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August-September 2006

**Special Section:**

## *Back to School!*

Valuable information to help your children —  
and their educators — succeed!

**Is Flu Vaccination for You?**

**Special Editorial:  
She Begged for Her Life**

A community service from FFF Enterprises and NuFACTOR, its specialty pharmacy services division U.S. \$1.50

**Update on Treatment of Immunological Abortion With Low-dose IVIG**

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### About IG Living

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# She Begged for Her Life



Rose Mary Istre, of Texas, says it's a national tragedy. "We lost two members of our support group already, and we will lose more—it's just a matter of time. Because patients, when they miss an IVIG treatment, they don't usually die immediately; they don't crash and burn..." and she pauses, a little too long.

What Rose Mary can't say is: *It takes them longer to die, but they die.* She can't quite say the words, because she lost a friend. She lost a friend who needed immune globulin to stay alive, but couldn't get it.

"Pam Way had a disease, CIDP overlapping with myositis, which caused tremendous fatigue and muscle weakness. When I first met her, she was not walking; she was near death. Then, with IVIG, she was improving; she was walking; she was on her way to becoming a healthy person again. But when the Medicare [Modernization] bill was enacted, she was rerouted from her doctor's office to the hospital; she was unable to get the treatments and the brand of IVIG she needed."

Rose Mary explains something that too many decision-makers just don't grasp:

"Patients with immune problems require very brand-specific IVIG, because each product is different. It's a very individual type of treatment."

In fact, patients treated with brands their bodies don't tolerate can suffer life-threatening anaphylactic reactions.

"And when you miss treatment," Rose Mary continues, "it takes its toll. Gradually, Pam went downhill to the point that she was again becoming nonfunctioning..."

"Eventually, it took all the strength she had, so I pushed her in her wheelchair to speak before the Blood Safety Committee meeting, May of 2005. She literally begged for her life. The committee promised us they would take action immediately, and push for [declaration of] a national public health emergency. We represented thousands of patients across the country who were too sick to fight for themselves."

Although the committee tried to help them, the decision-makers *still* didn't understand that reimbursement is inadequate, that some products are scarce, that patients will die.

"The national emergency never came, Pam never got the continuity of treatment she needed, and she died. And we will have more deaths," Rose Mary says,

"while Washington studies the problem."

Today, the data gathering continues, the public health emergency has yet to be declared, and patients are losing hope. Patients are losing their lives.

"I want to ask our government why these people are expendable—one of my senators even said that they were concerned that doctors might profit from this. Oh, it's OK for oil companies to make millions, but it's not OK for doctors to make a little money saving lives?"

"Hurricanes happen; wars happen; we can't stop them. But this was a mistake in the Medicare bill that could easily be corrected."

Rose Mary is right: We don't have time to wait for studies or investigations or endless debates about whether the problem is short supply or excessively high pricing. Even with new reimbursement rate increases, effective July 1, only *one* immune globulin brand will become affordable and available to most patients.

But most patients need the brand that keeps them alive, not just the brand that's least expensive.

And still, patients are begging for their lives. Patients are dying. Patients are dead.

Rose Mary Istre says it's a national tragedy.

No, it's worse. It's a national abomination that this problem has persisted since January 2005.

In our great United States of America, how many dead patients does it take to make a public health emergency? ■

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If you are having a problem getting your immune globulin or covering the cost, report your situation to the Department of Health and Human Services Center for Biologics Evaluation and Research (CBER) at 800-835-4709 or email your story to [CBERProductShortages@cber.fda.gov](mailto:CBERProductShortages@cber.fda.gov).

Learn more at [www.hhs.gov/bloodsafety/igiv.html](http://www.hhs.gov/bloodsafety/igiv.html), [www.gbsfi.com](http://www.gbsfi.com), [www.myositis.org](http://www.myositis.org), [www.primaryimmune.org](http://www.primaryimmune.org) and [www.neuropathy.org](http://www.neuropathy.org).

## Readers Write

For our next Readers Write, email us about the most important thing you've learned from your disease. Send your email to [editor@igiving.com](mailto:editor@igiving.com).

Kit-Bacon Gressitt, Editor

# Juvenile Myositis: Seeking Both Diagnosis and Cure

by Dan Bennett

*Shari Hume needed someone to talk to  
about her son Parker's illness*

**F**our years ago, at age 4, Parker began rapidly losing strength, to the point that he could barely walk or sit up. As doctors puzzled over his condition, Parker became increasingly weak, until finally he was diagnosed—with juvenile myositis.

Juvenile myositis (JM)—including juvenile dermatomyositis, juvenile polymyositis and juvenile amyopathic dermatomyositis—is a rare autoimmune disease that affects only about 5,000 children in the United States. JM causes a variety of debilitating

symptoms, including muscle weakness and pain, severe fatigue, rashes, digestive difficulties, lung and heart problems, vasculitic ulcers and calcinosis. While some children experience a remission, others will battle JM for life. Though complications from this disease can prove fatal, medication can help to alleviate the symptoms of JM.

Because JM is such a rare disease, it wasn't likely that Shari, a Carlsbad, Calif., mother of three, could find another parent in her neighborhood with whom she could share experiences concerning her son's illness. No wonder, then, her surprise and relief when she connected with a woman in Vista, only a few miles away from Shari, who has a grandchild with JM.

Together, they realized the need for support and information sharing, and along with other active parents, they founded the nonprofit Cure JM Foundation.

"We realized there was a lack of support with this illness," Shari said. "We started the family support network. We hooked up parent to parent and child to child."

And now, Cure JM is able to help connect parents and patients for those one-on-one connections they so desperately need, along with providing networking opportunities



*Eight-year-old Parker Hume was diagnosed with JM at age 4.*

and emotional support. The foundation also works to raise awareness among the public and medical community.

"The first year following Parker's diagnosis, we had to get a better understanding of the illness to be able to cope with our emotions," Shari said. "At the time, we were simply trying to understand the disease itself, get a better grasp of what it is. After we did that, we realized there wasn't significant funding for research into a cure."

Despite many obstacles, Cure JM has made headway in bringing attention to the disease. "Once you make your group known," Shari said, "amazing things can happen that are completely unexpected."

Lauren M. Pachman, MD, is professor of pediatrics in the immunology and rheumatology division of the Feinberg School of Medicine, Northwestern University, and the director of molecular and cellular pathobiology at Children's Memorial Research Center in Chicago. Dr. Pachman is a leading authority on JM. She says juvenile myositis is receiving more attention in the medical community than it did a few years ago.

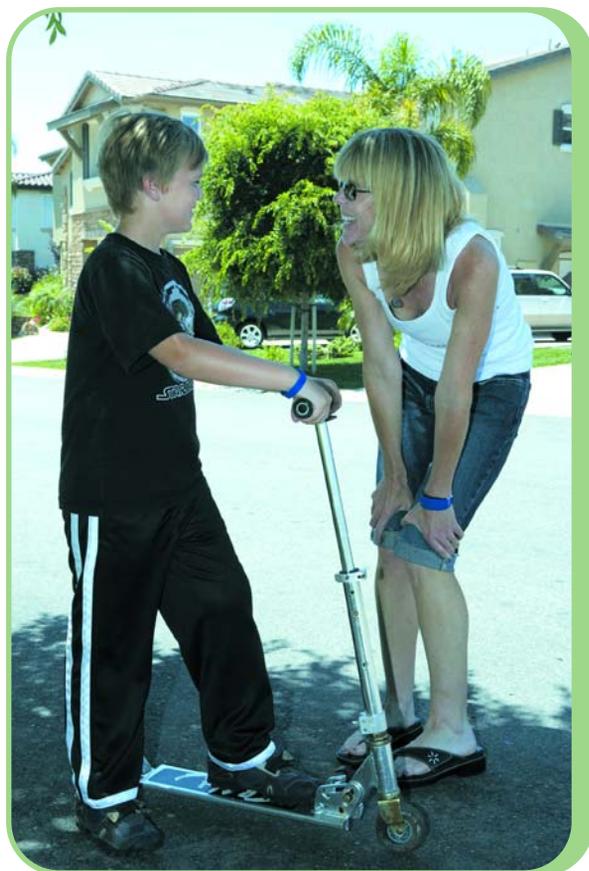


*Parker and his brothers at batting practice.*

"This is reflected in the shorter time to diagnosis, from about six months or more to about four months in the past few years," Dr. Pachman said.

Still, JM remains an underserved research area. "There are not enough pediatric rheumatologists to provide the clinical care that is needed," Dr. Pachman explained, "and even fewer of those people who are clinically trained are proficient in research methods, such as epidemiology, molecular biology and pharmacology, to name a few areas. A critical mass of trained investigators is needed."

Dr. Pachman became interested in the illness when she saw its terrible toll: "When I first came to Children's Memorial Hospital, as the head of the newly created division of immunology/rheumatology, I was asked to see a young boy who had had JDM [juvenile dermatomyositis] for some time, and who went on to die. After finding out what knowledge existed, I realized that really not much was known about his illness. For example, ➤



*Parker and his mom share a laugh.*

what caused it, why he was not showing the effects of the steroids he was given, and many other aspects of the problem. I promised his mother I would do the best I could to find some answers to these questions. We have made some progress.”

Awareness is key, Dr. Pachman says.

“Cure JM and other organizations, medical and nonmedical, can increase awareness of this illness among healthcare providers and the general population, so that the early symptoms are recognized even more rapidly,” she said. “Early treatment makes a great difference in outcome. In particular, Cure JM can be a resource for families to turn to for comfort when they have a child who has been recently diagnosed.”

Dr. Pachman is also one of three editors of a book about JM, “Myositis and You—A Guide to Juvenile Dermatomyositis for Patients, Families, and



Lauren M. Pachman, MD

Healthcare Providers.” This medical text is being published by The Myositis Association, along with a collection of real-life experiences with the disease from parents of JM patients, “In Their Own Words: Children and Families on Juvenile Myositis.” The Myositis Association, the national organization representing and advocating for all forms of myositis, expects to release the books in September 2006.

The two publications are intended to provide patients and their families insight into JM, its treatment and mechanisms for living with it.

“As we know more about the process of myositis in children, we will be able to devise better therapies, so that some children may not require further treatment,” Dr. Pachman said. “However, there is more than one form of myositis in children, and each form of myositis behaves differently, so the future is difficult to predict.”

Lisa Rider, MD, a physician at the National Institutes of Health, says increasing collaborations between key JM researchers has provided momentum.

“We’ve had international studies, some interesting clinical trials leading to new therapies and some environmental studies gauging how surroundings affect this disease, so all of these collaborative efforts are increasing awareness,” Dr. Rider said, and she added that patient organizations are instrumental in increasing disease awareness that leads to more research funding.



The Hume family participates in all Cure JM events.

This is funding that is clearly needed. “There are multiple environmental and genetic factors involved with JM, so it is a more difficult disease to dissect underlying causes than some others,” Dr. Rider explained. “But I am very optimistic about an improved understanding and improved outcomes. As for a cure, those are almost always not predicted, and if they do arrive, they arrive unpredictably.”

Meanwhile, families with affected children are brought closer together by Cure JM. This is true for Shari’s own family. Parker is the middle child of three brothers, and all three participate in Cure JM events. Tom, their father, maintains a full-time job and also serves as a financial officer for Cure JM.

The family supports Parker, who receives regular IVIG treatments and is recently doing better with muscle strength although he suffers from fatigue.

“It’s amazing how an illness can bring a family together,” Shari said. “It’s changed our lives, and in some ways for the better. This illness has tested our endurance and courage. Parker’s 10-year-old brother, Connor, said he would give his heart to his brother to save his life. He would do anything to save his brother. We are all in this fight together.” ■

#### Learn more at these websites:

**Children’s Memorial Hospital, Chicago, JDM:**

<http://www.childrensmemorial.org/depts/immunology/jdm/default.asp>

**Cure JM Foundation:** [www.curejm.com](http://www.curejm.com)

**The Myositis Association:** [www.myositis.org](http://www.myositis.org)

**National Institutes of Health:** [www.nih.gov](http://www.nih.gov)

Hume family photos by Tom Henderson.

# Is Flu Vaccination for You?

By Jeff Siegel



Patients with immune deficiencies face a mountain of challenges that people with normally functioning immune systems can't even begin to contemplate. But when it comes to one of the simplest, most basic medical decisions—whether to be vaccinated against the influenza virus—those with and without immune disorders are in almost exactly the same situation: Although there's no absolute guarantee that the flu vaccine will prevent the flu, the Centers for Disease Control and Prevention (CDC) provides the guidance that “the single best way to prevent the flu is to get vaccinated each fall, but good health habits and antiviral medications are other measures that can help protect against the flu.” And, the CDC does recommend vaccination for people with a “weakened immune system.”

Whatever you do to avoid getting the flu, the CDC advises patients to “[w]ork with your healthcare professional to choose the best health strategy for you, including choices about vaccination.” For those with immune disorders, the CDC advice is particularly important.

Most immunologists recommend the flu vaccine to primary immune deficient patients, excluding live virus products. The rationale is that the immune globulin supply, manufactured over many months, is not likely to contain antibodies to the influenza strains of the current flu season. Flu vaccine is generally deemed to be safe for most patients, unless a patient has sensitivity to eggs (which are used in the vaccine manufacturing process) or a proven poor antibody response to vaccines.

Marc Riedl, MD, an assistant professor of clinical immunology and allergies at UCLA, says that there aren't necessarily any hard and fast rules when it comes to flu vaccinations. It is something that patients need to look at individually, in consultation with their physicians.

“There's less of a chance that it's going to work for someone with autoimmune problems,” says Dr. Riedl. “But there's no guarantee that it's going to work for

anyone. It's never 100 percent protection for everybody, because it depends on which flu strain you're vaccinated for and which strain you're infected with.”

Patients with primary immune deficiency diseases (PIDD) and autoimmune disorders, along with their caregivers, should keep the following things in mind when flu season arrives:

- **Avoid live vaccine.** Most flu vaccine isn't live, except for the new nasal flu vaccine sprays.
- **Avoid contact with people who have the flu.** Although the vaccine should provide protection, people with immune deficiencies should exercise extra precautions to avoid exposure to people with the flu.
- **What about allergic reactions?** Dr. Riedl says this is one of the most serious considerations. It's not a given for people with autoimmune disorders, but it is something that physicians and their patients must be aware of.
- **A false sense of security.** In some respects, says Dr. Riedel, this might be one of the biggest problems facing PIDD patients: “They can get a false sense of security because they think they're protected, and they may not be.”

In other words, flu vaccine is not contraindicated in most cases, but be as careful in making this decision—with your physician—as you are in making any other healthcare decision. And, even if you are vaccinated, stay away from folks with the flu! ■

## Want to know more?

The CDC flu vaccine website is loaded with easy-to-understand information for patients, schools, childcare providers, parents and healthcare practitioners:

<http://www.cdc.gov/flu/>

# Womb to the Tomb

by Cheryl Haggard



The icky-sweet sounds of lullaby Muzak piping into the hospital's receiving room intruded on my worrisome thoughts of registering my infant son for his second sinus procedure.

"What's the deal with the music?" I asked the registrar, handing her our well-worn insurance card.

"We play Brahms' Lullaby whenever a baby is born. Isn't it cute," she quipped.

"Yeah," I responded with reservation in my tone, "cute."

I wonder if they'll play Lynyrd Skynyrd's, "Ooh, That Smell" when Caleb's sinus surgery is completed.

A nice but obviously pain-stricken man who shared the waiting space with me asked, "Wu'd she say about the music?"

"A baby was just born," I gently responded, trying not to inflict any more anguish on the doubled-over blob of human suffering.

"Hey, Bill!" his hunting buddy retorted, "maybe they will play 'Hit Me With Your Best Shot' when they take the slug outta your leg."

"Or how about Handel's 'Hallelujah Chorus' for a hysterectomy?" I teased.

Our giddy moment was quickly interrupted by something you'd see on the 10 o'clock news: Two mortuary attendants were dashing a gurney, adorned with an occupied body

bag, out of what we thought was the hospital's front door.

"Not exactly good advertising for a healthcare facility," the hunting buddy mocked.

"We have to reroute hospital traffic due to construction," the registrar chirped, trying to sound apologetic. "This is the only way in or out of the hospital for now. Sorry about the difficult display."

When Caleb's surgery issues were in order, I decided to take my show on the road. The heebie-jeebies crawled up and down my spine as I passed through the same glass doors the dirge had just exited. Other than some minor emotional trauma and a smidge of nagging nausea, I was grateful to be leaving the facility the same way I came in.

Because it was noon and the kids were happily playing at a friend's house, I decided to call my husband, Mark, and see if he'd like me to bring lunch. I snapped myself into the SUV, turned the engine over and punched in the school's number on the cell phone.

"Hi, Hon!" I gleefully greeted my husband. "How's about me coming by with some burgers?"

His generic, "Sounds good!" answer made me a bit giddy as we rarely get a chance to "do lunch."

I gently accelerated the SUV into reverse, savoring thoughts of our classroom tête-à-tête. My daydreaming was painfully interrupted as the aching sound of metal

crunching metal invaded my picnic plans like red ants all over my red and white checkered cloth, fried chicken and apple pie.

"Omigosh, Mark!" I gasped.

"What's wrong, Hon?" he begged.

"I think I just backed into something. Hang on just a minute." I pulled back into my parking spot and jumped out of the car like it was on fire.

"Mark! I just backed into a hearse!"

"You backed into a wha'...."

"Babe, I gotta go!"

As I pressed the "end" button on the phone, nagging nausea came back to haunt me. I had never been in an accident before, so I didn't know what to do. There was nobody around other than the driver of a florist's delivery truck, his mouth resembling a gaping hole much like the Grand Canyon.

Because the human condition is self-centered, I first inspected the backend of my Monster Truck. A minuscule stripe of white paint adorned the bumper, which provided reason for great celebration.

The 1986 Cadillac Krystaline Hearse was not so lucky. My Beast had gotten the better of Beauty: Flecks of her white paint were scattered over the fresh asphalt of the hospital's "under construction" parking lot. The back of the hearse was completely crumpled like a tin can ready for recycling, and the red reflector cover on the passenger side was in pieces, the light bulb dangling like a foolish bungee jumper.

Then the inevitable: I had to see if anyone inside was injured.

Thankfully, the occupied body bag was the only thing visible.

A burly forearm reached through the fog of my post-accident existence: The hunting buddy, with his arm on my shoulder, opined: "Well, at least you didn't hurt 'im any worse than he already was!"

The driver of the florist's van joined our little *rencontre* saying, "I'll go get the funeral home guys. I think they are finishing some paperwork in the hospital."

"OK, you go do that." I shot back at him, "When you come back, you will find me curled up next to the body bag."

Melting on the July pavement, I felt as if I needed to do *something*, so I called my insurance company. This is when the fun began, as my pathetic story was greeted with: "Hey everybody, we got our first hearse!"

"Well, we have to ask you some questions," the insurance guy said, trying to muffle his giggles. "Do you want to answer them now or do you want to call us back?"

"No, I want to get this over with. Staring at this mess

I've gotten into is giving me the creeps."

I wondered if it were possible for him to get through the questions without losing it completely:

What is the nature of the accident?

Was anybody seriously injured or was there a fatality?

Does the other party admit fault?

Does the other party have insurance?

When the assault of humiliating questions and stinging snickering subsided, the insurance representative said, "I have to ask you one more thing."

"Go ahead," I responded, cradling my throbbing head in my sticky hands.

"Aren't you mortified?"

One of the gentlemen from the funeral home shuffled my way and extended a sympathetic hand toward mine, saying, "You know, these things happen sometimes." Morticians must take classes in comforting the ones "left behind," and his hospitable attitude and the sincere grin on his face made me want to crawl into his lap as I did Santa's when I was 6.

We exchanged insurance information and he gave me his business card. I wanted the torture to end, so I began the tedious task of trying to escape, but the merciful mortician asked, "Why don't you take a look at the other side of my business card."

Perplexed, I flipped the card over and read a bulleted list of personal items: "Dental records or dentures, Social Security card, burial clothes, photo identification, insurance papers..."

"What's all this for?" I inquired impatiently.

The funeral home guy smiled and replied, "Do you realize what kind of responsibility you are leaving if you are not prepared should you pass away suddenly?"

At first, I began to mentally address his question. Yah, no more blood tests, saliva tests, sweat tests and urine tests. No more IV infusions or antibiotics. No more EOBs from insurance companies, appeals, or hour-long telephone conversations trying to explain why IVIG is beneficial to my children.

Then I snapped to and realized he was trying to sell me funeral insurance!

I almost kept my promise of crawling into the back of his hearse, but I decided to remain amongst the living.

A few days after Caleb's surgery, a letter from my car insurance company arrived. It reminded me that, "By state law it is required that the operator of a vehicle avoid all stationary objects."

And somewhere off in the distance, I thought I heard Sinatra crooning, "Come fly with me, let's fly, let's fly away." ■

# Talecris Talents Program

In Search of Innovation by Jeff Siegel



It's bad enough that it's difficult to diagnose chronic inflammatory demyelinating polyneuropathy, or CIDP, which damages the insulation of the peripheral nerves and causes progressive weakness, sensory loss, poor coordination and even paralysis. But what's worse is that, though there are effective treatments available, most insurance companies won't pay for treatment without a definitive diagnosis. This means, given the difficulty in diagnosis, many patients with CIDP are not treated for it.

Hence, the work Norman Latov, MD, a researcher at Weill Medical College of Cornell University in Ithaca, N.Y., is doing. His goal? To find a way to use a simple skin biopsy to test for CIDP instead of the more complicated and painful method that uses a nerve in the foot. Dr. Latov wants to see if the genes that are increased in CIDP nerves do the same thing in the skin.

But even that has a catch, since it's difficult to find money for this kind of research.

Enter Talecris Biotherapeutics, a North Carolina-based immune globulin manufacturer, and its grant program, Talents—Talecris New Trials Support.

which they might otherwise not have the funding.

"This research would not be possible without the grant," says Dr. Latov. "The NIH [National Institutes of Health] does not provide research funding for CIDP, so we have to rely on donations or grants from industry for the research. That is an important way by which industry can help physicians provide better care for their patients."

It's money—almost \$2 million over the past three years, plus the \$1 million this year—that Talecris considers well spent.

"What we're looking for are new ways to use IVIG or ideas to explore how and why it works," says Rene McRogers, Talecris' deputy director for scientific relations and communications. "It's all about increasing the quality of life for the patient community. We're always getting applications for ideas for researching IVIG, and we wanted to put a mechanism in place to handle inquiries."

Talecris expects to award five or six grants beginning in early 2007, with recipients getting a combination of cash and product. The grant program

is open to any MD, PhD, DO, or PharmD affiliated with a university, hospital, clinic, blood center or laboratory that uses immune globulin in research settings or to treat patients. However, employees of for-profit companies are not eligible.

There is a two-part selection process for applicants. They must submit a letter of intent, outlining the project, by August 15. McRogers says she expects to receive about 50 such letters this year. Then, the company's review panel narrows the applicant pool to 20, and those applicants are asked to submit complete proposals by the middle of October.

The review committee is made up of experts in neurology, immunology and hematology, and other disciplines when appropriate, along with Talecris researchers. The group looks at the scientific merit of the letters and proposals, the quality of the applicants, the quality of the research environments, and how well the proposals fit into the goals of the Talents program.

"It's probably unusual for a company as small as we are to do something like this in such a specialty area," says McRogers, who notes that Talecris' \$1 billion in annual revenue is well shy of the biggest pharmaceutical companies, such as Pfizer and Merck, that regularly offer research grants. "So, in that way, I do think what we're doing is unique. Obviously, part of the reason we're doing it is for the public relations value, but this is also going to be the way that gets us the best possible ideas for research."

Indeed, as Dr. Latov will attest. ■

# Update on Treatment of Immunologic Abortion With Low-dose Intravenous Immunoglobulin

By Raphael B. Stricker, MD, and Edward E. Winger, MD

## Problem

Recurrent spontaneous abortion associated with immunologic abnormalities has been termed immunologic abortion. Previously we showed that treatment with low-dose intravenous immunoglobulin (IVIg) appears to be beneficial for older women with immunologic abortion. We now report the results of IVIg treatment in a larger group of women with this disorder.

## Method of Study

A total of 99 women were prospectively evaluated for immunologic abortion, which was defined as three or more miscarriages and the presence of specific immunologic abnormalities. Prior to the next conception, patients were treated with IVIg at a dose of 0.2 g/kg. Once conception was achieved, IVIg treatment was continued on a monthly basis through 26–30 weeks of pregnancy.

## Results

The average age of the women was 37 years (range: 28–49), and the average number of miscarriages was 3.8 (range: 3–12). Of the 99 women, 72 received initial IVIg treatment, and 50 subsequently became pregnant. Of these women, 42 (84%) had a successful term pregnancy. Of the 27 women who refused IVIg therapy, 20 became pregnant and 18 (90%) miscarried. The difference in pregnancy success rate between the IVIg-treated and untreated groups was significant ( $P=0.001$ ). Four women had mild allergic reactions during IVIg infusion, and these reactions resolved when the IVIg brand was changed. Fetal abnormalities were not observed.

## Conclusion

We conclude that low-dose IVIg therapy is safe and effective for older women with immunologic abortion.

## Introduction

Recurrent spontaneous abortion (RSA) is a growing problem in our society, particularly among women over 30 years of age.<sup>1–3</sup> In these women, RSA occurs with both natural and artificial fertilization techniques.<sup>4,5</sup> There is increasing evidence that immunologic factors play an important role in RSA.<sup>6–11</sup> These factors include various

humoral abnormalities [antiphospholipid antibodies, antithyroid antibodies, antinuclear antibodies, antiovarian antibodies, and increased immunoglobulin (Ig)M levels] as well as cellular components (increased natural killer cells and decreased suppressor T cells). The immunologic factors may be associated with toxicity to the trophoblast, placenta or fetus, leading to recurrent pregnancy loss.<sup>12–16</sup> The association of RSA with immunologic abnormalities has been termed immunologic abortion. Treatment of immunologic abortion has been controversial.<sup>1–3,17–29</sup> Previously we showed that low-dose intravenous immunoglobulin (IVIg) therapy was beneficial for older women with immunologic abortion.<sup>29</sup> We have now examined the efficacy of low-dose IVIg therapy in a larger group of women with this disorder.

## Materials and Methods

### Patient Selection

Ninety-nine women were prospectively enrolled in the study. Eighty-three of these women were described in a previous study.<sup>29</sup> Entry criteria included a history of three or more unexplained miscarriages and aged >28 years. There was no upper age limit for the study participants. Women using both natural and in vitro fertilization (IVF) techniques were included in the study. Anatomic, infectious, and hormonal causes for RSA were excluded, and male factor was also ruled out.

Women were screened with a battery of immunologic tests including antiphospholipid antibody (IgG, IgA, and IgM), antimicrobial antibody, antithyroglobulin antibody, antinuclear antibody, antiovarian antibody, and serum immunoglobulin levels, as previously described.<sup>29</sup> CD4 and CD8 T-cell counts and CD3-negative/CD56-positive natural killer cell levels were determined using flow cytometry.<sup>29</sup> An abnormal result of one or more of these tests was required for inclusion in the study. Antiphospholipid antibody testing was performed by Genetics & IVF Institute (Fairfax, VA, USA) or Reproductive Immunology Associates (Van Nuys, CA, USA). All other immunologic testing was performed by Immunodiagnostic Laboratories >

(San Leandro, CA, USA; now Laboratory Corporation of America). All of the tests were standardized and validated in accordance with the guidelines of the College of American Pathologists. Women with endometriosis were included in the study following appropriate treatment for this disease.

#### Treatment Protocol

Women were treated with IVIG (Venoglobulin-S; Alpha Therapeutic Corporation, Los Angeles, CA, USA or Gamimune-N; Bayer Biologics, West Haven, CT, USA) after informed consent was obtained. The consent form was approved by the Institutional Review Board of California Pacific Medical Center. IVIG therapy was initiated within 2 weeks prior to attempted conception either by natural means or IVF. The dose of IVIG was 0.2 g/kg per treatment, and the rate of infusion did not exceed 75 cc/hr. Once conception was achieved, IVIG was given every 4 weeks through 26–30 weeks of gestation. Thus on average, eight IVIG treatments were administered during a term pregnancy. Routine high-risk obstetric care including periodic uterine ultrasonography, amniocentesis, and fetal heart monitoring was provided in all cases. Patients were also monitored for side-effects of the IVIG therapy. Statistical analysis was performed using the unpaired Student's t-test for parametric variables.

#### Results

Patient characteristics are shown in Table I. The mean patient age was 37 years with a range of 28–49, and the median age was 37 years. The mean number of prior abortions was 3.8 with a range of 3–12, and the median number of abortions was 3. Among the women enrolled in the study, 83% had never had a successful pregnancy (primary recurrent abortion) while 17% had one prior successful pregnancy (secondary recurrent abortion). Twenty-four women (24%) used natural fertilization methods while 75 (76%) used IVF techniques.

Immunologic abnormalities in the study subjects are shown in Table II. The most common abnormality was the presence of antithyroid antibodies (54%), followed by antiphospholipid antibodies (34%), increased natural killer cells >12% of total lymphocytes (29%), antinuclear antibodies (26%), increased IgM level (20%), increased CD4/CD8 T-cell ratio (13%), and antiovarian antibodies (12%). In addition, IgA deficiency was found in two patients, and seven patients had endometriosis. In 67 of 99 patients (68%), more than one immunologic abnormality was detected. In particular, increased IgM levels were always associated with some other abnormality, particularly the presence of antiphospholipid antibodies and antithyroid

antibodies. Patients with increased CD4/CD8 T-cell ratios had normal levels of CD4 T cells but decreased CD8 T cells. Further testing in these patients revealed low or absent suppressor/cytotoxic (CD57) CD8 T cells.

The pregnancy outcomes of the study are illustrated in Fig. 1. Of the 99 patients, 72 underwent IVIG therapy while 27 patients refused treatment. Of the 72 treated patients, 50 became pregnant and had evaluable pregnancy outcomes. There was no difference in mean age, number of prior abortions, use of IVF therapy or type of immunologic abnormalities between the women who became pregnant and those who did not (data not shown). Of the 50 pregnant women, 44 received IVIG therapy (or intended to receive it) for 26–30 weeks of gestation. Of these patients, 38 (86%) had a term pregnancy while six patients miscarried at 7–9 weeks of gestation. The karyotype of the abortus was not determined in these patients. Six patients discontinued IVIG therapy after 10–12 weeks of gestation, and four of these women (67%) had successful pregnancies. The other two patients discontinued treatment at 10 weeks and miscarried at 15–16 weeks of gestation. The karyotype of the abortus was normal in one of these women. Twin pregnancies occurred in six (14%) of the IVIG-treated women.

Of the 27 patients who refused IVIG therapy, 20 patients subsequently became pregnant and 18 (90%) had first-trimester miscarriages. The overall pregnancy success rate in the IVIG-treated group (84%) compared with the untreated group (10%) was statistically significant ( $P=0.001$ ). There was no difference between the treated and untreated women in terms of mean age, number of prior abortions, use of IVF therapy or type of immunologic abnormalities (data not shown).

**Table I** Patient Characteristics

Variable	Value
Number of patients	99
Mean age, years (range)	37 (28–49)
Median age (years)	37
Mean number of abortions, n (range)	3.8 (3–12)
Median number of abortions	3
Number of patients (%) with:	
primary recurrent abortion	82 (83)
secondary recurrent abortion	17 (17)
In vitro fertilization (%)	75 (76)
No in vitro fertilization (%)	24 (24)

**Table II** Immunologic Abnormalities in 99 Study Subjects<sup>a</sup>

Test result	Positive (%)
Antiphospholipid antibodies	34
Antithyroid antibodies	54
Antinuclear antibodies	26
Antiovarian antibodies	12
Increased natural killer cells	29
Increased IgM level	20
Increased CD4/CD8 T-cell ratio	13
IgA deficiency	2
Endometriosis	7

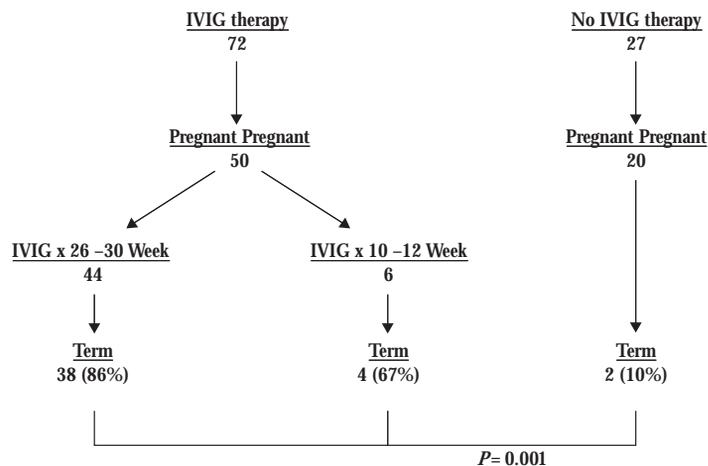
<sup>a</sup>Note that 67 of 99 patients (68%) had more than one immunologic abnormality. Ig, immunoglobulin.

Side-effects of IVIG therapy are shown in Table III. Four patients (8%) had adverse reactions during the IVIG infusion. These reactions occurred toward the end of the infusion, and they were characterized by cold sensation followed by chills, nausea, and vomiting. Vital signs were stable during the reaction, which subsided within 20 min of stopping the IVIG infusion. These reactions were associated exclusively with Venoglobulin-S, and they did not occur when Gamimune-N was substituted for the other IVIG brand.

Other side-effects included headache in 12% of patients. This symptom usually occurred several hours after the IVIG infusion, and no evidence was found for aseptic meningitis. Preterm labor occurred in 8% of patients and responded to conventional therapy. One patient who underwent IVF had both an intrauterine and an ectopic pregnancy. The ectopic site was resected, and the intrauterine pregnancy was successful. There was no evidence of intrauterine growth retardation or fetal abnormalities in any of the women treated with IVIG.

### Discussion

Recurrent abortion is a growing problem in industrialized countries where women are delaying childbearing into their 30s and 40s. As gestational age increases, various immunologic abnormalities that interfere with successful pregnancy become common.<sup>30-32</sup> These immunologic abnormalities appear to be caused by a shift in the immune response away from the so-called Th2 (humoral) pattern that promotes pregnancy toward the so-called Th1 (cellular) pattern that is deleterious to reproductive outcome.<sup>31,32</sup> This shift may be an adjustment of the immune response from the 'reproductive mode' of younger women to the 'pathogen-defense mode' of older women.<sup>30</sup> Because of



**Fig. 1** Pregnancy outcomes in 99 study subjects. Difference in pregnancy outcome between intravenous immunoglobulin (IVIG)-treated and untreated patients was significant ( $P = 0.001$ ).

the postulated immune rejection associated with RSA, the term 'immunologic abortion' has been used to describe women with RSA and various immunologic abnormalities. Although IVF treatment has been advocated for these women, the success rate with IVF has only been on the order of 16–24%.<sup>5,26</sup> Limited success with IVF may be due in part to the same immunologic factors that interfere with natural pregnancy in these women.<sup>26</sup>

Treatment for immunologic abortion has been controversial. The initial association with the lupus anticoagulant syndrome and antiphospholipid antibody, which promotes vascular thrombosis, prompted the use of anticoagulant strategies using aspirin and heparin.<sup>17,18</sup> Although this approach has been successful in about 50% of cases, significant bleeding occurs in about 16% of women, and fatal hemorrhage has been reported in at least one patient.<sup>19,20</sup> Subsequent recognition of other immunologic factors prompted the use of immunomodulatory treatments for women with recurrent miscarriages. Corticosteroid ➤

**Table III** Side-effects of Intravenous Immunoglobulin (IVIG)

Therapy During 50 Pregnancies

Side-effect	Positive, N (%)
Infusion reactions	4 (8)
Headache	6 (12)
Preterm labor	4 (8)
Ectopic pregnancy	1 (2)
Intrauterine growth retardation	0
Fetal abnormalities	0

therapy has been shown to be ineffective for immunologic abortion, and this treatment is associated with numerous complications during pregnancy, especially preterm delivery.<sup>21</sup> Allogeneic lymphocyte immunization (ALI) usually involving maternal immunization with paternal lymphocytes has been used successfully in some women with immunologic abortion.<sup>22,23</sup> However the overall response rate has not been encouraging, and ALI has been associated with severe allergic reactions and painful scarring at the immunization site. The procedure is also non-standardized and labor-intensive.

IVIg therapy for immunologic abortion has also been controversial.<sup>29,33</sup> Several studies have shown significant benefit of IVIg treatment in women with recurrent miscarriages, while other studies have failed to confirm this beneficial effect.<sup>29</sup> A major yet often unrecognized problem with the latter studies involves poor patient selection, with deliberate exclusion of older women.<sup>29</sup> The resultant comparison between younger women who have a high pregnancy success rate without any treatment has significantly biased the outcome of these studies against IVIg therapy.<sup>29,33</sup> Other problems include irrational or excessive IVIg regimens and inadequate patient screening for immunologic abnormalities.<sup>29</sup> These concerns have yet to be addressed in a large multicenter trial.

The present report extends and confirms the results of our previous study of low-dose IVIg therapy for women with immunologic abortion.<sup>29</sup> Our study included only women over 28 years of age; 98% of the women were over 30, and 35% were over 40. Each woman had experienced at least three miscarriages, and every subject was screened for immunologic abnormalities. Antithyroid antibodies were again found to be the most common immunologic abnormality in these patients, followed by antiphospholipid antibodies and increased natural killer cells. Furthermore, 68% of the women were found to have more than one abnormal immunologic test. In contrast, the incidence of immunologic abnormalities in women with normal reproductive outcomes is reportedly <10%.<sup>7,8,11</sup> The presence of multiple immunologic aberrations in our patients reinforces the concept of immunologic abortion and the need for rational immunomodulatory treatment for this disorder.

Previous IVIg regimens for immunologic abortion have often used excessive amounts of IVIg in nonphysiologic treatment intervals.<sup>2,4,28</sup> Since the half-life of IVIg is about 23 days, treatment every 4 weeks should be adequate for immune modulation. Furthermore, the immunomodulatory effect of IVIg appears to be qualitative rather than quantitative.<sup>34-37</sup> Although the standard dose of IVIg used

in many protocols is 0.4 g/kg per treatment, we and others have postulated that a lower dose of IVIg (0.2 g/kg per treatment) should be effective in modulating the 'Th1 to Th2 switch' necessary for successful pregnancy.<sup>25,29,36,37</sup> Although the exact mechanism of IVIg therapy is still not understood, modulation of lymphocyte reactivity and cytokine production is probably at the core of the immune response to IVIg.<sup>34-37</sup> Thus, the low dose of IVIg used in our patients should be adequate for immune modulation in pregnancy. The response to this treatment appeared to be significant, as illustrated in Fig. 1.

IVIg therapy was continued through the end of the second trimester in most patients. The rationale for this length of treatment is based on studies showing a 25% abortion rate in the second trimester for women with immunologic abnormalities.<sup>7,8</sup> Indeed, in the women who discontinued IVIg after the first trimester, two of six (33%) miscarried. As IVIg is relatively expensive, shorter treatment courses for immunologic abortion would certainly be attractive. Although our study was too small to evaluate this issue, the high success rate with longer treatment suggests that the 6-month regimen should remain the standard, particularly in older women with limited pregnancy potential, pending larger trials of a short-course IVIg protocol.

In general, IVIg was well tolerated. A stereotypical infusion reaction was seen in 8% of patients. This reaction could be avoided by changing the brand of IVIg, suggesting that it was probably due to a brand-specific preservative in the IVIg preparation. None of the patients discontinued IVIg therapy because of this side-effect. Significant toxicity to mother or fetus was not seen in our study. Although renal insufficiency caused by a sugar stabilizer has been associated with high-dose IVIg therapy<sup>38</sup> this complication did not occur with the low-dose IVIg regimen used in the study. IVIg was always administered by slow infusion, and rate-related reactions to the IVIg were not encountered.

In the present study, 29% of patients failed to become pregnant after testing for immunologic abnormalities. It is possible that other factors contributed to failure of conception in these women, and the variability of fertilization success underscores the difficulty in evaluating IVIg therapy in this older female population. The possibility that different IVIg strategies in conjunction with IVF treatment may be more useful in these women also merits consideration.<sup>29</sup> Our study represents a cohort-controlled trial that was prospective but not randomized. It has been shown that cohort-controlled trials do not produce a bias toward a treatment effect when compared with

randomized controlled trials<sup>39,40</sup> and the results of randomized and non-randomized studies appear to be similar.<sup>40–42</sup> Given the chronic shortages of IVIG products, the expense of IVIG therapy and the reluctance of women to be randomized to placebo treatment during pregnancy, it is uncertain whether appropriately randomized IVIG trials can be implemented. Our results require confirmation in larger groups of women with immunologic abortion.

In conclusion, the present study extends our previous observation that low-dose IVIG therapy is safe and effective for older women with immunologic abortion. Pending the results of larger controlled clinical trials, monthly administration of low-dose IVIG through the end of the second trimester of pregnancy appears to be the optimal treatment regimen for these patients.

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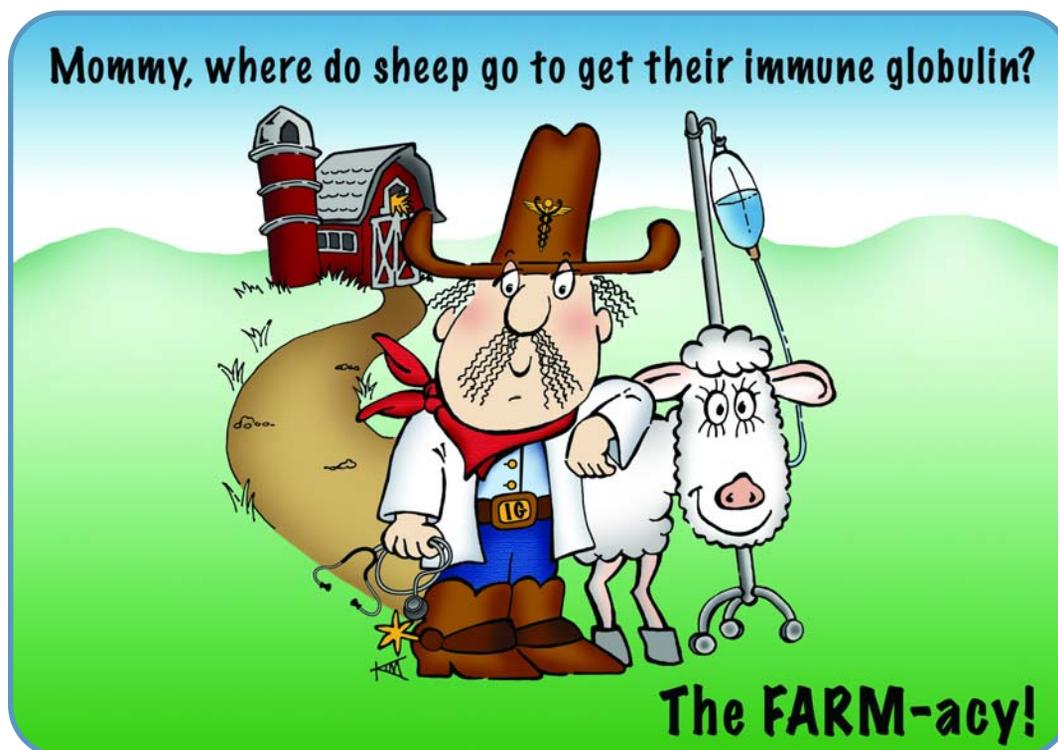
*Dr. Stricker is Medical Director of the Alan E. Beer Center for Reproductive Immunology in Los Gatos, Calif. Dr. Winger is the Laboratory Director for the Center: <http://repro-med.net/index.php>.*

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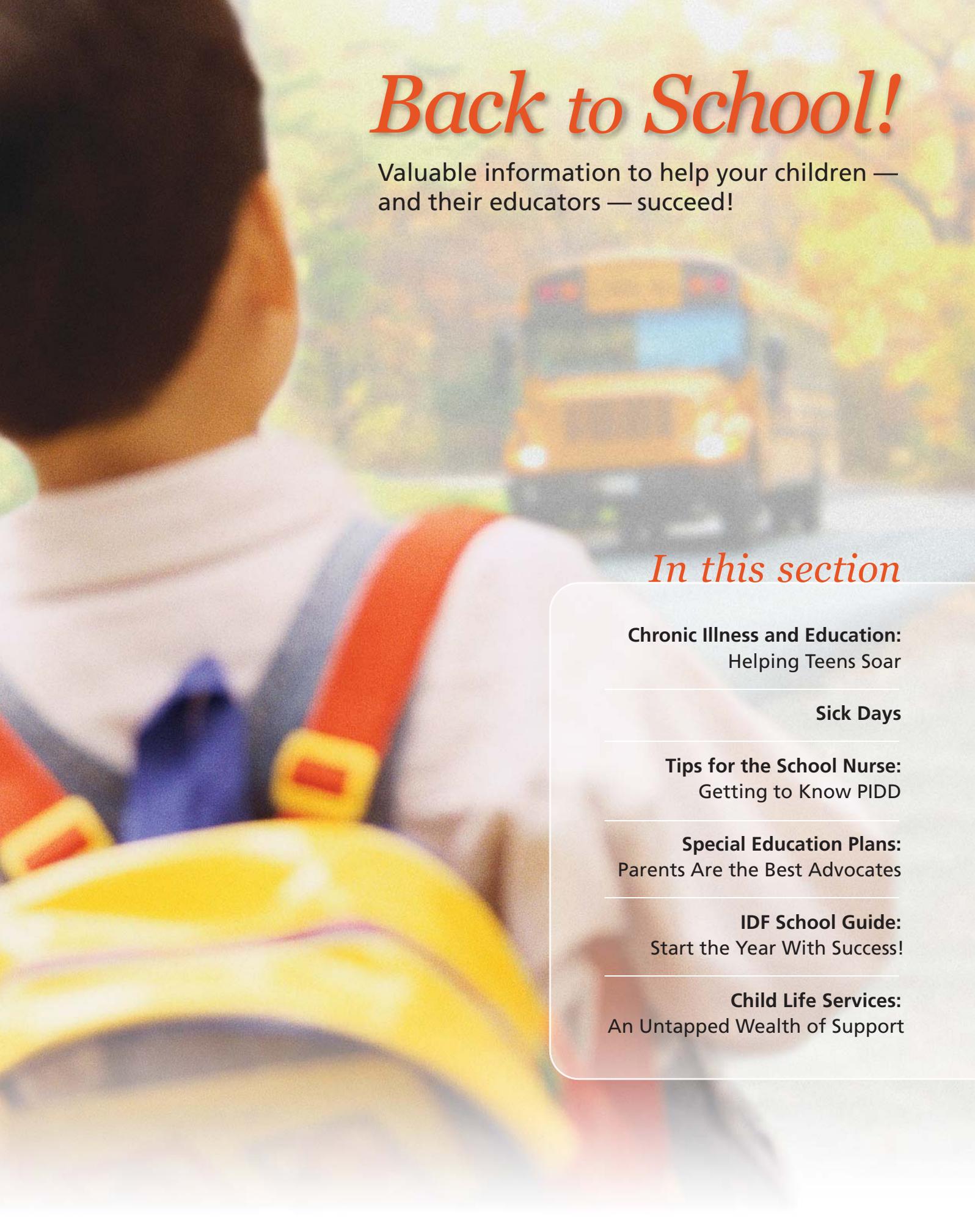
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Joke submitted by a 4-year-old living with common variable immune deficiency, California



# *Back to School!*

Valuable information to help your children —  
and their educators — succeed!

## *In this section*

**Chronic Illness and Education:**  
Helping Teens Soar

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**Sick Days**

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**Tips for the School Nurse:**  
Getting to Know PIDD

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**Special Education Plans:**  
Parents Are the Best Advocates

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**IDF School Guide:**  
Start the Year With Success!

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**Child Life Services:**  
An Untapped Wealth of Support

# Chronic Illness and Education: *Helping Teens Soar*

By Dayna Fladhammer and Annaben Kazemi

The World Health Organization, in 1948, defined health as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.” Successfully living with chronic illness is a true testament to the above. No longer should we think of health as being “not sick,” but, rather, as our emotional, physical and social well-being. This is especially true of chronically ill teenagers and the school system. Combine this idea with a parent’s support and a school system that is willing to explore accommodations, and you enable a teen with a chronic illness not only to survive, but to thrive in the school setting.

Joan Fleitas, EdD, RN, and associate professor of nursing, Lehman College, created a website just for students with chronic illnesses, called Band-aides and Blackboards. The website began as part of her dissertation, and the work gave her great insight into the minds of ill teens. Now the site helps teens manage the challenges of attending school with a chronic illness.

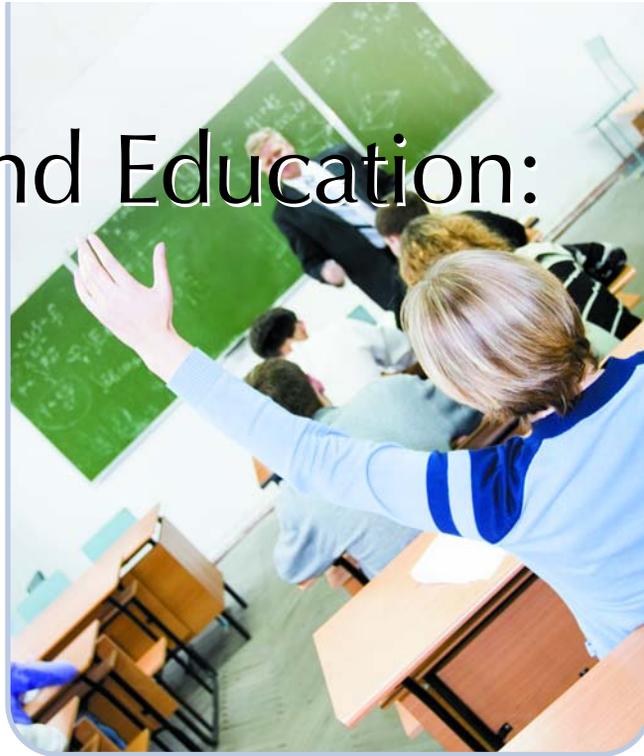
Through her website, Fleitas has come to realize that not all teens with chronic illness are the same, nor will they respond the same way to similar situations. “Kids are as different with chronic illness as they are without it, some quite resilient and accepted by most, and others quite vulnerable, both physically and psychosocially.”

The role of parents of a teen with a chronic illness is no less challenging than the teen’s. The parents’ job is threefold: to help their teen know his or her limitations and abilities; to help their child find what works for him or her; and to be their child’s best advocate. These three factors contribute significantly to a teenager’s success in school.

## **Maintaining Social Connections**

While not allowing teens to be defined by their illness, a parent must also be aware of the psychosocial “bumps” that a teen with a chronic illness can encounter. Fleitas believes that the single most important success factor for a teen with a chronic illness attending school is “acceptance of the student by classmates and teachers.”

One of the challenges of having a chronic illness and continuing in school is finding a balance that sustains a child’s social life. It is essential to keep up with schoolwork,



but it is equally—if not more—important to continue to “have a life.” Teens rarely thrive without this.

Absenteeism, a frequent occurrence for many chronically ill teens, can directly affect the social life of a student, straining relationships within his or her social circle, especially if the absences are of extended lengths. Often, the teen returns from an absence to changes in the social circles or common experiences that he or she has missed—anything from a party to a sporting event, or even a prom. While many teens will be able to pop right back into their social positions, some will find it problematic, experiencing difficulties with some peers or feeling isolated.

Parents must observe their teen carefully, keeping an eye out for any signs that the child might be experiencing difficulties with his or her social circle that could lead to depression. One intervention parents can consider is allowing their teen to continue socializing when they are home sick or hospitalized. While it is important to consider your teen’s personality and comfort with “exposing” him or herself in this way, it is also important that a teen with a chronic illness experience as little isolation from peers as possible. Including peers in the teen’s experience with his or her illness can actually be a powerful bonding experience.

One cautionary note: Faking sickness to get out of school is a possibility with any teen, regardless of his or her health status, but your familiarity with your child’s disease and its symptoms should help you make astute determinations.

## **Achieving Academic Success**

Chronic illness in an adolescent can present complex challenges to acquiring an education. Fleitas has advice for

parents in the academic arena: "In terms of academic success, parents need to support their youngsters, rather than 'do for' them as they confront the demands of school. [This] makes for much better self-esteem and achievement."

There are many different ways to help your teen learn to do for themselves, and you can provide support by identifying options that work for your teen's individual personality, style and needs. (As tempting as it may be, though, doing your child's assignments is not a good option.)

Traditional schooling is not geared toward students with the complications presented by chronic illness. Therefore, teenagers dealing with such complications may find themselves in situations in which they do not fit or cannot meet the expectations of a traditional schedule and workload. Parents, doctors and educators can help a student develop a plan for balancing the illness and the education.

### Developing a Plan

The student's educational, social and psychological needs at school must all be considered when developing a plan. It can be helpful to review a variety of options to determine which best fits the needs of your student, but whatever you do, do not feel bound by the traditional route. While some schools may not have extensive experience in dealing with chronic illness, you can educate them and suggest options that might not otherwise have been offered. Regardless of the school's experience, your child's potential should not be limited, and you will need to advocate for this.

There are various legal requirements for accommodating students with special needs that schools must honor (see "Special Education Plans," Page 22, and "IDF School Guide," Page 27). However, even if your teen is determined to be eligible for any of these accommodations, you must continue to be an avid advocate for the best education your child can receive. Make sure the unique characteristics of your child's illness are reflected in his or her education plan. Fatigue, for example, is common to many diseases, and it can be accommodated with schedule and course load adjustments. Students are not required to take six core classes a semester—there is always summer school or community college classes (often awarded double the high school credits!), which can allow a student to work at his or her pace, but still graduate with peers. A combination of traditional classes and independent study can help some students manage fatigue and still keep up. And, some students may simply need an extra semester or two to complete high school requirements. Remember that the goal is to graduate, so present taking extra semesters as an option early on, so it doesn't feel like failure to your teen.

### Developing a Sense of Self

Teenagers suffering a chronic illness must deal with a lot, both the problems the illness presents and also the burden it adds to the normal adolescent struggle for self.

While it is critically important that school staff are well informed about your child, it is also essential that a teen's right to privacy in the school setting be respected. While some teens will talk freely about their illnesses and struggles, others will not. It is important to respect the wishes of the child in this case. Teens will choose their own ways to communicate about their illnesses—who they will tell about their disease, when they will share it and in what way. Their willingness to reveal such information can be affected by how comfortable they are in their peer groups, their personalities, how long they have been diagnosed, and their parents' reactions to their illness. Let your teen take the lead on this one; it is an area in which he or she can enjoy some control and, hence, some beneficial self-determination.

Sometimes teachers can unintentionally draw unwanted attention to the differences between a teen with a chronic illness and his or her peers by doing something as simple as asking publicly for a volunteer to help orient a student who has returned to class after a long absence or openly offering a student special consideration or accommodation. If this occurs and it is unwanted, it should be addressed with the teacher immediately, either by the teen or the parent.

Teens can learn some creative and proven ways to deal with their diseases and the demands of school in peer support groups, but this may not be for every teen. Fleitas explains, "Support groups are effective for the kids who need a peer group, [but they are] not for everyone. In fact, some youngsters with pretty serious medical conditions would die before they'd participate in something that further marks them [as different]."

Ask your teen if you should seek out others with similar conditions, but do not push it if he or she is not interested. Of course, you can always repeat the question in a few months, in case things have changed for your child, but respect the answer you receive.

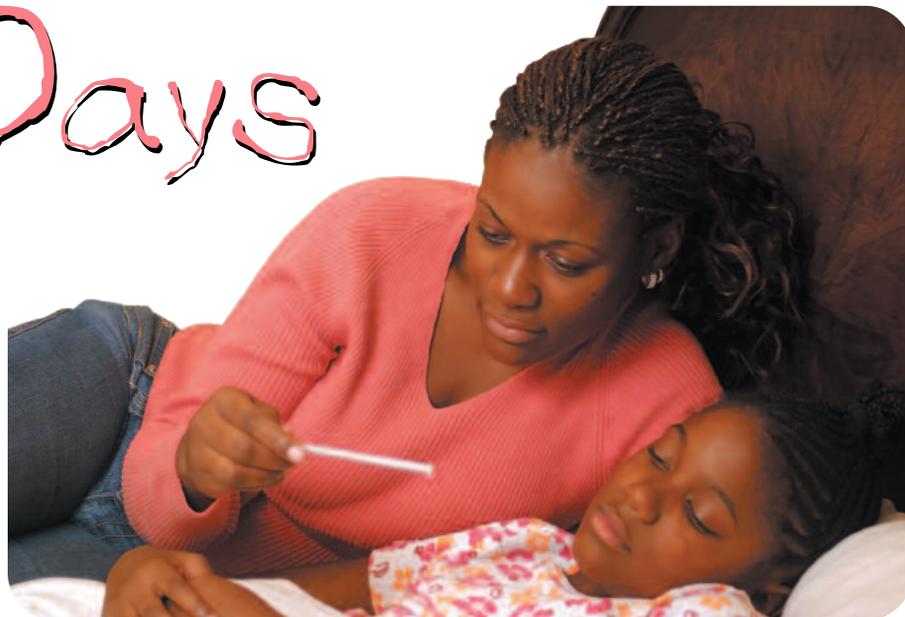
As hard as it is, with or without a chronic illness, teenagers are still teenagers. Your job is to provide them with healthy options, but they must be given room to spread their wings and the freedom to make mistakes, while at the same time have a safety net so they don't fall too far or too hard. ■

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Visit Band-aides and Blackboards at  
<http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>.

# Sick Days

by Carol K. Miletti



A question that plagues parents of kids with primary immune deficiency diseases (PIDD) is whether to send their child to school or to keep them home on “sick” days. The answers to this question are as different as the people I asked recently on a PIDD bulletin board.

Many adults who had undiagnosed PIDD when they were kids admit to often missing quite a bit of school. In the words of Tish, “I had to drag myself to school.”

There were also times when they had to “fake it,” because they knew they weren’t up to it, but, since no diagnosis had been made yet, they had no justifiable excuse to stay home.

Kids go through various stages when they are chronically ill, but the teen years seem to be the most difficult for parent and child to navigate. Being accepted by your peers is far more important at this age than following your parents’ rules. Some parents, such as Carol, are lucky, though. Her daughter, Emily, who is 14, stays home for fever or asthma symptoms. “She is old enough now that she can tell me how she feels and she knows her limitations,” claims the proud mom. She adds, “Emily never fakes being sick to stay home from school.”

But typically, teens are in an age of “emotional upheaval filled with hormonal changes and academic demands very different than in middle school,” suggests Sherri, who has 14 years of teaching under her belt. Sherri recommends that “when a kid is dealing with a chronic illness, it’s hard as a parent to sort out what is disease related and what is normal teenage angst.”

Several parents and teachers have suggested working out some type of deal with the child. If the child truly needs to stay home, it’s to see a doctor or to stay in bed and rest (or study). Sherri also recommends that if “fatigue is a major issue, you might be able to work out a shorter school day or week.”

All the way from Australia, Graham, who is both a PIDD patient and a counselor, suggests that “healthy kids try the same excuses on their parents as PIDD kids do.” He believes in tough love and advises that “children shouldn’t feel like giving up when there is a life ahead of them.”

Many teens stay very active with PIDD and don’t try to skip school. One father who sends his son to a boarding school makes sure the nursing staff is on the same page he is and won’t let his son’s “illness define who he is.” If his son needs to miss class, “every bed in the health center is video conferenced to every classroom.” Dad insists that his son have an elevated temperature of 100 plus to skip school. “They need to learn to play with a bit of pain... life goes on,” says Dad.

And yet, another parent, Kathy, claims that it’s easy to tell when Isaac, her 14-year-old son with PIDD, needs to stay home. “Isaac will lose every bit of energy. Even if it is a beautiful, sunny day, he will choose to rest.” Kathy says Isaac is such an honest and social kid that he would rather be at school with his friends.

In Isaac’s words, “No one realizes how boring it can be hanging out at home when everyone else is at school.”

Whatever your child’s attitude toward school, it can be very helpful for him or her to be in contact with other kids who have a chronic illness and have successfully adapted to it. And, you can help your child maintain as normal a routine as possible, including school when attendance is reasonable. One of the things parents sometimes forget is to focus on the child’s strengths, not just the illness. This will help your child cope. ■

# Tips for the School Nurse

## Getting to Know PIDD

by Jennifer Richlin, RN, MSN, PNP



**P**rimarily immune deficiency diseases (PIDD) include more than 70 different forms of the disease. Some deficiencies are more severe than others, but every form puts the individual at risk for serious and sometimes life-threatening illness. One of the most important aspects of caring for children who have PIDD is in the early detection and treatment of illnesses.

One of the most common forms of PIDD involves antibody deficiencies. Antibodies, which are produced by B cells, are not produced properly due to inborn defects leading to increased risk for infections. Immune globulins are the part of our blood plasma that contains these antibodies or globulins. Most children with these defects receive temporary replacement of the antibodies they cannot make, in the form of intravenous immune globulin (IVIG), to help them fight infections. This therapy occurs every two to four weeks, and is often a lifelong therapeutic intervention. The infusions normally occur in an infusion center, outpatient clinic or student's home, and typically last from four to six hours.

Side effects from IVIG vary, but the most common late side effects include headaches, joint pain, low grade fevers and occasionally aseptic meningitis. The side effects can occur two to seven days after the infusion. Any side effects a child reports to the school nurse need to be taken seriously and immediately reported to the child's caregivers.

Children with PIDD will miss school for their infusions and for doctor appointments. Infusion centers are usually not open on the weekends, so the therapy must occur during the week. Be aware that, although children with PIDD may look healthy, the child and their caregivers will be well aware of specific symptoms of their illness exacerbations, and their opinions need to be respected and trusted. If a child comes to the nurse to complain of a specific problem, this needs to be given immediate attention.

Children with PIDD may need frequent visits to the nurse's office for antibiotic administration, respiratory treatments or for other medical intervention. They may also need more frequent visits to the restroom, due to gastrointestinal complications of their illness. These children know their bodies very well, and they should be given every opportunity to use the restroom.

Children may also need to have frequent snack and meal breaks or breaks for nutritional supplements, due to weight loss and other dietary issues. Every attempt should be made to fit these breaks in with the other children to maintain a sense of normalcy for the child with PIDD.

Any disease outbreak in school—including varicella zoster, influenza, measles, meningitis or hepatitis—must be reported to the child's caregiver immediately, even if the outbreak occurs in a different classroom.

Children with PIDD are more likely to suffer from chronic ear infections, sinus infections, fungal infections, pneumonia and any other communicable disease of childhood. Take any complaint seriously and report to caregivers immediately. If a child with an immune deficiency suffers a cut or abrasion while at school, clean the wound thoroughly and apply appropriate antibiotic ointment. Contact and update the child's caregivers immediately, as the child has an increased risk of a serious infection from any opening in the skin.

A quick word regarding vaccines: Children with PIDD cannot receive any live vaccines. Their healthcare provider should prepare a note for the school explaining this fact and their condition. Children with PIDD are also at a very serious health risk if exposed to anyone who has received live vaccines recently, such as Varivax or Flumist. If you have any questions, contact the child's caregivers.

If you have a child with PIDD in your care, contact the caregivers for more specific information regarding the child's specific health concerns. You may need to ask the caregivers to complete a note for their school file. A PIDD caregiver note template can be downloaded at <http://www.immunedisease.com/US/patients/living/school.html>.

A helpful publication, "A Guide for School Personnel," is available at [www.primaryimmune.org](http://www.primaryimmune.org). ■

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# Special Education Plans:

## *Parents Are the Best Advocates*

By Annaben Kazemi

**B**eing a parent can be the most wonderful, and yet most difficult, job in the world. For parents of a child with a chronic disease, the job is no less wonderful, but it can be more complicated, particularly in addressing your child's education needs. However, knowing the basics of the special education process and keeping your child's educators informed allows you to be effective partners with the child's school.

Students with chronic diseases often fight a vicious cycle. Thies (1999) writes, "Chronicity of the illness saps energy, making it difficult to participate fully in the academic life of the school. The combination of chronicity, absence and side effects of illness and treatment are subtle, but the cumulative effect is potentially damaging. Falling behind academically leads to catching up, and catching up takes away from keeping up. Self-confidence and achievement are undermined."

The course of chronic illness can be uneven and unpredictable, and the burden is on parents to teach their child's educators what to expect. Parents should talk with their child's teacher in order to make any necessary accommodations for bathroom breaks, health-related absences from school, school trips, and flexible homework arrangements during any periods of hospitalization. Teachers must also be taught that a student's illness may not be obvious.

### **Federal Law: IDEA**

Thanks to a federal law called the Individuals with Disabilities Education Improvement Act, or IDEA, children with disabilities are entitled to a "free appropriate public education" (often called FAPE). This means that schools must provide eligible children with specially designed instruction, known as "special education," to meet their unique needs at no cost to the child's parents.

The IDEA definition of a "child with a disability" includes a list of 13 different disability categories under which a child may be found eligible for special education and related services. Children with a chronic illness that impacts their

schooling may be found eligible for services under the category "other health impairment."

Although many students with chronic diseases can participate in their classrooms with minimal modifications, many other students will experience a drop in performance associated with their illness, either because of the disease itself or medical treatment. For these students, Individualized Education Programs (IEPs) may be necessary to assist them in fully accessing the curriculum.

### **Individualized Education Programs**

Parents or guardians must ask the school administrator to have their child evaluated for special services. After the formal request has been made, the school district must respond in a specified period of time. A school psychologist will perform an assessment of the child, including psychological and academic testing, and conduct a thorough review of the child's medical, developmental and school history.

Parents and the school's IEP team then meet to create the child's unique IEP. Parents may bring a doctor, nurse or any professional they choose. The IEP team will review the child's assessment and discuss any findings and other relevant information. The resulting IEP is the map for your child's education, and you are a very important member of the team that develops it. Your child's IEP lists the specific special education services your child will receive, based upon his or her individual needs. This is why it is so important that you understand and help develop your child's IEP.

An annual review of the IEP is required by law, to make sure the child's needs are indeed being met, and to plan for the coming school year. Additionally, the parent has the right to call for an IEP meeting at anytime that the child's needs have changed, requiring adjustment to the IEP.

If the IEP team decides that your child needs a particular *modification* or *accommodation*, this information must be included in the IEP. Sometimes people get confused about what it means to have a modification and what it means



to have an accommodation. Usually a modification means a change in what is being taught to or expected from the student. Making an assignment easier so the student is not doing the same level of work as other students is an example of a modification. An accommodation is a change that helps a student overcome or work around the disability. Allowing a student with trouble writing to give answers orally is an example of an accommodation. The student is still expected to know the same material and answer the same questions as fully as the other students, but he or she doesn't have to write the answers.

Just because a child has a chronic illness does not mean that he or she automatically qualifies for special education services under the IDEA. For instance, a child with a primary immune deficiency disease who does not need special education services will not qualify for special education and related services under the IDEA. He or she may, however, receive protections under Section 504 of the Rehabilitation Act.

### **Protection Under Section 504**

Section 504 of the Rehabilitation Act of 1973 is a federal civil rights law. It extends the rights for full inclusion, and may help in supporting a specific plan for a child. The purpose of a Section 504 plan is to protect people with disabilities against discrimination for reasons related to their disabilities. Unlike IDEA, Section 504 does not guarantee that a child with a chronic illness will receive an IEP. However, under a Section 504 plan, a child with a chronic illness may receive accommodations and modifications that are not available to other children who are not characterized as disabled. Some examples of such accommodations and modifications include:

- Tests taken in a separate location with time limits waived or extended
- Giving the child frequent breaks out of the classroom to go to the bathroom, rest in the nurse's office, etc.

- The use of a word processor due to fine motor, visual motor deficits
- Shortened assignments
- Standardized test answers written directly in the test booklet and transferred onto answer sheet by teacher or assistant
- Class notes provided to the student, rather than having the student copy from the chalkboard or overhead
- Allowing the child to leave the classroom two to three minutes early to avoid crowded hallways
- Preferential seating in the classroom

Eligibility for a Section 504 plan depends on the child in question having a physical or mental impairment that must substantially limit at least one major life activity. Major life activities include walking, seeing, hearing, speaking, breathing, learning, reading, writing, performing math calculations, working, caring for oneself and performing manual tasks. The question that must be addressed by the school's special education team is whether the child has an "impairment" that "substantially limits one or more major life activities."

While a Section 504 plan does not require a meeting before a change in a child's placement, a child who receives Section 504 protections has fewer rights than the child who receives special education services under the IEP. However, a child who receives special education services under the IDEA is automatically protected under Section 504.

### **Limitations of IDEA Law**

Children with chronic illness face two issues that are not well addressed by the IDEA law. First, children who do well in school are presumed not to need help. Jaff (2005) writes, "The IDEA defines 'child with a disability' to mean a child with health problems 'who, by reason thereof, needs special education and related services.' A student who does not need special education because she is performing well academically is not a 'child with □a

disability' under the IDEA," despite diagnosis of a chronic illness. Because many children with chronic disease issues do not suffer academically, they may not be covered under the IDEA.

Second, neither statute provides guidance for children with a chronic disease that remits and relapses. There will be times when a student needs home schooling and other times when the student has no need for help. This presents a challenge for both the parents and the school, since neither the IEP nor the Section 504 plan is intended to apply only some of the time, and flexibility is difficult to build into a plan. Convincing the school to respond quickly to the student's ever-changing circumstances is challenging, but worth the effort.

The impacts of chronic illness can vary considerably and are a factor in deciding whether an IEP or a Section 504 plan is appropriate for each individual child. However, the single most important tool in obtaining the best possible education for your child remains constant: you! ■

## For more information about special education law...

### **A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed**

by Linda Wilmshurst and Alan W. Brue

Available on Amazon

### **The Everyday Guide to Special Education Law**

By Randy Chapman, Esq.

<http://www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15>

### **IDEA 2004 Resources**

<http://www.ed.gov/policy/speced/guid/idea/idea2004.html>

News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities

### **U.S. Department of Health and Human Services, Office of Civil Rights**

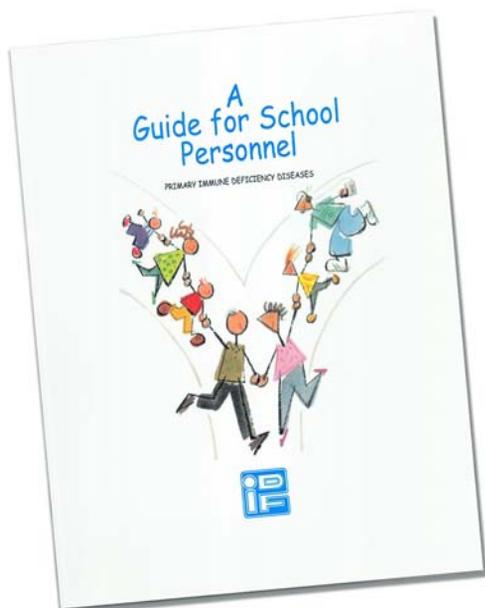
<http://www.hhs.gov/ocr/504.html>

Your rights under Section 504 of the Rehabilitation Act

### **Wrightslaw**

<http://www.wrightslaw.com/>

Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities



# IDF School Guide: Start the Year With Success!

From the Immune Deficiency Foundation

"Back to school" means changes for families. Students get new schedules, teachers, classes and friends, while most parents contend with new routines, carpool duties and shopping for school clothes and supplies. For parents of children with primary immune deficiency diseases, add setting up meetings with new teachers, talking to the school nurse and discussing your child's needs with school administrators. During this hectic time, with so much information to cover with so many people, it would not be surprising if you were overwhelmed. Wouldn't it be nice to have a comprehensive, professional resource to help you get your child's school year off to a successful start?

There is help: Published by the Immune Deficiency Foundation (IDF), "A Guide for School Personnel: Primary Immune Deficiency Diseases" can help you create a smooth transition between home and school. Specifically designed to educate school personnel about primary immune deficiency diseases (PIDD) and the

children who are affected by them, the publication is the perfect guide to help develop an agenda for that all-important parent-teacher meeting at the beginning of the school year. The guide can be the basis of this meeting, facilitate effective communication with school personnel and help assure the safety and well-being of your child within the school setting.

## Practical Information about Students With Primary Immune Deficiency Disease

For students enrolling in preschool, college or any grade in between, the guide addresses a range of issues that might affect them and their classroom performance. "A Guide for School Personnel: Primary Immune Deficiency Diseases" provides key medical information about PIDD and helps school staff understand the nature of these diseases. Different types of medical therapies are explained, including the possible side effects that might affect a student's functioning in school. The guide provides helpful information and advice about the impact of vaccinations and the heightened susceptibility to infection. Since students with PIDD often miss more school than their classmates, the issue of increased absenteeism is covered.

There is also a chapter on student special needs. These can range from a need for hall passes for medication administration to a physical limitation that might prevent participating in a physical education activity. Whatever the needs, discussing them at the beginning of the year can set the stage for a safe and smooth school year. Depending on the individual student's needs, it may be necessary to establish a Section 504 plan or an Individualized Education Program (IEP). Information about these plans and federal laws to protect children with disabilities are detailed, along with specific information on educational rights under federal law.

Since primary immune deficiency diseases are chronic illnesses and the symptoms and impacts vary by disease diagnosis and by person, it is crucial to make specific information about the individual student available to school personnel. To make this easy, the guide includes a personal medical history section for information on the student's diagnosis, current treatment, allergies and emergency information and physician contacts. There is even a handy back pocket to hold supporting documents and medical records.

## The Importance of Communication

Using the IDF's "A Guide for School Personnel: Primary Immune [ ]

Deficiency Diseases” can help get the school year off to a great start for students and school staff alike. Before your first meeting this fall, be sure to prepare yourself with a copy of the guide. You can also order a copy for your school administrators, teachers and nurses to ensure improved disease management and minimize the social stressors associated with PID. Use the booklet to initiate meetings, maintain regular communication and foster an

ongoing relationship between your family and your school system throughout the school year. ■

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*“A Guide for School Personnel: Primary Immune Deficiency Diseases” was made possible through a generous grant from the American Legion Child Welfare Foundation Inc. The guide can be downloaded from the IDF website, [www.primaryimmune.org](http://www.primaryimmune.org). Printed copies are available by phoning 800-296-4433 or emailing [idf@primaryimmune.org](mailto:idf@primaryimmune.org).*

## Possible Accommodations and Modifications for PID Kids

From IG Living

The following is a list of accommodations and modifications that some of our parents have used in developing a school environment that best serves a child with a primary immune deficiency disease.

- Due to gastrointestinal complications of the disease, a child should never be denied access to a bathroom.
- The child should be allowed to carry a water bottle and drink from it as needed.
- The child should be allowed to carry soap for waterless hand washing, and allowed to use the soap at any time.
- To gain a true showing of the child’s ability, the child should not be tested the week before an infusion.
- The child will not be held back due to the number of school absences.
- Homework missed during absences will be adjusted to reflect a reasonable amount of work, i.e., even or odd problems in math as opposed to all problems.
- The child will not be expected to take makeup tests or quizzes on the same day of return from a lengthy illness (three or more days).
- The child’s disease can cause extreme fatigue, so extra time will be allowed, when necessary, to complete homework or class work.
- Participation points will be counted only on days present, and child will not be penalized for days absent.
- Makeup tests and quizzes will be done during the normal school day, or a parent will moderate at home, but the school day will not be extended.
- The child will be allowed to rest as needed.
- Allow the child to self-limit as needed, especially in relation to physical activity.
- The school will provide a tutor after two consecutive days missed, regardless of total number of days missed.
- The school will provide one hour of tutoring in the home for each full day absent.
- All cuts the child experiences must be cleaned and covered, and parents should be notified to continue care at home.
- The child’s seat will be moved if another child comes to school sick and sits in close proximity. This should be done in a way that avoids pointing out the child’s differences.

## Other Resources

From IG Living

- **Band-aides and Blackboards**  
<http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>  
A website started by a nurse working on her dissertation, its focus is on children with chronic illness in the classroom.
- **Immune Deficiency Foundation**  
[www.primaryimmune.org](http://www.primaryimmune.org)  
Ask for their “Patient and Family Handbook” and “A Guide for School Personnel.”
- **Jeffery Model Foundation**  
[www.info4pi.org](http://www.info4pi.org) and [www.jmfworld.org](http://www.jmfworld.org)  
Ask for their “10 Warning Signs of Primary Immunodeficiency” poster.
- **The National Disabilities Rights Network**  
[www.ndrn.org](http://www.ndrn.org)  
This website offers a search tool to find resources in your state to assist with school rights and advocacy.
- **U.S. Department of Education Website**  
[www.ed.gov](http://www.ed.gov)  
This U.S. federal government website offers a parents section that has a subsection titled “My Child’s Special Needs” that can be most helpful.
- **Wrightslaw**  
<http://www.Wrightslaw.com/>  
Parents, educators, advocates and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities.

# Child Life Services

## An Untapped Wealth of Support

By Jennifer Richlin, RN, MSN, PNP

If you have never had a child hospitalized in a major medical center, you probably have never encountered the division of Child Life Services.

Imagine a kind, empathetic teacher who spends time with a sick or hospitalized child in order to help the child acquire new coping skills to better deal with the situation, and you can imagine the best that Child Life has to offer.

We do not need a research study to tell us that children do not enjoy being sick or in the hospital. The ever-increasing ability of modern healthcare to provide more and more complex medical interventions has led to children spending longer durations as inpatients in the hospital and their increased exposure to intensive medical treatments. Most pediatric hospitals or large pediatric programs have Child Life divisions to help combat the challenges that come along with these advances in pediatric therapy. In fact, the number of Child Life programs has doubled since 1988 in order to provide therapeutic intervention for children coping with the emotional demands of modern medicine.

### Someone Who Cares

Child Life programs are the standard for pediatric inpatient facilities and for many pediatric outpatient centers. Sub-specialty divisions such as oncology and pediatric neurology may employ their own Child Life practitioners as well. Child Life professionals provide many critical services to the pediatric patient and family including:

- Play experiences
- Developmentally appropriate information regarding medical tests and procedures
- Assistance establishing a therapeutic relationship with the pediatric patient in order to provide support during the course of the illness or hospital stay

The Child Life practitioner has a unique role on the healthcare team, serving as a supportive advocate whose sole purpose is to be on the child's side.

"Child Life is here to help the child with scary tests



*Adina Bodolay, Child Life practitioner, works her magic with a young patient.*

and procedures, but not to actually perform the tests," explained Adina Bodolay, Child Life practitioner for UCLA outpatient pediatrics. "The Child Life provider is a non-threatening person who never has to do anything painful to the child. The child trusts us completely, and through this relationship we are able to support the child and help them to be less fearful—through play and other activities."

Bodolay recounted an experience with a child who was experiencing panic-like fear prior to an intravenous start. Through discussion and play, Bodolay was able to work through the child's emotions and discover they were the result of a previous IV start. "The child had been held tight at his upper arm during the IV start in such a way that he felt trapped and violated," Bodolay said. Working as the Child Life professional, she was able to share this fear with the nursing staff and they were able to coach the child through the IV start with a less fearful and calmer result. □

## Play Time

Play is an integral component in any Child Life program. This does not mean to convey that the primary function of the trained staff is to merely manage the play and activity rooms or provide toys. This would be a vast understatement of the myriad services provided by the compassionate and educated Child Life staff. Yes, the Child Life staff does manage the playrooms and activity areas in the inpatient and outpatient settings, but the goals of these areas are not only for play and distraction, but also to provide a semblance of normalcy and safety for the child patient. Through these areas of safety, where the child cannot be hurt or tested in any way, the Child Life staff is able to bond with the child and pave the way for communication in a developmentally appropriate way.

Children are often more likely to discuss fears and concerns with a Child Life professional through the daily childhood play activities, such as coloring or doll play. In this way the Child Life practitioner becomes an integral part of the child's medical support system and the bonds formed are often very strong.

## Medical Play

Medical play involves the child in a directed activity led by the Child Life professional, using medical themes and common healthcare items such as syringes and Band-Aids. Through the use of medical play, the child may engage dolls with medical themes or make art projects with the medical items. In this way, the child may become more at ease in the medical setting. The child also is able to feel some control over the new items such as gauze or syringes, and feels less frightened when the medical equipment is used on them.

## Scary Procedures

Medical procedures, whether the procedure is having an IV placed or being prepared for surgery, can be extremely frightening for anyone, but especially so for a child. Most Child Life programs use the Child Life professional in preparation for potentially scary procedures to help reduce pre-procedural anxiety in the child.

New research from Miller Children's Hospital in Long Beach, Calif., demonstrates that children who received Child Life intervention prior to painful procedures showed a reduction in feelings of fear and anxiety during the procedure. The research study also demonstrates that pre-procedural anxiety levels increase with the child's age. These data are relevant as they validate the need for comprehensive Child Life programs that attend to both

younger and older children's fears and concerns. It is not only the youngest of children who develop fearful responses to new and scary medical procedures.

Children who have experienced Child Life intervention have demonstrated a decreased need for analgesia during procedures and improvement in recovery time. Other documented positive outcomes include better coping, easier adjustments and decreased stress levels in children. Research and anecdotal experiences demonstrate that Child Life is a valuable part of the healthcare team, engendering increased trust between the child and the healthcare practitioner.

## Child Life Qualifications

Child Life professionals may have differing qualifications within the Child Life division. Certified Child Life specialists are certified through the Child Life Council after they have successfully completed 480 hours of supervised clinical interaction with pediatric patients and an objective exam. Their educational background includes the completion of a bachelor's degree in early education, child development or psychology. Individuals involved in Child Life programs should possess empathy, kindness, good communication skills, patience and the personal desire to improve the pediatric patient's experiences during times of stress and illness.

## Get Tapped Into Child Life

If you are unsure if your facility has a Child Life program, ask your child's healthcare provider or nursing staff. If your child has never been hospitalized, you may not have made contact with anyone in your hospital's Child Life program. Many children who are treated as outpatients do not receive Child Life Services unless a healthcare provider or parent requests them.

With so much data to support the benefits of Child Life interventions, don't you think it is time that you and your child explore the Child Life team in your facility?

Want more information? Visit [www.childlife.org](http://www.childlife.org). ■

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Dear IG Living,

Dan Bennett's recent article "Port Access for IVIG: Another Option" fails to adequately highlight the risks of having a port or other indwelling access device to receive IVIG therapy.

The article does mention "risk of infection." Any foreign object can serve as a focal point for infection and presents risk to the patient. This is a greater concern in an individual who does not have a complete immune system to begin with. Although closed infusion system "ports" present lower risk of infection, there is still a measurable incidence of bacterial blood infection resulting from the port, which can result in death (Am J. Infect Control 2004). Depending on the patient population, bloodstream infection rate can be as high as 25% (Infect Control Hosp Epidemiol 1999).

The article does not mention the pro-thrombotic nature of indwelling intravenous access devices (predisposing to blood clots). Blood clots have been reported to complicate more than 10% of long-term central venous access devices (J. Am. Coll. Surg 2000). This risk may be even greater to patients receiving IVIG as "thrombosis" is listed in package inserts as an adverse event related to IVIG administration.

The overall rate of complications of ports can be as high as 45% (Br. J. Cancer 2004) and there are a number of other documented problems including operative complications, pneumothorax (collapsed lung), bleeding and device breakage or failure (J. Vasc. Access 2004).

For these reasons, two expert consensus statements on primary immunodeficiency diseases both recommend against the use of ports for patients with primary immunodeficiency diseases for the sole purpose of receiving IVIG: 1: *Practice Parameter for the diagnosis and management of primary immunodeficiency*. 2005, Ann. Allergy; and 2: Use of intravenous immunoglobulin in human disease. 2006. J. Allergy Clin. Immunol.

Anecdotal experience is very valuable and an undeniable impetus for change. Higher quality research regarding the use of ports in patients who have primary immunodeficiency, however, is needed before they should be specifically recommended. Potential quality of life benefits need to be carefully weighed against risks, which in this case can be very serious.

– Jordan Orange, MD, PhD

University of Pennsylvania School of Medicine  
Children's Hospital of Philadelphia

I received a complimentary copy of your magazine but, never having had the IVIG therapy, I just glanced through it. Never did I expect that three weeks later, my neurologist scheduled me for the therapy. Your article on what IVIG was and what to expect was so well timed; I wasn't so scared. I took the magazine to the hospital with me and showed it to one of my nurses on the oncology wing where I was. She was so impressed that she copied the article to give to all new IVIG patients so they could better understand the therapy. Thank you for the article from me and all the oncology nurses at Ft. Sanders Regional Hospital in Knoxville, TN.

– Barbara, Tennessee



My son Andrew was diagnosed with an immune deficiency requiring monthly IVIG since he was 18 months old. He is 6 years old now and actually looks forward to his monthly "poke," because he gets a new toy after each infusion.

He really likes his nurse coming to our house for infusions instead of going to the hospital. He feels special and thinks the nurse is there just to play with him for three hours!

– Jackie

Hello, my name is Alec. I am 9 years old and I live with my mom, dad and little sister.

I have common variable immune deficiency. That means I get sick all the time, and I get infusions every five days to keep me healthy. I also have to go to the doctor all the time.

There are some cool things about having an immune disease. I get to pick out a new toy after I go to the doctor's office. I also get to play video games when I get my infusions. We got to go to three Red Sox games with NEPIN (New England Primary Immune Network). I get to drink a lot of smoothies. And when I am in the hospital, I get to spend alone time with my mom and my dad. I even got a Make-A-Wish. I haven't gone yet, but I know it will be cool!

But the best thing about having an immune disease is that I made the best friend in the world named Victoria. She has the same disease as me, so we can talk and share a lot of the same stories. These are some things that I like about having an immune disease.

– Alec, Florida

# Let's Talk!

By Shirley German Vulpe, EdD

**L**et's Talk is an opportunity to share our experiences of living with a condition that requires immune globulin therapy. It behooves us to learn as much as possible about all the ramifications of our illnesses and their IG treatment, and we can learn from one another. In each bimonthly issue of IG Living, we will share here how one or another of us has handled an aspect of our illness or immune globulin therapy—and, perhaps, discover a new solution that could profoundly affect our lives.

I interviewed Barbara, who had e-mailed a message to IG Living, writing that she had received a complimentary copy of the magazine, but had only taken a cursory glance at it, as she had never expected to receive IVIG therapy. Three weeks later, she wrote, her neurologist scheduled her for IVIG! She remembered an article I had written about IVIG therapy, reread it, and found that she was not as scared as she had been. I knew she would have an interesting story to tell.

**Shirley:** Hi, Barbara. Can you tell me a little about your illness?

**Barbara:** Sure. I have CIDP, chronic inflammatory demyelinating polyneuropathy. I was very healthy until nine years ago, when I developed numbness in my hands and feet, sores in my mouth and my bones ached. I went to many doctors to try and find out what was wrong with me. It took many MD visits and one year, before I found the right doctor. He ordered an EMG [a test that measures electrical activity in muscles and nerves]. The results of this test and a nerve biopsy he had done confirmed my diagnosis for him.

**Shirley:** What was the treatment?

**Barbara:** I was put on many medications, some for the symptoms and

some to manage side effects of the medications. I also became depressed and started on antidepressants, had difficulty sleeping and had a lot of pain, so I received pain and sleeping medications. Thank goodness I have pretty good insurance as they cost so much—one was \$216!

**Shirley:** Did the medications help you?

**Barbara:** Yes. There were changes and adjustments as the eight years passed, and the drugs helped me a lot. But the high doses of immunosuppressant drugs made me a prisoner in my home. I was able to get a job

when I went into remission for 17 or 18 months, and then I experienced a rapid decline, going downhill fast over a matter of weeks. Medication didn't help much, and I had to quit work. It was then that my neurologist said I needed IVIG therapy. I was frightened. I had been told little about it, and didn't understand what it really was.

**Shirley:** Is that when you remembered IG Living?

**Barbara:** Yes, your article on what IVIG was and what to expect. It was so well timed. I wasn't as scared. I took the magazine to the hospital with me and showed it to one of my nurses. She was so impressed she copied the article to give to all new IVIG patients so they could better

# Everyone Has a Story, and This Is Tim's

By Carol K. Miletti

*Character cannot be developed in ease and quiet. Only through experiences of trial and suffering can the soul be strengthened, vision cleared, ambition inspired and success achieved.*

—Helen Keller

"People who live sanitized lives have no idea what the impact of illness can do and how it can turn their world upside down," said Tim Tarulli. Tim's world had been turned upside down and inside out ever since he was 4 years old. Today, though, his life is much different.

Today, Tim has the appearance of a healthy, well-adjusted family and business man. He and his wife, Teresa, have three healthy kids aged 5, 9 and 13. Tim has owned his own business for 15 years and also serves as a city councilman. His level of activity for a 44-year-old man speaks to his self-proclaimed Type-A personality.

Tim believes "attitude is everything," and his goal is to

"keep getting better at everything—every day." These are high aspirations for a man with a primary immune deficiency disease (PIDD). But Tim's life has not always been this rosy.

When he was 4, Tim began to get very sick. He was so sick, that he was taken to the Mayo Clinic in Minnesota, the Cleveland Clinic in Ohio, and Sloan Kettering in New York, in an effort to find a diagnosis for his illness. At first the doctors believed Tim had leukemia, and he endured very painful bone marrow testing. Next, they thought it might be cystic fibrosis.

By the time Tim was finally diagnosed with PIDD, at ➤

understand the therapy.

**Shirley:** It is always wonderful to hear that something you have done has helped others. Has the IVIG helped you?

**Barbara:** Yes it has. Initially, I felt great. I had increased energy and felt better than I had for a long time. Even though it seems to be wearing off a bit, I still feel good. I decided to schedule a visit to see my mother for Mother's Day, just after my next scheduled IG infusion. I haven't been able to travel for years!

**Shirley:** That is great! Are there any other resources that have helped you?

**Barbara:** Yes. I have found the chat board of The Neuropathy Association very helpful. You know you're not alone. ■

## CIDP Information and Resources

From The Neuropathy Association

### What is chronic inflammatory demyelinating polyneuropathy (CIDP)?

Chronic inflammatory demyelinating polyneuropathy is a neurological disorder characterized by progressive weakness and impaired sensory function in the legs and arms. The disorder, which is sometimes called chronic relapsing polyneuropathy, is caused by damage to the myelin sheath (the fatty covering that wraps around and protects nerve fibers) of the peripheral nerves. Although it can occur at any age and in both genders, CIDP is more common in young adults, and in men more so than women. It often presents with symptoms that include tingling or numbness (beginning in the toes and fingers), weakness of the arms and legs, loss of deep tendon reflexes (areflexia), fatigue and abnormal sensations. CIDP is closely related to Guillain-Barré syndrome and it is considered the chronic counterpart of that acute disease.

### Is there any treatment?

Treatment for CIDP includes corticosteroids such as prednisone, which may be prescribed alone or in combination with immunosuppressant drugs. Plasmapheresis (plasma exchange) and intravenous immunoglobulin (IVIG) therapy are effective. IVIG may be used even as a first-line therapy. Physiotherapy may improve muscle strength, function and mobility, and minimize the shrinkage of muscles and tendons and distortions of the joints.

National Institute of Neurological Disorders and Stroke (NINDS) [www.ninds.nih.gov](http://www.ninds.nih.gov) 800-352-9424

CIDP pages: <http://www.ninds.nih.gov/disorders/cidp/cidp.htm>

The Neuropathy Association [www.neuropathy.org](http://www.neuropathy.org) 212-692-0662

GBS/CIDP Foundation International [www.gbsfi.com](http://www.gbsfi.com) 610-667-0131

American Autoimmune Related Diseases Association [www.aarda.org](http://www.aarda.org) 586-776-3900

Literature request: 800-598-4668

the University Hospital of Cleveland, he had had so many bouts of pneumonia that his lungs were already fairly scarred. His initial course of treatment was a “bazooka-sized gamma globulin syringe shot” into his thigh.

The next phase of treatment for Tim included regular visits to a wing of the Cleveland hospital where his dad gave blood, and the plasma was removed and then injected into Tim. But the loving support and better health did not help alleviate the fact that Tim felt left out. He describes feeling humiliated, and wondering what his buddies thought of him because of his illness and his treatments.

In the 1980s, Tim advanced to the next type of treatment, intravenous immune globulin (IVIG). He went to Cleveland every two and a half to three weeks to receive IVIG, and he began to feel real improvement in his health.

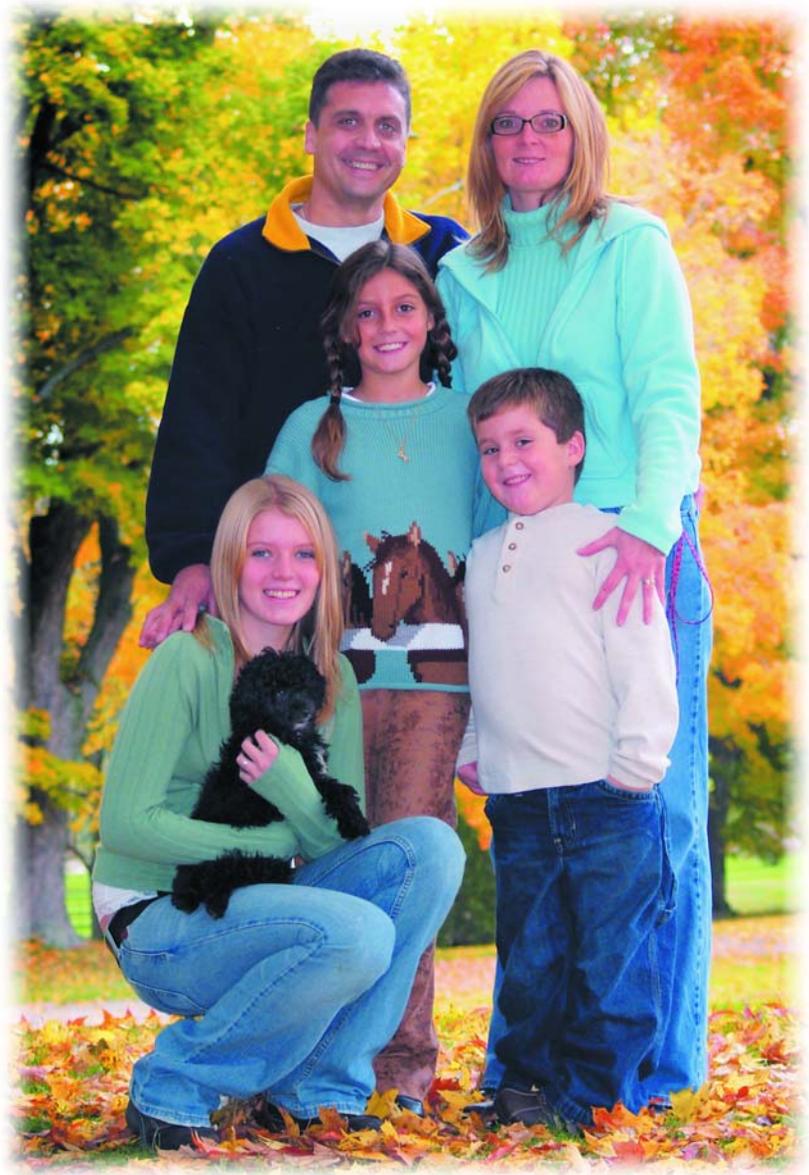
Next, he began to infuse himself at home. However, he found that if he got too stressed when setting up the infusion, he might “blow a vein,” and would then have to go to the local hospital and talk them into helping him, which could take hours.

He had terrible side effects from this method of immune globulin administration, including headaches, total body aches and trough levels dropping rapidly.

In 2001, Tim was asked to join a clinical trial for a new drug manufactured by ZLB Behring. This new drug was self-administered using a subcutaneous route (SCIG or SubQ).

Tim agreed to be included in this study, although he was somewhat resistant at times because he found the first few months difficult. Now, however, he is happy that he stuck with it, because he claims he has not gotten sick once since starting SCIG.

“I have no side effects and I have a very good lifestyle now,” Tim said. He is able to lead a very active life. He exercises, swims, bikes, water-skis and is able to play with his kids. Tim admits to being a bit naïve and claims, “I have no fears in regard to my condition.” But he does experience the challenge of dealing with intermittent fatigue and being that Type-A personality.



Still, Tim’s life is a reminder of how good it can be when all the pieces fall into place.

He is fortunate to have a good doctor; treatment that is life giving; a loving family and friends; a supportive work environment; a strong faith; and a very healthy and positive attitude. Secret fears? Of course Tim has them. But for now, he’s keeping them on the back burner of his life.

Instead, Tim exudes confidence, a positive attitude and outlook, and good health. When asked what he wishes others knew, he responded, “Learn to prioritize—what’s important and what’s not.” ■

# Nurturing Normalcy

By Terri Cerda

**B**y 16 months of age, it became clearly evident that our 5-year-old daughter had an immune disorder. I mentioned it to her pediatrician, first with mild persistence followed by passionate insistence, that my child may have the same immune disorder that I had been diagnosed with some 40 years earlier. Three years later, we would learn that both of my young daughters and I will live with a primary immune deficiency disease (PID) for the rest of our lives.

Living with an immune disorder is not something we can choose to deal with on a weekend, after school or on vacation. It is something that affects everything about the way we live, 24 hours a day, seven days a week. It forces our children to mature before they are ready, and it has the power to strip away precious parts of childhood—if we let it.

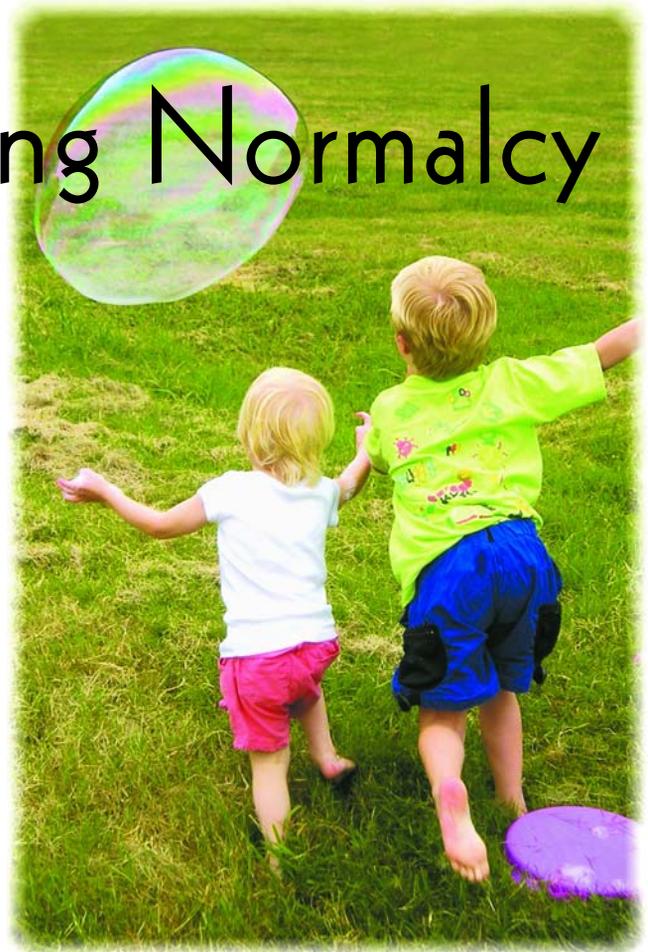
Early intervention can prevent many of the potential negative impacts on a child dealing with PID. Identifying possible or probable challenges before they become problems sets the stage for effective intervention, and what I like to call “nurturing normalcy.”

Among the many challenges that families living with a PID face is the seemingly constant struggle to gain acknowledgment: Our children can appear to be well much of the time. As a result, they can be regarded as healthy by family, peers and physicians.

I will never forget the day that my daughter’s pediatrician told me that my child, suffering with her second bout with mycoplasma pneumonia in six weeks, could not possibly have an immune disorder. He declared that a child with hair as healthy as Molly’s could not have a problem like that. Such a lack of understanding can make it difficult to find the support our children need, so we must fight for it by intervening to educate their healthcare providers.

## Developing Awareness

Children with an immune disorder often begin life with far too many trips to the doctors, hospital stays, pokes with needles and repeated bouts of illness. Children can become increasingly frightened and lonely, feeling *different* because of their disease. “Mommy, I just wish I was normal” is something no parent wants to hear. But such pleas are a message to parents that we must change the



way we live to accommodate the needs of our chronically ill children.

Depending on their age, children can be affected in very different ways by the emotional stress of living with a PID. Normally, infants begin to learn to trust those they live with and the environment in which they live from day one, but the circumstances of a PID can put children’s ability to feel secure and trust those who care for them at stake.

By preschool age, children with a PID can easily feel a lack of ability to control their environment. This can be characterized in the responses of our children in other environments outside of a healthcare setting.

Tonie Valesano, PhD, is a licensed social worker for the Nevada Childhood Cancer Foundation. She feels that children at this stage often have difficulty learning boundaries and a sense of safety. She asks, “How can a child learn boundaries and safety when their own boundaries are being violated?” This dilemma can be witnessed in children’s behaviors as they challenge limits and boundaries that parents set for them in their need to gain some control. As children get a bit older, they may begin to develop that sense of being *different* from other children and ➤

they may think that somehow it is their fault that they have a chronic disorder.

As children become teens, they are better equipped to understand their PIDD and the treatment for it. On the other hand, it is very easy for them to feel left out of their peer groups, and they can easily feel lonely and become reclusive.

As parents of children living with a PIDD, we have the ability to be proactive with our young children's emotional development from the beginning. When we realize that our children have a PIDD, we need to take every opportunity to empower and encourage them to accept, embrace and live with it in a positive manner. We can use their disease as a tool to help them become emotionally strong and resilient.

### Open, Honest Communication

Our children look to us for reassurance and guidance about their disease, and they are vulnerable to our own reactions and feelings as we struggle with their diagnosis. Our behaviors and actions dictate how they react to their disease.

According to Dr. Valesano, our children are sensitive not only to verbal communication, but also to nonverbal. She states that "nonverbal communication can often enable a stressful environment because it leaves our child to interpret our nonverbal communication in their own way." She encourages parents to verbalize, in a healthy way and at an age-appropriate level, our own emotions not only about the disease, but about every situation that may be stressful for our children. By modeling emotions in a non-aggressive manner, we are helping our children to respond calmly to stressful situations. Children who learn positive coping strategies through a supportive, communicative environment become more resilient.

Still, it is very important to acknowledge our children's feelings and let them know that it is OK to feel afraid, lonely or angry. Validate their emotions and allow them to express them, and, at the same time, know when it is time to seek help.

Dr. Valesano points out the following as warning signs that indicate when it is appropriate to seek professional help:

- Drastic changes in your child's behavior—be aware of what is normal for your child and know that "normal" is different for every child
- Significant regression in terms of age-appropriate behavior



*On IVIG day, Molly and Maggie Cerda and Christopher Varkarotas enjoy crafts.*

- A non-aggressive child who is becoming increasingly aggressive
- A child who is showing signs of under-attachment, over-attachment or isolation behavior
- Drastic changes in sleep patterns, attention span and routine stress response
- A change in motivation
- A child who easily cries
- Increased nightmares
- Increased fearfulness of others

### Routine Mixed With Options Lends a Sense of Control

Children thrive in environments where there is a routine and there are clear boundaries. Routine helps our children feel safe and secure and allows children to cope with the occasional disruption in their lives. Concurrently, offering children choices is important, not only with respect to their disease and treatment, but in every facet of their development and interactions. We are careful to be firm with our own children in situations in which they have no control, but we give them choices over the flexible aspects of their lives and treatment.

Children facing a chronic medical condition need the chance to make choices and be given control of the parts of their lives where they can safely exert it. By utilizing this strategy with respect to children's medical care, their sense of lack of control may easily be replaced with a feeling that they are empowered to play an active role in their care, making it less stressful and frightening.

## Focus on the Positive

There are many interactions that we can include in our child's normal routine that can play an integral role in moving the focus from their PIDD to positive experiences and interactions. Here is a list of a few that have proven useful to my family.

- Make a list of 10 things that your child enjoys. Pick a couple of things from that list and set time and money aside. Do not ever be afraid to ask for help. Our daughter Molly showed stress in night terrors, and we knew she loved horses, so we decided to give her something positive to dream about. We went on a mission to find an instructor with a lot of patience and a horse. By the time Molly was 4 years old, she was showing horses at the local horse shows, riding once or twice a week, and her night terrors stopped. Suddenly, the focus was no longer on how sick she was, but, rather, on how strong and healthy she was because she was able to ride a horse.
- To cope better with their day of IVIG, we taught the children that it was a time to look forward to. We changed the focus from the stressful events and put it on the positive aspects. Now, they look forward to their IVIG day as a time to go play with their friends, do arts and crafts, and eat a lot of junk food. We get the kids up out of their treatment chairs and get them active. Rather than being in fear of the IVIG day, they look forward to it.
- Encourage your children to be problem solvers. Be careful not to jump up and help every time they face a seemingly insurmountable challenge. Instead, help them by telling them how smart they are and help them think things through to resolution—and be patient. As adults, it is difficult to sit back and watch our child struggle, and time often seems to stand still, but avoid rushing them. Allow them the opportunity to succeed. Taking this stand will promote independence and a sense of control and achievement in your child that will carry over into other aspects of their lives.
- Be proactive. Don't wait until something becomes a problem before beginning to look for ways to prevent it or at least diminish its negative impact. Recognize that your child will have educational and emotional

challenges. Realize that your family may likely face financial challenges. Plan for these things. Explore and prepare for ways to deal with them. And, again, don't be afraid to ask for help. Find a support group of other families facing similar disorders.

- Teach your children the importance of helping others. Teaching them compassion at a young age, through service to others, can go a long way toward building healthy self-esteem. As a parent, set an example for your child by supporting another family or cause. Again, this can play an integral role in changing the focus away from your children's disease and on to something positive and rewarding.
- It is never too early to teach your children positive habits that promote health. Teach them the importance of nutrition. Encourage them to be physically fit by involving them in sports. It is no secret that a healthy lifestyle plays an active role in immune system function and supports a strong emotional base. Again, be a role model and involve the whole family.
- Don't forget other siblings. It is all too easy for them to feel left out. Realize that they are also susceptible to the stress that a family dealing with a PIDD faces. Just as you watch for stress warning signs in your PIDD child, keep an eye on your other family members for the same signs.
- Finally, teach your children the importance of not comparing themselves to others. When we hear from our child that she wishes she were normal, we remind her that no one is normal. "Normal" means something different to everyone, and our experience is what is normal for us. Focus on the positive things and find humor in everything.

Along those lines: At some point in our lives, most of us receive the veritable "icing on the cake." Ours was a day in early spring when we were sitting in the veterinarian's office with our 2-year-old German shepherd. He was suffering from an unexplained loss of hair from his face. After a series of tests, the veterinarian walked into the room. "Mrs. Cerda," the vet said, "your dog has an immune disorder." In between the fits of laughter that followed, we realized our cake was iced! 🍰

# The Dating Game

By Ever Fecske

**A** one-night stand for even the healthiest person isn't a good idea, but for those of us with immune deficiencies, it is out of the question. We need to *date!*

According to Kim Geringer, LCSW, "For people with an illness, it is important to establish a courtship. These days, dating is almost nonexistent, everything moves so fast. It's best to create a relationship with the ability to share and be honest with one another."

Let's face it. Dating is tricky with just the usual complications, but immune deficiencies give dating a whole other dimension. Getting to know someone goes far deeper when there is a health issue involved. And therein lies the problem: When do you break the news?



You've met someone! He's attractive, smart and funny, at least from what you can tell after a brief encounter at the coffeehouse around the corner. You exchanged numbers and he just called to make a date. "Friday night at 8 o'clock," you will meet formally for the first time!

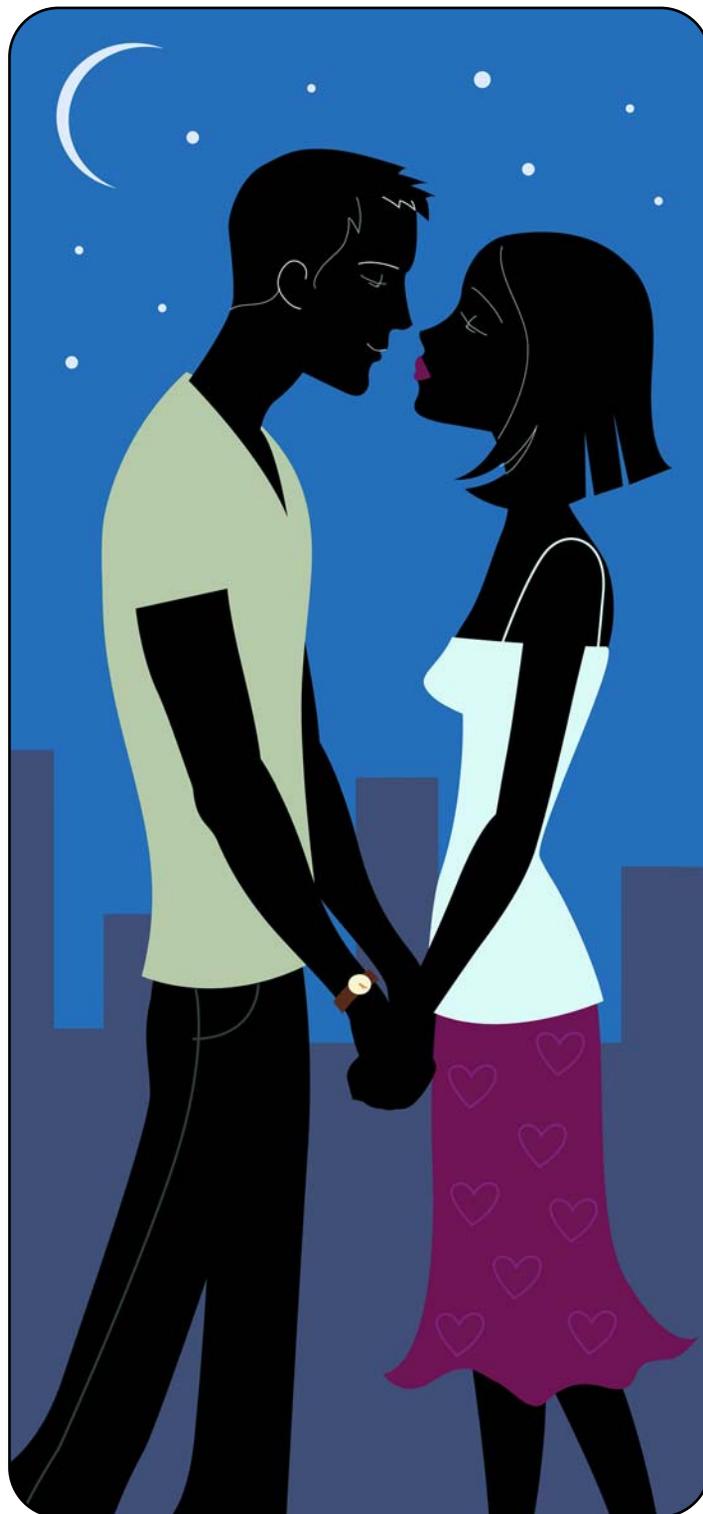
But what is dating like with an immune deficiency? Do you have to take extra precautions? What if you don't feel well on that day?

My first suggestion is not to think like that! Chances are it's just nerves. My next suggestion is to tough it out. Once you are out with him and having fun, you will forget all about how you feel. Besides, is there ever a time you feel completely healthy?

Of course, if you really don't feel well, it's all right to cancel, but suggest another day to get together, so he knows you are interested.

So, tonight is the night. It's about 7 p.m., and you have almost completed the perfect first date outfit. Every hair is in place, and you just slipped on the shoes you picked up earlier that day that were half the rent, with heels far too high to be comfortable, but so worth it.

Your self-confidence is kicking in at this point. You look great! Not like a sick person, but like a person with many attributes, whom people want to know. That's the understanding that we have to reach within ourselves. We all have so many different things to offer. And let me tell you, if a pair of designer shoes gives you a little push into self-confidence, by all means, charge it!



So, here you are at dinner, and you are offered some wine. Do you drink? I mean, sure a drink here and there is fine, but what antibiotics are you taking? It's OK to turn down an alcoholic beverage because of medication; don't think you are giving yourself away. It may not be the right time to share your "complication." Besides, you don't even know if you like this person yet. Cuteness can't be the only factor!

You are having a great time, and the chicken Marsala is the best you ever had. You've learned a lot about each other. His favorite book is "Catcher in the Rye." He works in marketing, but his dream has always been to become a toy designer (he took the more practical approach). Sometimes he likes to put ranch dressing on his pizza, and he has been in two serious relationships.

Things are going well! He doesn't seem to have scales, but then again you haven't seen him without clothes... yet. Ha-ha. And, to top it all off, he ordered chocolate cake for dessert (a man after my own heart)!

After dinner, he suggests going to a club. You agree, but once you get there, you realize it's a crowded, smoke-filled dance club. Everyone is drinking, and, although it looks like fun, you don't know if you are exactly up for dancing the night away.

This should raise a question in your mind, not because going to clubs isn't fun, but about the kind of lifestyle this man leads.

When you are diagnosed with an immune deficiency, you are pushed into becoming aware of your body and its limits. The last thing you need is to get into a relationship with a person whose behavior is detrimental to your well-being. It makes sense to pick a partner based on your illness. It's for your own benefit.

This poses another issue. Some experts recommend dating a person who has the same diagnosis as you. OK, I know what you are thinking... drama! But when you think about it, this partner could really sympathize and understand what you are going through. Sure, there would be twice as many prescription bottles, twice as many doctor visits and twice as many sick days, but who knows—maybe it would work.

When I asked immunologist Bruce Goldberg, MD, PhD, about dating someone with an immune deficiency, he said, "It depends. Some immune deficiency diseases are genetically transmitted, and, in some cases, if both parents are affected, there is a very high risk of the child being affected as well."

I guess it's a personal choice—you might want to check with your own doctor to learn more.

So, now he's walking you to your door. Although it feels a little cliché, you know that this is the moment. The two of you had the best time, but do you kiss him?

Suddenly you hear a sniffle. A sniffle! Oh no, does he have a cold? You hadn't seen the slightest sign of a cold all night. Not a cough, not a sneeze, not even a little wipe of the nose. Maybe it's just allergies? Oh gosh, you hope it's just allergies.

Now the idea of not kissing him seems intolerable. What would you say to him? "Is your nose running? Oh well, maybe we can save the kiss for another night." That's no good!

Do you just go for it anyway, and leave it up to chance that you may be a running, dripping mess the next day? No!

Or, do you just play hard to get? A little kiss on the cheek, and run like hell!

It's a tough call.

Regardless of what you choose to do on your front porch, it is your decision, so be proud of it. It's so important to feel good about yourself and your choices at the end of the day. Sure, there are times you wish you had done something differently, but these are the lessons you learn.

After a relatively successful date like this one, you should begin to ponder how you will tell the object of your growing affection that you indeed are not completely perfect. I know it may be hard for him to believe, but the goal is to open up and share. It is only when he truly understands you, can he truly love you. And isn't that the whole point?

When you do tell him, be patient, but be detail oriented. Tell him some of your medical history, and what you deal with today. Be prepared to answer questions about your diagnosis, symptoms, complications and treatment. Let him know that this is a part of you, but not even close to all of you.

Here's an idea: When you are comfortable enough, and after opening up about your illness, make a date during an infusion or whatever treatment you receive. Make a picnic of it, pack some games, and really let this person in on something very personal—something that saves your life. ■

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*So now it's your turn. Send me your stories, questions and comments. I am sure there are plenty of you dying to share. Email me at [editor@igliving.com](mailto:editor@igliving.com).*

# Give a Little Control

Recently, my 5-year-old told me he needed to “go IVIG.” I pressed him on the issue, wondering if he actually needed an intravenous infusion of immune globulin or if this was a ploy to see girlfriend-nurse extraordinaire, Jennifer.

“I just think I need IG,” he replied after the 10th time of being asked.

“Why do you need IG?” I pressed, hoping he’ll tell me why he wanted to head over for a treatment a week early.

“Mom” he replied, slightly annoyed with me, “I get IG because I don’t have enough B cells. You know, the ones that help fight bacteria,” he finished with a slight sigh, as if to indicate he was horribly tired of explaining this to me.

I giggled to myself and remembered back two years before, when he cried every time we hit the elevator that would lead us to the best nurse in the entire world, despite her seeming to hold the world’s largest needle.

Mine are not the only children who have experienced anxiety surrounding their medical treatment, so here are a few secrets we’ve learned that might help your child with the emotional impacts of IVIG.

## Allow Your Child Some Control

Even the youngest of children can feel out of control when they are constantly being poked and prodded. When possible, allow them choices. While at the treatment, if there is a choice between a liquid or tablet pre-med, and the effects are the same, consider asking your child to choose. Even such small choices as picking their own snacks can be affirming in a situation that is so out of their control.

At the same time I’ve learned not to give the kids a choice when there really isn’t one. If it’s time for their needle stick, I never ask, “Do you want to get your needle now?” When there is no choice involved, I don’t want to be faced with a resounding “No!” Instead, I might present it as, “It’s time for your needle stick. Do you want to do it on my lap in the chair or on the bed?” I’m still giving them a choice, yet not allowing them the option of backing out or refusing treatment.

## Make Sure Your Child Understands the Treatment

Today, we as healthcare consumers, have a much better



understanding of what is happening to our bodies and our children’s than in the not too distant past. It is possible for kids to also understand their treatment in age-appropriate terms. Often, not telling a child what is going on leads to their filling in the blanks with active imaginations: “I got sick, because I was mean” is not a healthy assumption for a child to bear.

The Riley family has one son, Ian, on IVIG, and has made it a point to explain to Ian his disease and his treatments. “Before Ian was diagnosed, and when he was really sick and in the hospital, he realized something was wrong and was scared there would be no help for him,” Ian’s mom, Valerie, explained. “So, we are very open and free with Ian, in talking about his illness and his treatments. We also encourage our doctors to talk directly to Ian. He’s 10 now, and we feel it’s important, because eventually he’ll be responsible for his own care.”

If you’re unsure how to talk to your child, consult your doctor, a psychologist, social worker, Child Life specialist

# and Gain Some Understanding

By Dayna Fladhammer



or even other parents dealing with chronic medical issues. They are there to help.

## Allow Feelings and Give Words

IG therapies have the potential to evoke emotions, no matter what the age of the patient. I've learned that allowing a child to feel and express those feelings, without dismissing them as unimportant, will be very empowering. My daughter Katie used to cry out, "This is scary!" as the needle was being inserted. I learned not to tell her it's not scary. I want her to learn to trust her judgment and feelings, and get past them when necessary. At a recent IVIG treatment, Katie invoked her right to independence, and refused to sit on my lap or even

have me sit near her while she got her infusion. "I'm brave now, Mom," she said. "It's scary, but I'm brave."

For our youngest children, giving them the words to help identify their emotions has been really helpful: "Are you scared?" teaches them to express what they're feeling and validates it. For older children, it might be best to ask them an open-ended question, and truly wait for them to answer. "How does that make you feel?" gives them the freedom to express more than one emotion.

## Offer Distractions

Distractions may not be good for the classroom, but can work beautifully in the infusion room. Our youngest, Thomas, now 2 1/2 years old, started his infusions at 11 months. It was around that time he also discovered his favorite character, Buzz Lightyear, from "Toy Story." To the shock of all in the room, after about 6 months into his infusions, Thomas stopped crying when getting his needle stick—as long as Buzz was on the TV. We've

since discovered this technique also works for our oldest son. Being able to mentally remove themselves, to "distract away" as we like to call it, is an effective coping skill for a stressful situation.

I hope as my kids get older that they'll still use this to meditate away from their needle sticks. Older children can benefit from visualization techniques, and there are many books available about meditation for children, complete with scenarios to read to them. Meditation can take a while for children to learn and fully enjoy the benefits, so it may be worth trying this at home first.

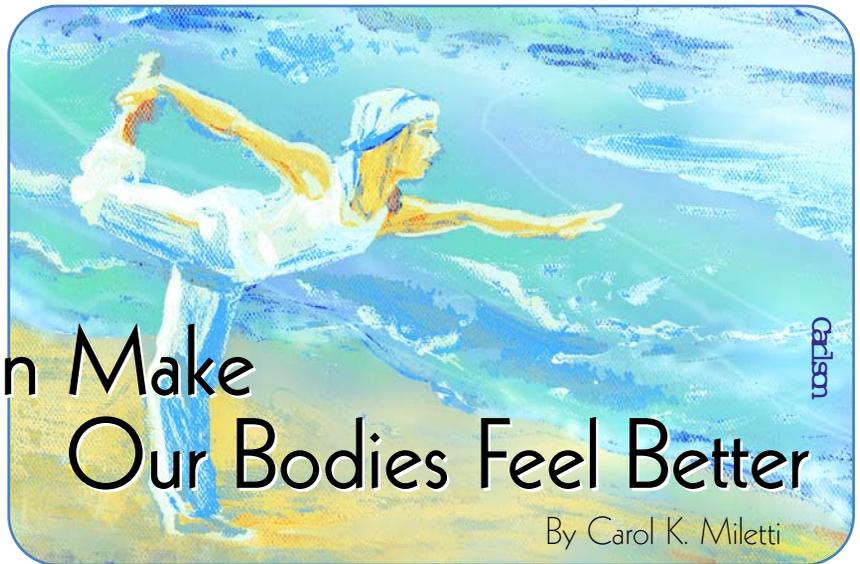
Parker is an adorable little boy with a very complicated medical history, including cancer and CVID. Early in Parker's medical treatment, at the suggestion of his Child Life specialist, his mom used photos to show him the objects that would be used in his procedures, to better prepare him. Parker has now picked up this technique and uses it to cope. He uses his camera to take pictures of every object he sees while going through medical procedures. He is able to view his treatments through the lens of a camera, slightly removing himself from the emotions of the events.

"It's awesome for Parker to be able to view his treatments through the camera. Maybe he'll be a famous filmmaker someday," his mom said.

## It's a Coping Evolution

Giving our kids the coping skills to deal with their treatments has not always been easy for my husband and me, perhaps because we are so emotionally involved in the situation ourselves. However, we feel lucky to have a wonderful support system to help. Everyone, from our nurses, the kids' teachers, and aunts and uncles, has come up with suggestions to help deal with the emotional impact of IVIG on the kids. So, ask for suggestions, and be willing to try new things!

Ultimately, there is no one right answer to helping your child learn how to cope. In many ways, it is an evolving process. Every child is different—and changes with age. Once you realize that the goal is not to take away the pain, but to help them deal with the fear, you will continually find new ways to do it. ■



# Our Minds Can Make Our Bodies Feel Better

By Carol K. Miletta

Yes, it's true, and let me count the ways. My mom preached—and I mean preached—the power of optimism and positive thinking to my sister and me. I guess quite a bit of it rubbed off, because now I live it. That's not to say that I believe I can cure my primary immune deficiency disease (PIDD) by positive thinking, but I certainly can make myself feel quite a bit better or, at the very least, improve my outlook.

I've learned that healing is not the absence of disease, but the absence of the suffering that can accompany a disease.

Sickness is physically based and, according to Richard P. Johnson, PhD, in "Body Mind Spirit," "our response to it is the result of our emotionally or spiritually driven choices."

Dr. Johnson makes the distinction very clear in that "illness is defined as an unhealthy condition of the body or the mind. Sickness is defined as an unsound condition or specific disease."

When we are sick, our bodies are not operating in the manner in which they should. We have had some type of breakdown in our body, but "illness is the name given to our emotional reactions to this sickness, including the lifestyle and behavioral responses we make as a direct consequence of the imposition of the sickness on our life."

So, what can we do about this illness we have? How can we heal ourselves?

Many of us have already quietly experienced the phenomenon of self-healing without realizing it. We were diagnosed, then we experienced different phases of adjustment to our diagnosis—grief, acceptance and finally learning to do the best we can with how we are feeling one day at a time. This constitutes a healing of the mind.

How can we get better at this? First of all, we need to become conscious of doing it.

Just before that needle pierces your body, in whatever fashion you are receiving IG therapy, do you go to some "happy place" in your mind? I do. In this action, I'm using my attitude to affect my perception of potential pain. I'm

not saying that it doesn't hurt; I'm saying that I concentrate on something other than the pain.

This can be the learned behavior we need to use our minds to control our body's response to our sickness. In "Journey to Healing," Deepak Chopra tells us "health is not just the absence of disease. It's an inner joyfulness that should be ours all of the time."

I guess that's how I can stay in such a good mood, even when I feel like you know what.

Along this same line, the Mayo Clinic teaches us that if we want to live to be 100, we "really need to start with attitude. Your way of thinking not only improves your outlook on life, but also how long you actually live."

Sounds like a call to action. How can we do this?

- ◆ Exercise and play more—get silly and have fun.
- ◆ Do yoga and stretching for relaxation.
- ◆ Listen to music and hang loose.
- ◆ Try biofeedback—sometimes it's very effective.
- ◆ Make healthy food choices—pay attention to your nutrition.
- ◆ Try to meditate—many websites and library books can help you learn how to do this.
- ◆ Find activities that bring you joy.
- ◆ Let your friends know when you need them (don't try to get through alone).
- ◆ Try something completely new and different that you've never done before.
- ◆ Laugh yourself silly even if you have to force it at first, it will then become natural to you.
- ◆ Try to be more optimistic, a little more every day. Soon it will be second nature.

Test this theory of the mind and body connection for yourself, one day at a time. It really does work. ■

# Everything You Ever Wanted to Know About...

## ...Guillain-Barré Syndrome (GBS)

### Websites and Chat Rooms

1. The GBS Foundation International, [www.gbsfi.com](http://www.gbsfi.com), has 23,000 members in 160 chapters on five continents. 610-667-0131
2. The GBS Foundation Discussion Forums provide the opportunity to talk to other GBS patients and learn more about ways to manage the illness: [www.guillain-barre.com/forums/](http://www.guillain-barre.com/forums/).

### Online Pamphlets

1. A GBS Fact Sheet is found on the National Institute of Neurological Disorders and Stroke website: [www.ninds.nih.gov/disorders/gbs/detail\\_gbs.htm](http://www.ninds.nih.gov/disorders/gbs/detail_gbs.htm).
2. The Mayo Clinic has an overview of Guillain-Barré syndrome at [www.mayoclinic.com/health/guillain-barre-syndrome/DS00413](http://www.mayoclinic.com/health/guillain-barre-syndrome/DS00413).
3. The National Institute of Neurological Disorders and Stroke has an information page about CIDP: <http://www.ninds.nih.gov/disorders/cidp/cidp.htm>

### Online Peer Support Links

1. GBS & CIDP Discussion Forum—UK Bulletin Board—For Ireland and England: <http://www.gbs.org.uk/cgi-bin/ikonboard3/ikonboard.cgi>
2. GBS Support group—UK Chat room—requires registration: <http://www.jsmarcussen.com/gbs/uk/chat.htm>
3. GBS Foundation Discussion Forums [www.guillain-barre.com/forums](http://www.guillain-barre.com/forums)
4. Yahoo Support Group Discussion Board: [http://health.groups.yahoo.com/group/GBS\\_CIDP/](http://health.groups.yahoo.com/group/GBS_CIDP/)

## ...Myositis

### Websites

1. 



**THE MYOSITIS ASSOCIATION**

The mission of The Myositis Association, [www.myositis.org](http://www.myositis.org), is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases. 202-887-0088
2. 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>.
3. 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>

### Online Peer Support Links

1. Juvenile Myositis Family Support Network: [http://www.curejm.com/family\\_support/index.htm](http://www.curejm.com/family_support/index.htm)
2. Myositis Association Community Forum: [www.myositis.org](http://www.myositis.org)
3. Myositis Support Group UK: <http://www.myositis.org.uk/>

4. Yahoo Myositis Support Group Discussion Board: <http://health.groups.yahoo.com/group/OurMyositis/>

## ...Peripheral Neuropathy (PN)

### Websites

1. 



The Neuropathy Association, [www.neuropathy.org](http://www.neuropathy.org), is devoted exclusively to all types of neuropathy, which affects upwards of 20 million Americans. The Association's mission is to increase public awareness of the nature and extent of PN, facilitate information exchanges about the disease, advocate the need for early intervention and support research into the causes and treatment of neuropathies. 212-692-0662
2. The National Institute of Neurological Disorders and Stroke has diverse topics about PN on its website at [www.ninds.nih.gov/disorders/stroke/](http://www.ninds.nih.gov/disorders/stroke/).
3. To learn about PN, how it is classified, the symptoms, causes and treatments, see the Peripheral Neuropathy Fact Sheet available at <http://www.ninds.nih.gov/disorders/peripheralneuropathy/peripheralneuropathy.htm>.

### Support Groups

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

### Online Peer Support Links

1. Calgary Neuropathy Support Group: <http://www.calgarypnrs.org/index.htm>
2. MSN Support Group: Discussion Board: <http://groups.msn.com/PNPARTNERS>
3. The Neuropathy Association Bulletin Board: [www.neuropathy.org](http://www.neuropathy.org)
4. Yahoo Neuropathy Support Group Discussion Board: <http://health.groups.yahoo.com/group/neuropathy/>
5. Yahoo Support Group—Australia Discussion Board: <http://au.groups.yahoo.com/group/LifeWithPN/>

## ...Primary Immune Deficiency Disease (PID)

### Websites and Chat Rooms

1. 



**IMMUNE DEFICIENCY FOUNDATION**

The Immune Deficiency Foundation (IDF), [www.primaryimmune.org](http://www.primaryimmune.org), is dedicated to improving the diagnosis and treatment of PID through research and education. 800-296-4433
2. 



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

# Everything You Ever Wanted to Know continued...

3. The National Institute of Child Health and Human Development (NICHD), [www.nichd.nih.gov/](http://www.nichd.nih.gov/), is part of the National Institutes of Health. Go to the "Health Information and Media" tab on the website and do a search under "primary immunodeficiency."
4. The American Academy of Allergy, Asthma & Immunology, [www.aaaai.org](http://www.aaaai.org), has a helpful Q&A section on its website, with resources and tips for those with various immune deficiencies.
5. Baxter's website, [www.immunedisease.com](http://www.immunedisease.com), offers in-depth information on immunology, PIDD and treatment with intravenous immune globulin.
6. The Michigan Immunodeficiency Foundation, [www.midf.org](http://www.midf.org), seeks to improve the quality of life for Michigan residents affected by PIDD.
7. The International Patient Organization for Primary Immunodeficiencies (IPOPI), [www.ipopi.org](http://www.ipopi.org), promotes the worldwide improvement in the care and treatment of PIDD patients.
8. To connect to a PIDD message board, go to [www.jmfworld.com](http://www.jmfworld.com).
9. To chat with peers on IDF's Forum, go to [www.primaryimmune.org](http://www.primaryimmune.org).
10. Chat with parents of children affected by primary immune deficiency at <http://health.groups.yahoo.com/group/PedPID/>.
11. Chat with peers with PIDD at <http://health.groups.yahoo.com/group/PIDsupport/>.
12. A group of family and friends of patients with primary immune deficiencies maintains a nonprofit network in the New England area: <http://www.nepin.org/>.

## Online Pamphlets

1. Go to the National Institute of Allergy and Infectious Diseases site at [www.niaid.nih.gov/](http://www.niaid.nih.gov/) and search for "primary immune deficiency."
2. "Understanding the Immune System: How It Works," by the U.S. Department of Health and Human Services, is found at [www.niaid.nih.gov/publications/immune/the\\_immune\\_system.pdf](http://www.niaid.nih.gov/publications/immune/the_immune_system.pdf).
3. "NIAID Initiative Addresses Primary Immune Deficiency Diseases by National Institute of Allergy and Infectious Diseases" is located at [www3.niaid.nih.gov/news/newsreleases/2003/pirc.htm](http://www3.niaid.nih.gov/news/newsreleases/2003/pirc.htm).

## Online Peer Support Links

1. Chat with parents of children affected by PIDD  
<http://health.groups.yahoo.com/group/PedPID/>
2. Chat with peers with PIDD  
<http://health.groups.yahoo.com/group/PIDsupport/>
3. Immune Deficiency Foundation Forum  
[www.primaryimmune.org/forums/forum\\_intro.htm](http://www.primaryimmune.org/forums/forum_intro.htm)
4. Jeffery Modell Foundation Message Board  
[www.jmfworld.com](http://www.jmfworld.com)

## ...General Resources

### Product Information

1. To learn more about Vivaglobin—the subcutaneous immune globulin (SCIG) go to: [www.vivaglobin.com](http://www.vivaglobin.com).
2. For more information about the new 10% IVIG solution Gammagard Liquid, go to [www.gammagardliquid.com](http://www.gammagardliquid.com).
3. Learn about IVIG treatment with Gamunex at [www.gamunex.com](http://www.gamunex.com).

## Other Organizations

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



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

4. WebMD, [www.webmd.com](http://www.webmd.com), is a handy medical reference that helps consumers take an active role in managing their health by providing objective healthcare and lifestyle information.
5. For a pediatrician's guide to your child's health and safety, visit [www.keepkidshealthy.com](http://www.keepkidshealthy.com).
6. The National Organization for Rare Diseases, at [www.rarediseases.org](http://www.rarediseases.org), provides links to numerous other organizations that have disease-specific support groups and virtual communities for patients and caregivers.
7. American Autoimmune Related Diseases Association (AARDA) [www.aarda.org](http://www.aarda.org) brings national focus to autoimmunity through research, education and patient services. 800-598-4668
8. Band-Aides and Blackboards: <http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>, started by a nurse working on her dissertation, focuses on children with chronic illness in the classroom.

## Education and Disability Resources

1. Continuation of Health Coverage—Consolidated Omnibus Budget Reconciliation Act (COBRA)  
<http://www.dol.gov/dol/topic/health-plans/cobra.htm>
2. Social Security: [www.ssa.gov/disability/](http://www.ssa.gov/disability/)
3. California State Disability Insurance (SDI): [www.edd.ca.gov](http://www.edd.ca.gov) (Please note that each state has a different disability program.)
4. IDEA 2004 Resources  
<http://www.ed.gov/policy/speced/guid/idea/idea2004.html>  
News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities.
5. The National Disabilities Rights Network: [www.ndrn.org](http://www.ndrn.org). This website offers a search tool to find resources in your state to assist with school rights and advocacy.
6. U.S. Department of Education: [www.ed.gov](http://www.ed.gov) offers a Parents section that has a subsection titled "My Child's Special Needs."

## Everything You Ever Wanted to Know continued...

7. U.S. Department of Health and Human Services, Office of Civil Rights: <http://www.hhs.gov/ocr/504.html> spells out your rights under Section 504 of the Rehabilitation Act.
8. Wrightslaw: <http://www.wrightslaw.com/>. Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities.

### Books and Articles

1. "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](http://Amazon.com)
2. "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 <http://www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15>
3. "Living With Myositis," edited by Jenny Fenton, is an accessible, realistic and sympathetic guide to facts, feelings and future hopes.
4. "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.
5. "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.

### IG Manufacturer Websites

Baxter: [www.baxter.com](http://www.baxter.com)  
 Grifols: [www.grifolsusa.com](http://www.grifolsusa.com)  
 Octapharma: [www.octapharma.com](http://www.octapharma.com)  
 Talecris: [www.talecris.com](http://www.talecris.com)  
 ZLB Behring: [www.zlbbehring.com](http://www.zlbbehring.com)

### Pump and Needle Websites

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

### ...Nutrition

For help contacting medical professionals who understand the links between nutrition and medicine, consult one of the following links.

1. American Board of Physician Nutrition Specialists: <http://www.ipnec.org>
2. American Dietetic Association: <http://www.eatright.org>
3. American Gastroenterological Association: <http://www.gastro.org>
4. North American Society for Pediatric Gastroenterology Hepatology and Nutrition: <http://www.naspgn.org/>

### ...Resources Just for Kids

1. "Germs Make Me Sick," by Melvin Berger, MD, explains with colorful illustrations how your body fights germs.
2. "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.

3. "This Is 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 <http://www.immunedisease.com/US/>.
4. "Our Immune System," enables children who are immune deficient and their families to explore together the immune system. Available from the Immune Deficiency Foundation at [www.primaryimmune.org](http://www.primaryimmune.org).

### ...Scholarships

#### Immune Deficiency Foundation Scholarship

This award is available to individuals diagnosed with a primary immune deficiency disease. <http://www.primaryimmune.org/services/scholarship.htm> 800-296-4433

#### The ELA Scholarship

This scholarship provides financial assistance to women with physical disabilities who are enrolled in a graduate program in a college or university in the United States. <http://www.ela.org/scholarships/scholarships.html> 626-398-8840

#### Bank of America Abilities Scholarship Program

These scholarships are awarded to students with disabilities who have a career interest in finance, business or computer systems. [http://www.scholarshipprograms.org/bada/bada\\_2005\\_ins.htm](http://www.scholarshipprograms.org/bada/bada_2005_ins.htm) 864-268-3363

#### Foundation for Exceptional Children

The Stanley E. Jackson Award for Gifted/Talented Students is awarded to students with a disability. <http://yesican.cec.sped.org/scholarship/index.html> 800-224-6830

#### Joyce Walsh Junior Scholarship for the Handicapped

This scholarship is awarded to disabled instrumentalists or vocalist members of National Federation of Music Clubs. <http://www.mfmc.net/scholarships.html> 317-638-4003

#### Panasonic Young Soloists Award

This award is given to vocalists or instrumentalists under age 25 who are permanently disabled and interested in studying music. [http://www.panasonic.com/corp\\_cont/celebrating.asp](http://www.panasonic.com/corp_cont/celebrating.asp) 202-628-2800

#### Horatio Alger Association Scholarship Program

The Horatio Alger Association provides financial assistance to students who have exhibited integrity and perseverance in overcoming personal adversity and who aspire to pursue higher education. <http://www.horatioalger.com> 703-684-9444

#### Central Intelligence Agency: Undergraduate Program

The CIA Summer Internship Program is open to undergraduate students, particularly minorities and people with disabilities, who have completed one or two years of college-level academic study. <http://www.cia.gov/employment/student.html> 800-368-3886

#### Through the Looking Glass

This nonprofit offers college scholarships for individuals with parents with disabilities. [www.lookingglass.org](http://www.lookingglass.org) 800-644-2666

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

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