoxygenpolicy.html
- TSA Call Center
(866) 289-9673 or tsa-contactcenter@dhs.gov

Gamunex Approved to Treat CIDP

By Amanda M. Traxler

For the approximate 25,000 Americans who suffer from chronic inflammatory demyelinating polyneuropathy (CIDP), Sept. 12 was an important day.

That Friday, the Food and Drug Administration (FDA) announced approval for Gamunex as a treatment for CIDP, a rare neurological disorder characterized by progressive weakness and impaired sensory function in the legs and, to a lesser extent, the arms.

The approval marks a couple of firsts for Gamunex. Currently the only therapy of any kind with an approved indication for the treatment of CIDP, Gamunex is also the only intravenous immune globulin (IVIG) therapy approved to treat a neurological disorder in the country.

And for patients, says Estelle Benson, executive and founding director of the GBS/CIDP Foundation International, that's a positive development.

"We're very proud of Talecris for taking the effort to do this," Benson said in October. "Our patient population has been waiting for some type of breakthrough."

According to Benson, U.S. patients with CIDP now have an FDA-approved medication to help limit CIDP's peripheral nerve damage, which improves both neurological function and quality of life.

"I speak on behalf of the 26,000 members of the GBS/CIDP Foundation who are excited to learn that Talecris has established that Gamunex is a successful treatment for patients with CIDP. What good news!" Benson said in the Sept. 15 press release.

IG Living readers with CIDP have similar sentiments.

"When I received the letter that Gamunex is now an approved treatment for CIDP, I felt validated," said Mary Klatt of Gresham, Ore. "Validated in the fact that I have this disease, there is a real treatment for it, and maybe now there are doctors who are becoming more aware of it. I see the approval not only as a form of validation for the insurance company and reimbursement issues but also for physicians to see that IVIG is an approved standard of care in CIDP."

Regarding doctor awareness, Talecris also announced that it is developing programs to educate neurologists on the new indication and the clinical trial that supported it.

That's something Klatt appreciates.

"It is sad that I no longer see my neurologist because she was not comfortable prescribing IVIG for me any longer," Klatt said. "She was more comfortable switching me from IVIG that worked for me to a more experimental treatment that had a possibility of causing cancer in the long run. This news was wonderful and lets me breathe easier knowing I can continue to receive my IVIG."

J. Armstrong of Fairfax, Va., began using IVIG for CIDP about four and a half years ago. Always aware of long-term access issues, she followed the clinical trial intently.

"I was truly surprised in my initial research about FDA policies

regarding IVIG use before starting the therapy, particularly as it has been an established and accepted practice, albeit an 'off-label' use, by a majority of medical insurance companies for well over 20 years," Armstrong said. "Yet the FDA could not act to approve it until this one trial, [which] is I believe the first one specifically for CIDP. I was following it closely and eager for results."

The study, published in the February 2008 issue of *Lancet Neurology*, is the first and only large-scale clinical trial documenting the long-term safety and efficacy of Gamunex to treat CIDP.

Even before the recent approval, Armstrong considered herself lucky.

"I am truly fortunate for having doctors who were knowledgeable and open to this treatment option, especially as prednisone for me was not considered due to other medical issues," Armstrong said.

Just a week after the Gamunex approval, a subanalysis of the *Lancet Neurology* study was presented at the American Neurological Association's annual meeting.

In the Sept. 22 presentation, study author Norman Latov, M.D., from Cornell University, reported that among patients who responded to IVIG therapy, 41 percent improved after the first treatment course, while 94 percent improved after the second treatment course.

According to study authors, some patients may require more than one treatment course to achieve clinical response. In conclusion, the authors recommended further studies in CIDP to "more clearly define the duration of treatment required to achieve and maintain maximal response to IVIG therapy."

For patients like Armstrong—for whom IVIG has been so helpful—any future studies will surely be greatly appreciated.

"I will not forget my first round of the 'loading dose' series. After the second day, I was able to walk and move for over an hour after treatments!" Armstrong said. "Whereas before I was lucky to be able to walk, at most, 15 minutes followed by two days of additional pain and serious naps to recover from the fatigue. I now time things I want to do for after infusions whenever possible."

In August, Talecris Biotherapeutics launched www.CIDPinfo.com, a peer-reviewed, clinical and scientific information center that offers health-care providers a comprehensive resource focused exclusively on CIDP. ■

Resources

GBS/CIDP Foundation International
www.gbs-cidp.org

CIDP Information Center
www.CIDPinfo.com



CELIAC DISEASE

and the Gluten

By Jessica Schulman, PhD, MPH, RD



Free Diet

Throughout Connor's early years, his mother, Wendy, noticed periods when he stopped gaining weight and did not grow. She took her son to doctors, who invariably recommended high-calorie diets and patience, and indeed these periods passed and Connor resumed growing normally. When Connor was 10 years old, it happened again. Wendy remembers: "He weighed only 45 pounds." They were referred to a pediatric gastroenterologist, who, finding no obvious problems, was prepared to send them home, suggesting that he had a "weak stomach." Then, just before the appointment ended, Wendy mentioned that her grandmother had celiac disease (CD). They decided to test Connor for it, and the results were positive. ➤



Connar, who has CD, is his family's main gluten-free baker.

What Is CD?

CD, which is also known as celiac sprue or gluten-sensitive enteropathy, is a lifelong autoimmune disorder characterized by an immunologically toxic reaction to gluten—the storage proteins found in wheat, rye, barley and triticale. The disease has a genetic basis, but genes alone will not cause symptoms of CD, nor will eating too much bread. Instead, CD arises through the interaction between the environment and genetics, similar to diabetes.

When people with CD consume foods containing gluten, the gluten particles are broken down to form a “complex.” The body misreads this complex as a dangerous invader, producing immune cells to fight against it. The antibodies that are the product of this autoimmune reaction cause microscopic damage to everything in their path. This overreaction leads to the inflammation, intestinal damage, and all of the short-term and long-term problems associated with the disease. The disease's current treatment is a gluten-free diet. Undiagnosed and untreated, CD can lead to other conditions, including osteoporosis and anemia.¹

What Are CD Symptoms?

CD manifests in various ways. Individuals can have the classical form (obvious gut problems), failure to thrive,

atypical CD (subtle symptoms), or silent CD (no symptoms). Classic symptoms in children include diarrhea, bloating, anemia and failure to thrive. For adolescents and adults, symptoms often include diarrhea, constipation, weight loss, weakness, short stature, gas, bloating and vomiting.^{1,2}

CD, which can masquerade as other problems, also can look different depending on age, the severity of the disease, and the presence of health problems outside of the gut (extraintestinal manifestations). For example, dermatitis herpetiformis is a skin manifestation of CD that looks like little blisters on the face, elbows, knees or bottom.

Absence of these problems does not rule out CD. According to CD expert Mary Niewinski, MS, RD, “Atypical clinical manifestations of celiac disease are characterized by few or no gastrointestinal (GI) symptoms, instead, extraintestinal symptoms.”¹ Looking back, Wendy was able to associate CD with various problems during the 10 months it took for diagnosis. She says: “I realized that Connar had several other symptoms the whole time, like emotional instability and very small stature. Also, he had stopped functioning academically.”

How Common Is CD?

In the general population, between 1 in 100 and 1 in 300 people live with CD. In specific groups, such as European immigrants and those with certain autoimmune conditions, rates are much higher.² Moreover, because symptoms of CD can be mild or nonspecific, the disease is underdiagnosed in the United States, and patients are frequently diagnosed with other conditions first.³ Once health professionals are more aware of the disease and more accustomed to screening for it, the true prevalence will likely be higher.

When Does CD Occur?

As the Celiac Disease Foundation noted in 2006: “Celiac disease may appear at any time in a person's life. The disease can be triggered for the first time after surgery, viral infection, severe emotional stress, pregnancy or childbirth.” It might become noticeable in babies when food is introduced. Symptoms can persist throughout childhood and decrease in adolescence. Other factors such as viruses (adenovirus and relapsing rotavirus infections), other genetic syndromes, drug treatment such as interferon and intestinal permeability may increase risk for CD as well.⁴

¹ Niewinski, MM. Advances in Celiac Disease and Gluten-Free Diet. *J of the Am Diet Assoc.* 2008;108:pp.661-672.

² Wolters VM and Wijmenga C. Genetic Background of Celiac Disease and Its Clinical Implications. *Am J Gastroenterol.* 2008;103(1):pp.190-195.

³ Niewinski, op.cit.

⁴ Wolters and Wijmenga, op.cit.

Examples of Extraintestinal Problems Associated With CD

Iron deficiency anemia

Decrease in red blood cells (hematocrit and hemoglobin) due to inadequate iron. May have small red blood cells, low serum ferritin, low serum iron, high iron binding capacity, blood (visible or microscopic) in the stool.

Reduced bone

Less bone as measured by bone mineral density (BMD) testing. Predicts bone strength, mineral density and its ability to bear weight. A reduced BMD correlates with risk of fracture.

Chronic fatigue

May be mild or an incapacitating fatigue that isn't improved by bed rest. Exacerbated by physical or mental activity. Associated with cognitive dysfunction, impaired memory, decreased concentration, joint or muscle pain, headaches, swollen lymph nodes and shortness of breath.

Irritable bowel

Abdominal pain or discomfort. May include cramping, bloating, swollen abdomen, gas, diarrhea, and/or constipation. Affects the large bowel. Some people are relieved by a bowel movement and others have the sensation that they have "not finished." Mucus may appear in the stool.

Dyspepsia

Pain or discomfort in the upper abdomen, belching, nausea, bloating, feeling of fullness, abdominal bloating.

Infertility

Not being able to conceive after one year of trying or the inability to carry a baby to term, when no other cause is found.

Miscarriage

The natural or spontaneous end of a pregnancy. Usually occurs prior to 20 weeks gestation.

Hypertransaminasemia

Blood test that indicates a liver disorder. Chronic and otherwise unexplained.

Coagulopathy

Problems with the body's ability to clot blood. This may be caused by impaired absorption of vitamin K (prothrombin deficiency). May lead to prolonged bleeding after an injury.

Short stature

Below-average growth in childhood or height is not progressing at a fairly steady pace over time. Bone age lags behind chronologic age.

Pubertal delay or hormonal disorders

When child has passed the normative age when puberty begins and there are no physical signs that it has started—usually no later than age 14.

Arthralgia

A form of joint pain that is not usually accompanied by inflammation.

Aphthous stomatitis

Occasional and self-limited ulcerations or canker sores that can last for one week. Some can become more long-term or debilitating.

Folate deficiency

Reduction in red blood cells. Megaloblastic anemia (red cells are abnormally large). Symptoms include fatigue, headaches, sore mouth and tongue, and pallor (pale color).

Zinc deficiency

Delayed growth and maturation, hair loss, eye and skin lesions, diarrhea, loss of appetite or weight, delayed wound healing, taste abnormalities, and mental lethargy, depression of immune function (reduced activation of T-cells).

Dental enamel hypoplasia

Decreased quality and quantity of the enamel on one or many teeth. May look mild (small pits that may or may not be discolored) or may be more noticeable (dents or misshapen teeth). Contributes to tooth sensitivity and susceptibility to cavities.

Unexplained neurological disorders

Unusual sensations such as tingling, burning and numbness in the hands and feet. Some people feel pain sensations in their arms or legs. Associated with weakness and cramping.

Psychological or behavioral

Problems with concentration or memory, depression, mood disorders, irritability.

Unfortunately, CD usually persists throughout life and will often reappear when the individual is in their 30s or 40s. Due to delayed diagnosis and nonspecific symptoms, the diagnosis of CD might not be given until much later in life. Niewinski reports that symptoms may be present for "an average of 11 to 12 years" before properly diagnosed.⁵

How Can You Get Correctly Diagnosed?

Blood tests are an important first step. IgA endomysial antibodies, IgA tissue transglutaminase, and IgG tissue transglutaminase may be useful in identifying patients at risk for CD. However, for people with antibody defects, such as an IgA deficiency (or more extensive primary ➤

⁵ Fasano A. Celiac Disease in the Clinical Spotlight: What's New and What's the Path Forward? Medscape. www.medscape.com/viewarticle/533251.

immune deficiencies), and for children under 5 years of age, results will not be reliable. In these cases, or if there is suspicion of CD, a small intestinal biopsy is recommended.⁶ An individual with CD will usually have distinctly patterned small lesions in their intestine. After dietary treatment,

biopsies should show that lesions are healing or in remission.

Genetic tests can also help to identify who is at risk or who is unlikely to have the condition, but genes do not always predict who will develop symptoms. Human leukocyte antigen (HLA-DQ2 or HLA-DQ8) are required to develop the disease but are not the only factors. People who do not carry these genes tend not to develop CD; however, one out of three individuals is a genetic carrier and most carriers do not develop the disease. Furthermore, non-HLA genes may also contribute to CD, and additional regions of the genome are under study but their associations are not well known.⁷

To get an accurate blood test or biopsy, the patient must be consuming gluten. This is one reason why it is important to consult with a qualified healthcare professional if you or a loved one is seeking evaluation for CD.

What Is the Gluten-Free Diet?

Strict adherence to a gluten-free diet is the only available treatment for CD. Some patients might develop tolerance to gluten over time but scientists don't know whether this is temporary. Distinguishing between patients who need life-long adherence to the gluten-free diet from those who don't is not yet possible. For now, a gluten-free diet remains the cornerstone of treatment. Many patients report relief from symptoms after a couple of weeks on the diet. Full recovery, confirmed by biopsy, may take months or, in complicated cases, years.

Wendy explains that adjusting to the diet was initially difficult: "I was frustrated because nothing I was

Allowed Grains Vs. Foods to Avoid in CD

Gluten-Free

Amaranth
Arrowroot
Bean flours
Buckwheat
Corn
Fava
Flaxseed
Garbanzo bean
Garfava™ flour
(garbanzo & fava bean)
Hominy
Mesquite
Millet
Montina™ flour
Nut flours and nut meals
Oats (uncontaminated and if approved by patient's physician)
Pea flour
Potato flour
Quinoa
Rice
Sago
Sorghum flour
Soy flour
Tapioca (manioc, cassava, yucca)
Teff (or tef) flour

Toxic With Celiac Disease

Barley
Bulgur
Cereal binding
Chapati flour (atta)
Couscous
Dinkel
Durum
Einkorn
Emmer
Garina
Farro (or faro)
Fu
Gluten, gluten flour
Graham flour
Kamut
Malt (malt extract, malt flavoring, malt syrup, malt vinegar)
Matzoh meal
Oats
(most commercial brands, oat bran, oat syrup)
Orzo (a pasta that looks like a rice)
Rye Seitan ("wheat meat")
Semolina
Spelt
Triticale
Wheat
(wheat bran, wheat germ, wheat starch)

Adapted from and reprinted with permission from Case, *Gluten-Free Diet: A Comprehensive Resource Guide*, 2006.

⁶ Celiac Disease Foundation. Brochure: Celiac Disease, 2006.

⁷ Wolters and Wijmenga, op.cit.



used to cooking tasted the same. Connor also felt very isolated.” With the support of a friend who was on a gluten-free diet, Wendy says, “I began to get my footing on gluten-free.” Families with CD are strongly encouraged to meet with a dietitian or gastroenterology nurse who has experience with CD, and to participate in a CD support group.⁸ Learning the gluten-free diet, which may be lacking in certain nutrients, takes time.

Wendy says that most people were supportive and understanding and Connor has been great about sticking to the diet. “He now reads every label and knows exactly what to look for ... he is our main gluten-free baker.” The Celiac Disease Foundation, www.celiac.org or (818) 990-2354, provides a “Quick Start Diet Guide for Celiac Disease.” What follows is an overview:

- Read labels. Become a good ingredient label reader and avoid the foods that are toxic for patients with CD (see table on Page 28). Labels must be read every time food is bought. Wheat-free is not gluten-free.
- Verify ingredients. Contact the food manufacturer and specify the ingredient and the lot number of the food in question (e.g., breading, brown rice syrup, croutons, energy bars, flour or cereal products, imitation bacon, imitation seafood, marinades, pasta, luncheon meats, sauces, gravies, self-basting poultry, soy sauce, soup bases, stuffings, dressing, thickeners, communion wafers, herbal supplements, drugs and over-the-counter medications, vitamins, nutritional supplements).
- When in doubt, go without!
- Keep a diary. Healing may take time. Not all adverse food reactions are due to CD.

Looking Ahead

The prognosis for patients who are correctly identified and treated for CD is excellent. However, a small number of individuals who implement a gluten-free diet still may not feel better; these individuals may require steroids or other treatments. An individual living with CD has an increased risk for structural damage and cancers in the small intestine, as well as lymphomas.

Eighteen months after his diagnosis, Connor is a different child. Wendy reports that he has gained 15 pounds and has grown. She says: “He doesn’t look sickly anymore. His positive attitude has returned. He is progressing again academically and he now has physical control over his body, which he has never had before.”

Connor’s fondest hope is to help families and find a cure for this condition. According to Wendy, “Many days he wonders why he has to have celiac, but he always turns it around with the idea that maybe he can find relief for others someday.” ■

Editor’s Note: The author is a credentialed dietitian, holds a doctorate in health behavior, and is a visiting scholar in the Department of Psychology at the University of California, Los Angeles. This article is intended for general information only. Individuals with medical conditions should consult a physician to determine what eating pattern is right for them.

Support Groups

Gluten Intolerance Group

www.gluten.net

Celiac Disease Foundation

www.celiac.org

Canadian Celiac Association

www.celiac.ca

Celiac Sprue Association

www.csaceliacs.org

Gluten-Free Diet Information

www.celiac.com

Celiac Disease Online Support Group

www.geocities.com/HotSprings/Spa/4003/delphi.html

⁸ Raymond N, Heap J, Case S. The Gluten-Free Diet: An Update for Health Professionals. *Practical Gastro*. 2006; Sept:67-92.

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

Richard: Is it possible to have symptoms of an immune disorder (recurrent respiratory infections, chronic sinusitis, chronic bronchitis) with low antibody levels, but with a normal Pneumovax response? I believe such individuals exist (I think I am one), but they are generally not diagnosed with primary immune deficiency disease (PIDD) because they do not fit the classic profile. In my particular case, I have low normal IgG, chronic respiratory infections and sinusitis, but a normal response to the vaccine challenges. My IgA and IgM are on the low side of normal. Because of my good vaccination response, my doctor is reluctant to give me a diagnosis of IgG subclass deficiency. In my support group, I've encountered other individuals with low IgG but, because of their good response to the vaccines, cannot get reimbursed by insurance and—in some cases—cannot even get a diagnosis, in spite of horrific and disabling symptoms. Many thanks, in advance, for any help or thoughts you may have.

Kris: Just because the medical community does not have the testing to verify a problem does not mean there is not one. I would encourage you not to give up. Please, if you are not already, keep a health journal of your infections and responses to treatment. Someday that may be the key for you and your doctors. I asked Dr. Terry Harville, medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences, to comment on your questions.

Dr. Harville: This is an important and difficult situation. The hallmarks of confirming an antibody deficiency syndrome, such as common variable immune deficiency (CVID), are:

- Decreased B lymphocytes (fewer than 200 cells per mL, for adults).
- Significantly subnormal immunoglobulin (IG) levels,

typically low to absent IgA with an IgG value less than 400 mg/dL. The IgM level may be absent to elevated, depending on where one is in the course of the illness.

- Evidence of decreased function, which is typically demonstrated by an inability to produce antibodies to challenge with recall antigens. In other words, check pre-titer and post-titer responses, typically using diphtheria and tetanus toxoids as protein antigens and pneumococcal vaccine for polysaccharide antigens. In a patient with recurrent/chronic sinopulmonary infections (sinusitis, otitis, bronchitis and pneumonitis), meeting all of these criteria (low immunoglobulins, low B lymphocyte count, and poor responses to making antibodies to diphtheria, tetanus, and pneumococcal vaccines) makes the diagnosis of an antibody deficiency somewhat straightforward.

The difficulty arises for those in the gray areas, which may unfortunately be a significant number of patients. As in the presented situation, the immunoglobulins may be somewhat low, but not severely low. The B lymphocyte count is not mentioned. Responses to diphtheria and tetanus are not mentioned, but the pneumococcal responses are reported to be "normal." Based on the accepted criteria, this patient does not meet the definition of having an antibody deficiency syndrome, despite recurrent sinopulmonary infections.

There are other possibilities that must be addressed in the evaluation of such a patient. Complement protein deficiencies will have the same clinical features as patients with antibody deficiencies but may not require IVIG; instead, daily antibiotic therapy may be appropriate. Less well understood is the role of MBL (mannin binding lectin), which may predispose to sinopulmonary disease; here again daily antibiotics, not IVIG, may be the proper course. Proteins known as TLRs (toll-like receptors) may have an important role in initiating immune responses,

but their role in chronic sinopulmonary disease is not well understood. And again, the role of IVIG therapy for this disease is not well understood.

Persons with allergic disease may be having recurrent sinopulmonary disease, when more aggressive allergic treatment is required. Gastroesophageal reflux is a very important, but underappreciated, cause of chronic sinopulmonary disease. And aggressive therapy, sometimes surgery, may be required to help with the problems.

Anatomic problems may be preventing the appropriate drainage of fluids, allowing for recurrent infections. Or problems may exist with the tissues directly, for example, cilia that do not perform well. Exposure to tobacco smoke may damage the tissues to such an extent that they cannot readily heal. Or, exposures to other irritants or pollutants may also prevent the tissue from healing well. All such issues must be considered.

Now, could there be an immunodeficiency, even though the pneumococcal responses appear “normal”?

First, the “true” pneumococcal responses must be clarified. Were the overwhelming majority of the responses in the high protective range? Were there significant rises in the titer values between the pre- and post-samples? If not, then this may not have been a “normal” response.

Second, what are the exact IgG, IgA and IgM levels? In the transition from “normal” immunity to “abnormal” immunity, the expected changes are typically first a fall in IgA, then a fall in IgG and finally a fall in IgM. During this process, the IgM may actually become elevated.

Third, what do the B lymphocyte subpopulations look like? B lymphocytes can be divided into CD5+ and CD5- subpopulations. We begin life with an overwhelming majority of CD5+ B lymphocytes (90 percent to 95 percent), which subside gradually to about 5 percent by the time we are adults. There is a specific polysaccharide antibody deficiency (SPAD) associated with the absence of CD5- B lymphocytes (this does not apply to the question, as the pneumococcal antibody responses reportedly are normal). More useful in this case, we can divide B lymphocytes into naïve cells that have not been exposed to antigens and are being constantly produced in the bone marrow. The younger you are, the more you are expected to have, but even older individuals should have a significant population. The other major B lymphocyte subpopulation to consider is mature B lymphocytes. As may be expected, the more exposure to anything that produces an antibody response, the more mature B

lymphocytes we expect. Therefore, we would expect to accumulate more as we age, but there should be a continued production of naïve B lymphocytes, so that both should be present.

In the more “typical” patient with CVID, or related antibody deficiency syndrome, it is more likely that we would see greatly reduced mature B lymphocytes and a relative increase in the presence of immature or naïve B lymphocytes, which are not capable of producing antibodies. Once again, we would expect a poor pneumococcal antibody response in the absence of mature B lymphocytes.

There is a situation that we, and others, have observed in patients as described in the question. This has to do with “senescence” of B lymphocytes. What we find is the absence of naïve B lymphocytes and only the presence of “mature” B lymphocytes. Because these cells carry the antibody “memory” of the individual, the patient can mount some antibody response to items such as pneumococcus. Normally, after pneumococcal vaccination, it is expected that “good” antibody titer levels will be maintained for at least two years, but by five to 10 years after, they may fall to non-protective levels. In patients with B lymphocyte senescence, the pneumococcal titers, while appearing adequate at about four weeks after vaccination, tend to fall rapidly following the challenge, and by three to six months after immunization may be back at pre-immunization levels. (It would be expected for the values to remain good for up to two years, so that falling by six months would be abnormal.) Further, once again performing a pre- and post-immunization challenge with pneumococcal vaccine (usually six to nine months after the previous one), one finds a poorer response, and even more rapid decline of the titers over the ensuing weeks to months.

In summary, there may be extraneous (i.e., not related to IG) reasons for recurrent sinopulmonary disease for which other treatments may be more relevant than IVIG. For fully evaluating the situation, B lymphocyte subpopulations should be measured. Finally, it can be informative to follow pneumococcal levels at intervals after the immunization, perhaps at three or six months, and a significant fall may indicate the inability to maintain an immune response, and that an antibody deficiency is present. Therefore, a patient with absence of naïve B lymphocytes and rapid fall in pneumococcal titers may be considered to have an antibody deficiency and deserves at least a trial of IVIG therapy. ■

The Friendly Skies

By Mark T. Haggard

"One of your bags is over 50 pounds."

Oh, the most feared statement given to a traveler by an airline ticketing agent. Unfortunately, when you travel with PIDD, you hear this often. And what is our response? Eat the \$25 charge or engage in our own personal game of baggage roulette.

"Give me a second," I reply to the well-groomed woman

behind the counter, and the game begins: I pull out a stack of underwear that includes my Valentine's Day boxers with red and pink hearts, then smile and say, "Those aren't mine." I stuff the stack of cotton into a second bag and weigh the first suitcase: 52 pounds. "Is that close enough?"

"Fifty pounds, Sir," the agent snarls. "You know there



are people waiting behind you.”

I pull more underwear and now socks from the offending bag and stuff them into the second, mumbling, “Sure, none of their bags are over 50 pounds.” I then smile at the agent in victory and say, “What does it weigh now?”

“49.2 pounds.”

“So I’m good?”

“Now we’ll have to weigh the other one,” she says grabbing my second suitcase. “Fifty-three pounds.”

We fly often as a family, and I have discovered that during our travels with PIDD, we make a few more stops, take a little more time, and butt up against a few more obstacles than the average traveler.

Two of my three kids have portacatheters, metal objects that set off alarms at airport security checkpoints. We have to remember to bring our kids’ port IDs with us in order



to stave off the suspicions of the Transportation Security Administration (TSA) officials that they might be 4-foot-tall Al Qaeda operatives. I don’t want my kids to suffer the same humiliation I did when I was sprawled out like da Vinci’s Vitruvian Man and a TSA official ran a metal-detecting wand over every nook and cranny of my being, only to find that I had forgotten to take my inhaler out of my pocket.

After successfully dodging the metal detectors, I’m often stopped on the other side of the X-ray machine to explain the plethora of medications that we are taking on the airplane. “Um, yes Sir, the albuterol is for my son, the Zithromax is for my daughter, the Zyrtec is for my other son. I’ll be taking the Advil as soon as we get to our hotel.”

“Are any of these explosive or flammable?” the TSA agent asks.

“Uh...”

“Why didn’t you put those in your checked bags?”

“Sir, we’re going to Seattle. I don’t want my kids’ medication going to Syracuse.”

“And can you explain this object?” the agent queries.

“That’s a nebulizer.”

“Looks like a bomb,” the agent says wrinkling his nose and sniffing like Barney Fife. He then looks up and calls, “Harry, can you come look at this?”

“What is that thing?” a second TSA official calls, approaching from behind a desk.

“It’s a nebulizer,” I answer again, trying to ignore the grumbling of the crowd behind me.

“Sure it is,” the Fife-looking agent says. “Don’t make any sudden moves. Ted, we better get a dog in here.” Ten minutes later a canine shows up, sniffing my bags.

“What’d you say that thing did?” the officer asks, putting a screwdriver down after more inspection.

“You pour the medication in here. The machine blows air through the medication and into the mouthpiece. My son breathes in the medication to clear his lungs.” I look at their blank faces and add, “*Voilà*, no more coughing.”

“Is it explosive or flammable?” Deputy Fife asks.

“My son’s still here, isn’t he?”

He isn’t. I look around the area for my PIDD-kid and mutter, “Where’d he go?”

A few feet away I hear the beeping of a metal detector. I look over. Underneath the detector, my son is stretched out like Vitruvian Man.

Ah, travels with PIDD. Something special in the air. Maybe I’ll take that Advil now. ■

Saving on Healthcare Costs With HSAs and FSAs

By Jim Trageser

For families with one or more members on long-term care for a chronic medical condition, managing healthcare costs can be crucial. For those with access, a health savings account (HSA) or flexible spending account (FSA) can be a useful tool.

These specialized accounts are intended to supplement health insurance by allowing anyone the ability to set aside money for medical care and draw on it as needed. As with the more familiar individual retirement account (IRA), no income tax is taken from money deposited from your paycheck into HSA and FSA accounts. And as long as you only withdraw money from your HSA or FSA to pay medical expenses, no taxes are levied when you take the funds out, either.

An added benefit is that eligible expenses paid out of these tax-free accounts can include items not normally covered by an insurance plan, like over-the-counter drugs or copayments for doctor visits and prescription drugs. You can also use these funds for dental or vision care. About the only health-related expense you can't use your HSA or FSA to pay is your regular insurance premiums; those have to come out of your regular, taxable income.

As with most programs involving our money and the government's desire to tax it, though, the devil is in the details as to whether either an HSA or FSA will help your family to save money.

Health Savings Accounts

The HSA was created by Congress in 2003. While HSAs offer more flexibility than FSAs, only people who are on a high-deductible health insurance plan are eligible for an HSA.

Thus, if your employer offers only an HMO plan, you can't set up an HSA, because an HMO plan has low deductibles. (Federal law currently defines a "high-deductible health plan" as one with a minimum \$1,100 annual deductible for one person, or \$2,200 for a family.)

But many employers today offer what are called "cafeteria benefits," in which you can choose from a variety of health

plans, with a variety of premiums and deductibles.

And if you're self-employed, you can purchase any plan you like (or can afford). However, the self-employed don't get all the same tax benefits for an HSA that those who work for someone else receive.

While a high-deductible plan may initially appear to cost more money out of pocket over the course of the year compared to other options, high-deductible plans have lower monthly premiums than a low-deductible HMO or midrange-deductible PPO. With more and more employers passing at least some of the cost of health insurance premiums to their employees, this is an important consideration. If the premium savings are significant enough, combining a high-deductible plan with an HSA (and its tax savings) may end up costing less overall than an HMO or PPO with their higher monthly premium payments.

Before choosing a health plan, you'll need to estimate your total cost for the next year's medical care for yourself and your dependents. Copayments for doctor visits, prescription and over-the-counter medication, dental and vision all figure in—and you'll want to add up your monthly premiums for each plan, too.

Talking with your company's human resources department or a financial adviser about your health insurance options should help you decide which plan—high deductible, PPO or HMO—makes the most sense for your family.

If you do decide to go with a high-deductible/HSA plan (or if this is your only option), keep in mind a few more things:

- As mentioned, you can only withdraw money from an HSA for a qualified medical expense (which has a legal definition) for yourself and any covered dependents. The Internal Revenue Service lists acceptable medical expenses in Publication 502, found online at irs.gov/pub/irs-pdf/p502.pdf. But it should also be pointed out that a Treasury Department Web page devoted to HSAs (ustreas.gov/offices/publicaffairs/hsa/faq_using.shtml) explains that there is great

flexibility in determining legitimate medical expenses, and that most accepted medical treatments will be covered.

- Also, unlike regular insurance where you're fully covered as soon as you enroll, you can only withdraw money from your HSA to pay qualified medical expenses after it has been deposited (which also differs from FSAs, explained below).

On the positive side, once you've deposited money in an HSA, it's yours to spend on medical expenses as long as you live. Unlike FSAs, HSA account balances roll over from year to year. And as with an IRA, you can invest the money in your HSA and earn interest on it—also tax-free. If you do withdraw the money to spend on something other than qualified medical bills, you'll face similar taxes and fines as with early withdrawals on an IRA.

Also, with the rollover feature of HSAs, you can deposit money in your HSA while you're working and then have that money available to help pay medical bills after retirement. (Once you enroll in Medicare, you can no longer make deposits to your HSA, but any money already in there is still available to spend on medical care tax-free.)

If you change jobs or enroll in a health plan that is not high-deductible, you can no longer contribute to your HSA, but your HSA funds are still available.

Finally, many businesses will contribute to their employees' HSAs as part of their benefits package—although there is a limit to how much an employer can contribute. (In 2009, the limits are \$3,000 per single employee, or \$5,950 for employees with a family.) These contributions are tax-free.

While your employer may assist you in creating an HSA and setting up your payroll withholdings for your HSA contributions, the HSA belongs to you and you are free to open one with any bank or credit union that offers them. (Insurance companies are also allowed by law to administer HSAs.) If you set up an HSA on your own, apart from your

	FSA	HSA
Premiums		
Maximum yearly out of pocket		
Annual deductible		
Estimated total copays		
Total		
Subtract employer contribution		
Grand Total		

Filling out a chart like this can help determine whether an HSA or FSA is a good option. Note: This chart does not include the tax savings.

employer, your HSA deposits are deducted from your taxable income on each year's tax return (similar to how IRA contributions work).

Flexible Spending Accounts

FSAs are similar to HSAs in many ways—money deposited in an FSA is not subject to income tax, nor is it taxed when you use it to pay expenses.

But an FSA can only be set up through your employer; unlike an HSA, the FSA is administered by your employer, not an outside bank or insurance company.

When you enroll in an FSA with your employer, you determine how much you're going to deposit out of each paycheck for the entire year, and that can't change (unlike with an HSA, where you can adjust your deposits to suit changing medical needs). Thus, at the start of each year you have a set amount that will be available to you for that year.

Some other differences between an FSA and an HSA are:

1. Anyone is eligible for an FSA, if your employer offers them; it is not limited to those on high-deductible plans.
2. You can't roll money deposited in an FSA over year to year: Any funds deposited that you don't use for a qualified medical expense by Dec. 31 are forfeited.
3. You can't invest FSA funds.
4. After you make your first FSA deposit, the full amount scheduled for deposit that year is immediately available to pay qualified medical expenses—even though you won't be done making those contributions for another 12 months.
5. When you leave your employer that provides your health benefits, your access to your FSA ends—even if you have money in your account. However, through COBRA, you can opt to continue your FSA, though contributions will be on a post-tax basis. (Also, if you enroll in an FSA and withdraw money for medical costs that exceed what you've deposited before leaving, your employer is supposed to absorb the difference, which means you can't be charged for it. However, some employers withdraw what they can of this amount from a last paycheck.)

Obviously, when enrolling in an FSA, it's important that you are very accurate in determining out-of-pocket medical costs for the coming year so you get maximum tax benefit without overcontributing.

If you are not eligible for an HSA (with its annual rollover and flexible contributions), an FSA can provide many of the same tax advantages. ■

study predicted that access would be reduced to 25 percent because of increases in prices of IVIG that are not immediately accounted for in reimbursement rates. (Manufacturers price their products quarterly; however, Medicare's reimbursement rates are based on prices two quarters prior, creating a six-month lag that only exacerbates the above issues when prices increase.)

Despite these reports, CMS has stated that there is stability in the marketplace and providers are continuing to administer IVIG; therefore there is no need for a continuation of the preadministration fee. As we know, patient care continues to be disrupted by change of location, change in IVIG brand, reduction in IVIG dosage, or elimination of treatment altogether due to no site of care available.

What to Expect in 2009?

Congress is determined to reform Medicare in 2009 and IVIG must be on that agenda. It's critical that legislation be introduced that will help restore access to IVIG for all patients in all sites of care, including patients in the Part D program, which will undoubtedly be a target for reform as well. To effect the changes that will improve IVIG access, the voice of the IG community must be heard. The more organized the IG community is, the stronger our voice will be and the better chance we will have to restore access for all patients.

It's inevitable that coverage determinations under the Medicare program and in the private insurance sector will continue to be a problem. Signs of that sector following Medicare's lead are increasingly evident. If you are a Medicare beneficiary and have trouble finding a site of care willing to administer IVIG due to the continued cuts in reimbursement and/or if your insurance company has stated that it now considers IVIG experimental for your condition and has denied access to IVIG, please contact your patient organizations, *IG Living* or the Alliance for Plasma Therapies for help in finding a site of care and appealing your case. ■

A Recap of Pricing Methodology

Before the MMA went into effect, Medicare payment for Part B drugs was based on the average wholesale price (AWP), "a term that had never been defined by statute or regulation."¹ Historically, manufacturers published AWP's for their drugs in industry publications such as the *Red Book*, *Blue Book* and *MediSpan*. The CMS used these prices to determine reimbursement. In fact, oftentimes physicians were able to acquire drugs at prices below the AWP (sometimes well below). Regardless of what they paid, they were still able to be reimbursed at 95 percent of AWP (however, the reimbursement for IVIG was later reduced to 85 percent of AWP). This apparent play in the system is what brought about change to the CMS' reimbursement formula: "This gap between the provider's cost for the drug and the reimbursement based on AWP, termed the 'spread,' has led prosecutors to contend that drug manufacturers have inflated the AWP of their drugs in order to entice physicians to buy their products based on the profit to be made on the spread."²

To tighten up standards, Congress changed the reimbursement methodology under the MMA. In a three-step process that was phased in over three years, the new methodology called for using the ASP in 2005 as its basis for reimbursement: "Multiple source drugs will be reimbursed at 106 percent of the volume-weighted average of the ASP at which all manufacturers of the drug sold the product."³ This does not include markup for distribution. The three steps required to calculate the volume-weighted average of the ASP ensure that providers are reimbursed the same amount for a multiple source drug regardless of the price charged by the manufacturer. Single source drugs and biologicals, however, were treated differently, as there's generally only one manufacturer for the product. For these, the amount reimbursed was either the lesser of the manufacturer's ASP or the wholesale acquisition cost (WAC), which is the most recent list price reported in wholesale price guides or other publications.⁴ However, since the implementation of the change in 2005, all pricing for IVIG has been predicated on the ASP plus model.

¹ "What Physicians Should Know About the Medicare Modernization Act Part B Drug Reimbursement," *Healthcare Review*, Winter 2005, p. 1, www.duanemorris.com/newsletters/static/HealthcareNewsletter_Winter2005.pdf.

² *ibid.*

³ *ibid.*

⁴ *ibid.*

Breaking the Highly Sensitized Immune System Barrier

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For one of every three kidney failure patients, a transplant is not possible even if a potential donor's tissue and blood types otherwise match perfectly. This is because they have a highly sensitized immune system that would attack the transplanted kidney or pancreas. At the Cedars-Sinai Kidney and Pancreas Transplant Program, an innovative procedure— intravenous immunoglobulin (IVIG) therapy—is being used to give new hope to kidney failure patients.

Causes of Sensitization

One of the ways that our bodies protect themselves from infection is the ability to recognize and destroy foreign cells. When the blood meets a foreign cell, it produces an antibody to fight the invader.

Tissue compatibility issues exist for all patients receiving transplanted organs. Rejection risks rise dramatically for those with a high exposure to non-self human leukocyte antigens (HLAs). This exposure results from:

- Blood transfusions
- A previous transplant
- Pregnancy. The mother is exposed to the father's antigens, which are expressed in the cells of the developing baby.

If a person has become *highly sensitized*, his or her immune system is hyper-vigilant to invaders—even when the invader is a life-saving transplanted organ.

How IVIG Therapy Works

Immunoglobulins are proteins naturally produced within the body that are natural defenses against invading organisms. Intravenous immunoglobulin therapy has been used for years to treat immune system disorders.

IVIG is a processed form of immunoglobulin. It is made from blood plasma. Immunoglobulin is injected into a vein to protect the patient from infection and immune diseases.

IVIG therapy reduces HLA sensitivity by adding helpful antibodies to the patient's bloodstream. This lowers the level of HLA antibodies and blocks their ability to attack a transplanted organ. IVIG therapy can be used successfully in both adults and children seeking kidney transplants.

Unlike many anti-rejection therapies, IVIG does not suppress the entire immune system, but actually boosts the patient's protection against infection.

Adding Rituxan® Shortens Time to Transplantation

Clinical research done at Cedars-Sinai shows that adding the drug Rituxan to IVIG therapy both improves transplant rate and reduces the time needed for treatment. Rituxan reduces the number of B-cells in the body. B-cells produce the HLA antibodies. Combining Rituxan and IVIG means that treatment can be reduced from 16 to four weeks. It currently is recommended for most patients.

How IVIG and Rituxan Therapy Are Given

IVIG therapy is given in two, four-hour dialysis treatments before transplant surgery. About two weeks after the first treatment with IVIG, Rituxan is given as an intravenous infusion over six hours. About two weeks after transplant, a final treatment with IVIG is given. Infusion of IVIG and Rituxan is associated with few side effects. The most common complaint is headache.

If IVIG Doesn't Work

Some patients don't respond to IVIG-Rituxan therapy and continue to have high HLA antibodies that prevent them from receiving a transplanted organ. This happens about 10% of the time. When this happens, the Cedars-Sinai Transplant Immunotherapy Program offers a therapy called *plasma exchange*. Plasma exchange is also known as antibody removal therapy. This approach usually requires patients to have a living donor.

Hope for the Highly Sensitized Patient

About 40% of the patients who come to Cedars-Sinai for a kidney transplant are highly sensitized. According to Dr. Jordan, between 95% and 97% can be successfully desensitized with IVIG and Rituxan.

"Somewhere between 25% to 30% of patients on the national kidney transplant list could benefit from this therapy," Dr. Jordan added.

IVIG therapy was first adapted for use in transplantation by Cedars-Sinai researchers led by Stanley C. Jordan, MD. Dr. Jordan is the Director of Kidney Transplantation and Transplant Immunology for the Transplant Program as well as Director of the Pediatric and Adult Nephrology Division. Cedars-Sinai holds the U.S. patent for this therapy. ■

An Important Amendment

In September, Congress expanded protections for people with disabilities by passing the ADA Amendments Act (ADAAA). Passed in 1990, the Americans with Disabilities Act (ADA) "is a federal employment law that prohibits discrimination against individuals with disabilities, both in the context of employment and places of public accommodation."¹

The need for the amendment was due to the narrow interpretation of the ADA. Specifically, the bill aimed to clarify congressional intent of the original disabilities law, which was to be inclusive: "The definition of disability in this act shall be construed in favor of broad coverage."

According to Rep. F. James Sensenbrenner Jr., R-Wis., certain Supreme Court decisions misconstrued the bill's intent by focusing "too heavily on whether individuals are covered by the law, rather than on whether discrimination occurred."² This led to the dismissal of the majority of cases brought under the act, as individuals were not able to meet the statute's definition of disability (which was defined as a physical or mental impairment that substantially limits a major life activity).

According to Advocacy for Patients with Chronic Illness, an advocacy organization in Connecticut, the "ground-breaking" amendments make the following changes:

- The phrase *major life activity* now includes operation of "major bodily functions, including but not limited to functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions."
- An impairment that is episodic or in remission is a disability if it substantially limits a major life activity when active.
- The question of whether an impairment is disabling must be made without regard to whether medication, equipment, prosthetics, assistive technology, or other treatment, devices, and supplies improve the impairment, although eyeglasses still are considered for determining the severity of vision impairment.

By recognizing that a chronic illness that is disabling during a flare-up still constitutes a disability even in remission, these amendments legally acknowledge *chronicity*.

Manufacturer Updates

In September, Talecris Biotherapeutics received approval from the Food and Drug Administration (FDA) for Gamunex as a treatment for chronic inflammatory demyelinating polyneuropathy (CIDP). For more details, and to read patient reactions, see the story on Page 20.

In October, Talecris announced its Gamunex Connexions Certificate Program for patients with primary immune deficiency disease (PID) or idiopathic thrombocytopenic purpura (ITP). Under the program, a patient who has a temporary lapse in private health insurance may qualify to receive continued treatment. To qualify for the program, patients must have third-party, private health insurance as their primary health insurance as well as be using Gamunex regularly. For information, call (888) 263-8243.

Grifols, a manufacturer of plasma therapies based in Barcelona, launched in September its product-information tracking system, Grifols PediGri® On Line, in the United States. With PediGri®, information on all Grifols plasma therapies sold stateside is now available online to medical professionals. To access the site, register online at www.pedigrionline.net.

In October, Grifols broke ground on a 92,000-square-foot, intravenous immune globulin (IVIG) production facility in Los Angeles. The new facility will be operational in 2013.

A Medicare Note

A recent Kaiser Foundation study found that in 2007, insurers placed three times more ads to promote Medicare Advantage (MA) plans than to promote stand-alone Medicare drug plans.³ According to Kaiser CEO and President Drew Altman, beneficiaries must still be careful to make sure a plan is right for them.

"Since ads for Medicare plans tend to be skimpy on basic, descriptive information, beneficiaries and their families really need to do their homework before they choose a plan or decide whether to switch plans during open enrollment," Altman said. For 2009, enrollment for Medicare drug plans will run through Dec. 31, while enrollment for MA plans will run through March. ■

¹ Nirenberg, J. "Senate Passes Amendments to Restore Americans With Disabilities Act to Protect Disabled Employees From Discrimination," www.Lawyers.com, Sept. 12, 2008. <http://labor-employment-law.lawyers.com/blogs/archives/277-Senate-Passes-Amendment-to-Restore-Americans-With-Disabilities-Act-to-Protect-Disabled-Employees-From-Discrimination.html>

² Pear, R. "Congress Passes Bill With Protections for Disabled," *The New York Times*, Sept. 18, 2008, p. A21.

³ Pitching Private Medicare Plans, www.kff.org/medicare/upload/7805.pdf, September 2008.

A Single Prolonged Breath

By Amanda M. Traxler



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As a poet, Sarah Manguso did not typically write longer pieces. But that all changed during a six-week period in which she quickly wrote “The Two Kinds of Decay,” a memoir that chronicles nine years of battling chronic inflammatory demyelinating polyradiculoneuropathy (CIDP),

as well as a depression severe enough to warrant hospitalization. Eventually, the CIDP went into remission.

Of the brief span during which she wrote the book, Manguso says: “I had never written a long book before. I was considering this just another exercise in writing a collection of pieces. But it was only later on that the pieces started to fit together that I thought about putting it in chronological order and really trying to work with it as a book that was a single prolonged breath as opposed to a collection of shorter breaths.”

A stunning book, “The Two Kinds of Decay” comprises dozens of smaller chapters. Manguso’s talent with language, combined with her fearless delving into her experience, is gift-like for the audience. Reading the work, I was continually astonished by her careful distillation of illness, memory and, ultimately, her own humanity.

As a 21-year-old junior at Harvard University in 1995, Manguso was struck with symptoms that included numbness, feebleness and difficulty breathing. What she would experience over the next nine years is harrowing. Though impossible to sum up, it includes more than 50 apheresis treatments (four-hour procedures that replaced her plasma) to stop her nerves’ terrifyingly quick descents into paralysis. And for much of the time, Manguso did not expect to see 30.

Recently, I had a chance to talk with Manguso. What follows is a selection of our talk, whose elements, I am betting for some of you, will be compellingly familiar.

When it comes to the practitioners you encountered, some were extremely sensitive, while others were less so. What are your ideas about the extremes of personalities?

SM ▶ A lot of the caretakers are complicated. I guess I have two answers, one being that the patient-caretaker relationship is one that I think is more complicated than we understand even now, even with all these new cam-

paigns to promote a sort of more empathic means of care. My writing about my experiences with caretakers—and this is the second part—was definitely colored by more variables than I can count: my mood on that particular day, what I had eaten, how my case was going, how long I had been sick. I was not an objective recorder or rememberer of what was happening to me. If I was having a bad week or month, I was very critical. And then sometimes when I was at my sickest, I was the least critical and the most patient with people. So it’s very hard for me as a patient to report absolutely accurately and selflessly what the degree of my care was.

All that said, there were definitely caretakers who were solidly empathic and those who were less engaged with me as a human patient. And some of those people are caricatures, you know, the surgeon is kind of an archetypal egotist dude. And several of the nurses are truly, truly generous people, so I guess my answer is that it’s complicated, and I’m glad it’s not my problem to solve.

Some practitioners revealed intimate details about their own lives to you. Can you describe what this was like?

SM ▶ I was actually just thinking about this experience I had with a psychiatrist that’s not included in the book. This was a Freudian psychoanalytic psychiatrist, and so his whole approach was that he would sit and listen without really saying anything, and then one day about two years into my having sessions with him, he said, ‘I can really understand how hard it is to be you right now.’ It made me feel awful. I came to the session with these preconceived ideas about what that doctor/patient metric was going to consist of: He was going to be this kind of objective robot and totally free from empathy, because that’s Freud’s rule. And when he broke that rule, I just thought, Oh my god, I’m so messed up—I’ve broken the doctor-patient relationship. And similarly in the hospital, it was both comforting to know that my caretakers were human, who had human problems, and yet it was upsetting that they weren’t all-powerful. I don’t think I’m alone in patients who secretly want all their doctors and nurses to be superheroes who have completely transcended the human condition and are these amazing healers.

I became aware early on that many things in your book are counted (for example, that your plasma was replaced more than 50 times, the number of EMGs you underwent,

etc.). *Then I got to the part where you question: "What are all these numbers for?" So I'd like to ask you that now, what are they for?*

SM ▶ I think I was looking for any kind of certainty of perception, and we all know the familiar dialectic between the qualitative and the quantitative. But we tend to privilege the quantitative as the more certain, the more correct, the more accurate means of perception. But turns out, it's a flawed system, maybe just as flawed as trying to remember things qualitatively. I was both disappointed and kind of excited to come to that conclusion after trying so hard to come to a certainty.

By the end of the book, you are clearly compassionate. But you also wrote that the only hard thing you'd ever done—which you said was recovering from a disease—had not left you compassionate. What helped you regain it?

SM ▶ To answer it simply, it was all of the rest of the story that I include in the book, including my depression and my hospitalization ... I wanted to include that sentence about my not having been left compassionate because I felt very susceptible to the idea that I think our culture has: that if something really hard happens to you, you automatically become stronger and better and, you know, your perspective widens and you become more tolerant and everything. But this was just so far from what I actually experienced. I had a fierceness in my personality, and the CIDP really just threw gas on that fierceness. I was not compassionate, I was not interested in helping people, I was interested only in getting the time back that I had lost. So it interested me enough that I pointed out that it took a much longer time for me to actually become a better person, you know, after the suffering, than what we expect is supposed to happen.

I am curious about your depression. Is it another condition that resulted from the CIDP? Or rather, from the steroids that treat it?

SM ▶ I think that causality is very difficult to be certain of, and I would say that everything, you know, all parts of the disease, the depression and the CIDP, just all existed and were expressed at different times. But it is certain that the treatments, like the steroids and other treatments, absolutely must have exacerbated my depression, so in that way there certainly was a kind of causality at work.

What brings you joy now? How about before?

SM ▶ I think I'm most sure of what brings me joy now,

and that's being with people I love, swimming and singing. Those are my things. I was very interested in interpersonal intrigue before I sort of took on the CIDP and its resulting problems, and after all that was over, after most of the story in "The Two Kinds of Decay" was over, I was no longer interested in intrigue, I was interested in certainty.

As acknowledged, certainty can be elusive. Perhaps, then, one's quest for it matters more than whether one finds it. With that in mind, what follows is a chapter from Manguso's book titled "The Signet."

I came from a public school with GED tutors and auto shop, but I was elected to the Signet Society, and for my initiation, instead of shimmying up to the pillar drunk while the officers held it at its wooden base, they laid the pillar on the ground and I stepped over it with my cane.

I wore a lavender gown and a twenty-inch tube that never clogged as long as blood thinner was shot into it every two days. From one direction it went into my right breast, under the collarbone and straight up, just under the skin, then into my jugular, so that halfway up my neck you couldn't see the shape of it anymore, and then it went into my subclavian vein and reached toward my heart. On the outside it hung like two white drinking straws, six inches long, with one red clamp and one blue one, like a piece of jewelry, and it was nothing like the expensive pendants the other Signet girls wore.

All spring I sat in my wooden chair like the others, and when it was my turn to ladle the soup at lunch I stood up proudly on my legs and did it. One girl wore a gold pendant shaped like a whale's tail. Her parents kept a summer house on Nantucket. I was proud to be as good as she was.

I already knew I could syringe the blood out of the tube in my chest and pick off the scabs where the tube went into me, and lie still while the doctors took fluid from my spine, or pierced my muscles with electrodes and turned on the juice, and for a long time I would not admit those things had been anything but an interruption in what seemed my life's larger projects, which was to infiltrate the upper class and to be as good as those rich girls, and not once in the next ten years did I consider that the project of my life was not to wonder that I could pick up a ladle at that exclusive table, but that I could pick up a ladle at all.

Manguso's work is available at www.sarahmanguso.com. ■

"I had a fierceness in my personality, and the CIDP just threw gas on that fierceness."

IG Living Columnist Publishes Nutrition Book

From *IG Living*

For many of us, our chosen career paths are unwittingly influenced by our family members. Such was the case with Jessica Schulman, PhD, MPH, RD and CLE, whose recently published "Nutrition in Sickness & in Health" collects many of her nutrition columns from *IG Living*. (Not just a collector of acronyms, Schulman is, among other things, a credentialed dietitian as well as a lactation educator.)

As a teen, Schulman used to accompany her stepfather, who had type 2 diabetes, to the Pritikin Center for Diet and Exercise.

Here, according to Schulman, she first encountered the idea that diet can improve one's health. Fascinated by the concept, Schulman landed her first professional job at Pritikin at 17.

A later opportunity to work with Dean Ornish, MD, as a nutritionist allowed Schulman to observe firsthand the connections between nutrition and medicine.

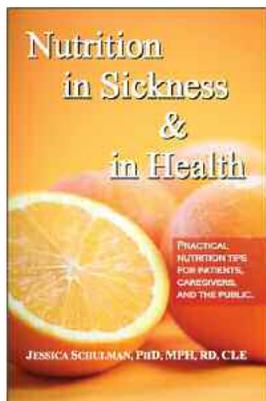
"From then on," Schulman says, "I knew I wanted to pursue my graduate studies in nutrition and health behavior, and that's pretty much what I ended up doing!"

Fast-forward a few years. Finished with her studies, Schulman was approached to write a column for *IG Living*. As a busy professional and mom, she saw herself as having enough time for only one piece. That was 16 articles ago.

"Even when I worked with patients," Schulman says, "I always saw myself as an educator. And I realized that writing articles for *IG Living* was a way of doing what I've done for years but reaching a much broader audience. It's been very rewarding, thanks to the readers and everyone who encouraged me to continue writing."

And the rewards aren't hers alone. Readers well aware of the value of her work played a part in the idea for a book.

"After I had been writing my nutrition column for a while, I started getting requests from people who wanted copies of my old columns," Schulman says. "I remember sitting at a brainstorming session with my editors when it occurred to me that the best way for people to have easy access to



my columns was to make them available as a book, something that could be a resource for continuing education for caregivers and professionals. From that point on, I had the eventual book in mind as I wrote and chose topics for my columns."

Helping readers sift through the vast amount of information out there is a main priority for her.

"My hope is that the columns collected in my book will help readers understand the complexities of nutrition and still see that there are correct answers to be found."

Such answers, which can be key to staying healthy, are still not necessarily magic bullets.

"When people who I meet learn that I am a registered dietitian, the first thing they want me to do is tell them the magic food or diet that will boost their immune system, reverse their inflammation, [or] halt their fibromyalgia," Schulman says. "I wish I had such answers! In fact, I believe there may very well be foods or supplements that can cure or reverse chronic diseases. But, in my experience, even with an efficacious medical and nutrition regimen, it takes time to heal. In most cases, there is no magic bullet or quick fix."

Some of the questions Schulman addresses include: Does milk make mucus? Should I starve a fever? What is a functional food? How can you tell the difference between quality nutrition science and pseudoscience? How does nutrition affect my immune system? What is a probiotic? Should I be concerned if my child is not eating well? What are dietary needs of older adults?

"Nutrition in Sickness & in Health" answers all of these questions and many more, drawing from the latest research on health and nutrition to offer useful guidelines for healthy living in clear, down-to-earth language suitable for patients, caregivers, medical professionals as well as the general public.

Those interested in this book can order it through www.amazon.com or www.trafford.com. ■

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 (CIPD)

Websites

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

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_Whats.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.mymviews.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>
- Bette's Myasthenia Gravis Support: <http://health.groups.yahoo.com/group/bettesmyastheniagravisupport>

- 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/rarediseases/p/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.calgarypn.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 (PID)

Websites and Chat Rooms



The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is dedicated to improving the diagnosis and treatment of PID 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 PID.
- The International Patient Organization for Primary Immunodeficiencies (IPOPI), www.ipopi.org, promotes the worldwide improvement in the care and treatment of PID patients.
- To connect to a PID message board, go to www.info4pi.org.
- 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 PID at <http://health.groups.yahoo.com/group/PIDsupport>.
- A group of family and friends of patients with primary immune deficiencies maintains a nonprofit network in the New England area: www.nepin.org
- Baxter’s website, www.immunedisease.com, offers in-depth information on immunology, PID and treatment with intravenous immune globulin. Click on “European” to see SCIG information.
- Rainbow Allergy-Immunology, www.rainbowbabies.org/immunology, 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 PID 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 <http://health.groups.yahoo.com/group/RhodelslandPID/>

Books and Articles

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

Scleroderma

Websites

- Johns Hopkins Medicine Scleroderma Center: scleroderma.jhmi.edu
- 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.aainc.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/US/therapies/gammagard/index.html
- 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



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/fleitas/bandaides, started by a nurse working on her dissertation, focuses on children with chronic illness.
- American Chronic Pain Association (ACPA) was founded in 1980 to provide resources for people coping with chronic pain. www.theacpa.org

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: www.ed.gov/policy/speced/guid/idea/idea2004.html
News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities.
- The National Disabilities Rights Network: www.ndrn.org. 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/504.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.usdoj.gov/crt/ada/adahom1.htm.

Additional Reading

- "Anatomy of an Illness," by Norman Cousins, is a best-seller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body's capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.
- "A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed," by Linda Wilmschurst and Alan W. Brue, is available on Amazon.com.
- "The Confused Consumer's Guide to Choosing a Health Care Plan: Everything You Need to Know," by Martin Gottlieb, helps consumers through the confusing maze of choosing a healthcare plan.
- "The Everyday Guide to Special Education Law," by Randy Chapman, Esq., makes the law accessible to parents so they can be more effective advocates for their children. Available at www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15.
- "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 Breznsy, 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
- Octapharma: www.octapharma.com
- CSL Behring: www.cslbehring.com
- Talecris: www.talecris.com
- Grifols: www.grifolsusa.com

Pump and Infusion Sets Websites

- EMED Corporation: www.safetymedicalproducts.com
- Graseby Marcal Medical: www.marcalmedical.com
- Intra Pump Infusion Systems: www.intrapump.com
- Rebro Med Systems, Inc: www.rebro-med.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.theallergyreport.com/reportindex.html
- 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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