K-12 Students
Programs for the Health-Impaired

Helping Children Cope with Ill Parents

The Role of an IG Infusion Nurse

A Letter to Patients with Chronic Illness

Parenting: What to Do While Infusing
GAMUNEX®-C
Immune Globulin Injection (Human) 10% Caprylate/Chromatography Purified

HIGHLIGHTS OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use GAMUNEX®-C safely and effectively. See full prescribing information for GAMUNEX-C.

GAMUNEX-C, [Immune Globulin Injection (Human) 10% Caprylate/Chromatography Purified]
Initial U.S. Approval: 2003

WARNING: ACUTE RENAL DYSFUNCTION and FAILURE
See full prescribing information for complete boxed warning.

- Renal dysfunction, acute renal failure, osmotic nephrosis, and death may occur with immune globulin intravenous (IGIV) products in predisposed patients.
- Renal dysfunction and acute renal failure occur more commonly in patients receiving IGIV products containing sucrose. GAMUNEX-C does not contain sucrose.
- For patients at risk of renal dysfunction or failure, administer GAMUNEX-C at the minimum concentration available and the minimum infusion rate practicable.

INDICATIONS AND USAGE
GAMUNEX-C is an immune globulin injection (human) 10% liquid indicated for treatment of:
- Primary Humoral Immunodeficiency (PI)
- Idiopathic Thrombocytopenic Purpura (ITP)
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

CONTRAINDICATIONS
- Anaphylactic or severe systemic reactions to human immunoglobulin
- IgA deficient patients with antibodies against IgA and a history of hypersensitivity

WARNINGS AND PRECAUTIONS
- IgA deficient patients with antibodies against IgA are at greater risk of developing severe hypersensitivity and anaphylactic reactions. Have epinephrine available immediately to treat any acute severe hypersensitivity reactions.
- Monitor renal function, including blood urea nitrogen, serum creatinine, and urine output in patients at risk of developing acute renal failure.
- GAMUNEX-C is not approved for subcutaneous use in ITP patients. Due to a potential risk of hematoma formation, do not administer GAMUNEX-C subcutaneously in patients with ITP.
- Hyperproteinemina, with resultant changes in serum viscosity and electrolyte imbalances may occur in patients receiving IGIV therapy.

ADVERSE REACTIONS
- PI – The most common adverse reactions (≥5%) with intravenous use of GAMUNEX-C were headache, cough, injection site reaction, nausea, pharyngitis and urticaria. The most common adverse reactions (≥5%) with subcutaneous use of GAMUNEX-C were infusion site reactions, headache, fatigue, arthralgia and pyrexia.
- ITP – The most common adverse reactions during clinical trials (reported in ≥5% of subjects) were headache, vomiting, fever, nausea, back pain and rash.
- CIDP – The most common adverse reactions during clinical trials (reported in ≥5% of subjects) were headache, fever, chills, hypertension, rash, nausea and asthenia.

DRUG INTERACTIONS
- The passive transfer of antibodies may transiently interfere with the response to live viral vaccines, such as measles, mumps and rubella. Passive transfer of antibodies may confound serologic testing.

USE IN SPECIFIC POPULATIONS
- Pregnancy: no human or animal data. Use only if clearly needed.
- Geriatric: In patients over 65 years of age do not exceed the recommended dose, and infuse GAMUNEX-C at the minimum infusion rate practicable.

Thrombotic events have occurred in patients receiving IGIV therapy. Monitor patients with known risk factors for thrombotic events; consider baseline assessment of blood viscosity for those at risk of hyperviscosity.

Aseptic Meningitis Syndrome (AMS) has been reported with GAMUNEX-C and other IGIV treatments, especially with high doses or rapid infusion.

Hemolytic anemia can develop subsequent to IGIV therapy due to enhanced RBC sequestration. Monitor patients for hemolysis and hemolytic anemia.

Monitor patients for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI]).

Volume overload

GAMUNEX-C is made from human plasma and may contain infectious agents, e.g., viruses and, theoretically, the Creutzfeldt-Jakob disease agent.

Passive transfer of antibodies may confound serologic testing.

To report SUSPECTED ADVERSE REACTIONS, contact Talecris Biotherapeutics, Inc. at 1-800-520-2807 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.
Important Safety Information for GAMUNEX-C

Gamunex-C, Immune Globulin Injection (Human), 10% Caprylate/Chromatography Purified, is indicated for the treatment of primary humoral immunodeficiency disease (PI), idiopathic thrombocytopenic purpura (ITP), and chronic inflammatory demyelinating polyneuropathy (CIDP).

Renal dysfunction, acute renal failure, osmotic nephrosis, and death may occur with immune globulin intravenous (IGIV) products in predisposed patients. Patients predisposed to renal dysfunction include those with any degree of pre-existing renal insufficiency, diabetes mellitus, age greater than 65, volume depletion, sepsis, paraproteinemia, or patients receiving known nephrotoxic drugs. Renal dysfunction and acute renal failure occur more commonly in patients receiving IGIV products containing sucrose. Gamunex-C does not contain sucrose. For patients at risk of renal dysfunction or failure, administer Gamunex-C at the minimum concentration available and the minimum infusion rate practicable.

Gamunex-C is contraindicated in individuals with acute severe hypersensitivity reactions to Immune Globulin (Human). It is contraindicated in IgA deficient patients with antibodies against IgA and history of hypersensitivity.

Gamunex-C is not approved for subcutaneous use in patients with ITP or CIDP. Due to the potential risk of hematoma formation, Gamunex-C should not be administered subcutaneously in patients with ITP.

Hyperproteinemia, increased serum viscosity, and hyponatremia may occur in patients receiving IGIV therapy.

Thrombotic events have been reported in association with IGIV. Patients at risk for thrombotic events may include those with a history of atherosclerosis, multiple cardiovascular risk factors, advanced age, impaired cardiac output, coagulation disorders, prolonged periods of immobilization and/or known or suspected hyperviscosity.

There have been reports of noncardiogenic pulmonary edema [Transfusion-Related Lung Injury (TRALI)], hemolytic anemia, and aseptic meningitis in patients administered with IGIV.

The high dose regimen (1g/kg x 1-2 days) is not recommended for individuals with expanded fluid volumes or where fluid volume may be a concern.

Gamunex-C is made from human plasma. Because this product is made from human plasma, it may carry a risk of transmitting infectious agents, e.g., viruses, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

After infusion of IgG, the transitory rise of the various passively transferred antibodies in the patient’s blood may yield positive serological testing results, with the potential for misleading interpretation.

In clinical studies, the most common adverse reactions with Gamunex-C were headache, fever, chills, hypertension, rash, nausea, and asthenia (in CIDP); headache, cough, injection site reaction, nausea, pharyngitis, and urticaria with intravenous use (in PI) and infusion site reactions, headache, fatigue, arthralgia and pyrexia with subcutaneous use (in PI); and headache, vomiting, fever, nausea, back pain, and rash (in ITP).

The most serious adverse reactions in clinical studies were pulmonary embolism (PE) in one subject with a history of PE (in CIDP), an exacerbation of autoimmune pure red cell aplasia in one subject (in PI), and myocarditis in one subject that occurred 50 days post-study drug infusion and was not considered drug related (in ITP).

*CIDP=Chronic inflammatory demyelinating polyneuropathy; PI=Primary immunodeficiency; ITP=Idiopathic thrombocytopenic purpura.


You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see adjacent page for brief summary of GAMUNEX-C full Prescribing Information.
About IG Living
IG Living is the only magazine dedicated to bringing comprehensive healthcare information, immune globulin information, community and reimbursement news, and resources for successful living directly to immune globulin consumers and their healthcare providers.

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Teen Talk: Preparing Ourselves for the Future
“We just have to be prepared to face any challenges that we may encounter and stand strong, knowing that those challenges are only temporary.”

Essay Contest Winner: A Father’s Pride
“Piercing her skin myself seemed the reverse of everything I had hoped to be as a parent, and I wept the first time I did it.”

IG Chronicles: Mother Love, Mother Guilt
“Somehow, it always comes down to the mother.”

A Letter to Patients with Chronic Disease
“Let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship.”

The Role of an IG Infusion Nurse
“The evolving use of IG has created new dosing guidelines and administration schedules, requiring special consideration and training for the infusion nurse and his or her patient.”

Be a Part of IG Living’s Blog and Facebook Discussions!
IG Living isn’t just a magazine; it’s an interactive community of people with interesting stories.
Our blog: www.igliving.com/blogengine
Our Facebook page: www.facebook.com/IGLivingMagazine

Connect with Other IG Living Readers through Monthly Teleconferences!
IGL’s Readers Group Teleconferences allow readers to connect with others to share their experiences living with chronic diseases. Here’s how you can participate:

• Email IG Living to be added to our email invitation list for the teleconferences.
• IG Living will send you invitations to let you know when the monthly, hosted, toll-free teleconferences will be held, as well as what topic relevant to the IG community will be discussed.
• The moderated, hour-long calls will be filled on a first-come, first-served basis and will be limited.

In addition to connecting with others, IG Living’s patient advocate can help you determine if there’s a patient organization support group in your area.

Sign up for the Teleconferences now by emailing akazemi@IGLiving.com or calling (800) 843-7477, ext. 1366.
The “Suckishness” of Being a Chronically Ill Patient

Having a chronic illness sucks. You know that all too well. But those who have never experienced the daily trials and tribulations that a chronic disease inflicts can’t possibly know how bad it is. Which is why being able to share stories of illnesses, diagnoses and what it takes to live in pain is so important. Not only is that one of the primary reasons IG Living was created, but it is why we continue to expand the number of opportunities for you to share your unique experiences. And, this issue of IG Living has many.

First, we feature the winning story from IG Living’s third annual essay contest. Benjamin Karney is the father of a little girl with common variable immune deficiency. In his essay, he describes his pain at having to “puncture my daughter’s skin for the first time” at age 5 when they made the switch from intravenous to subcutaneous immune globulin therapy, and how he wept when he did it. But Benjamin’s story goes from heart-wrenching to heartwarming when he describes the pride he feels for his daughter who with brave resolve has learned to take care of herself.

Valarie Kinney, in our IG Chronicles column, also shares her story of a parent with a sick child. She gives a tortured account in Mother Love, Mother Guilt column, also shares her story of a parent with a sick child. She gives a tortured account in Mother Love, Mother Guilt column, also shares her story of a parent with a sick child. She gives a tortured account in Mother Love, Mother Guilt. She describes the pride he feels for his daughter who with brave resolve has learned to take care of herself.

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The good news for parents is that chronically ill children so often cope with their disease better than their parents expect — especially as they get older. The teens we feature in our Teen Talk column are cases in point. In this issue, Tyler Carlsen talks about the difference between how he and other chronically ill kids feel on a typical school day compared with healthy kids — and how that difference can make going away to college unpredictable. But, as Tyler proves, while most teens don’t give much thought to this transition, Tyler has had the tough lessons that a chronic illness can teach to help him prepare for his future.

These stories and many others are testament to the power of sharing. How satisfying it is for patients and their caregivers to read stories that mirror their own. But, we turn the tables on sharing and the fact that a diagnosis didn’t end their journey of self-blame and guilt.

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**Legislation**

**Specialty Drug Tier Restrictions Law Proposed**

A new bill, called the Patient Access to Treatments Act 2013, was reintroduced into the House of Representatives in March. The bill was initially proposed in March 2012, but died in committee. According to government websites, the purpose of the Act is to “amend title XXVII of the Public Health Service Act to limit co-payment, co-insurance or other cost-sharing requirements applicable to prescription drugs in a specialty drug tier to the dollar amount (or its equivalent) of such requirements applicable to prescription drugs in a nonpreferred brand drug tier, and for other purposes.” Introduced by Reps. David McKinley (R-W.V.) and Lois Capps (D-Calif.), the Act would protect patients who suffer from chronic conditions from being forced to pay unreasonably high amounts for medications placed in a specialty tier by health plans and insurers. It also would reduce high out-of-pocket expenses and would limit some cost-sharing requirements, effectively making high-cost biologics more accessible to patients.

While the Affordable Care Act will require insurers to restrict out-of-pocket costs starting in 2014, “the law allows prescription drug co-pays to spiral up to $6,000 out-of-pocket for an individual and $12,000 for a family,” said McKinley. “Too many patients can’t afford the high cost-sharing requirements imposed on many specialty drugs and are forced to not take their medication as prescribed, or worse, not take it at all,” added Capps. The bill is backed and supported by the Coalition for Accessible Treatments, a 20-member organization including the American College of Rheumatology, the Arthritis Foundation, The Leukemia & Lymphoma Society, the Colon Cancer Alliance, Crohn’s and Colitis Foundation of America, Hemophilia Federation of America and the National Multiple Sclerosis Society.

**Research**

**New 20% SCIG Product Demonstrates Efficacy**

A recent study of CSL Behring’s new IgPro20, which is currently under review by the U.S. Food and Drug Administration (FDA) for use as a weekly immune globulin replacement therapy in patients with primary immunodeficiency (PIDD), has shown that it effectively protects patients with PIDDs against infection and sustains their serum IgG levels without causing unexpected rates of adverse events.

The results were derived from a study of 49 patients (5 years to 72 years of age) previously treated with intravenous immune globulin who received weekly subcutaneous infusions of L-proline stabilized IgPro20. The study lasted 15 months and included a 12-week wash-in/-out period and a 12-month efficacy period, with the annual rate of predefined serious bacterial infections (SBIs) per patient as the primary endpoint. During the study, no SBIs were reported, and 96 non-serious infections were identified. In addition, 99 percent of adverse events (AEs) were mild or moderate in intensity, with the most common being injection site reactions. No serious AEs were reported. If approved by the FDA, IgPro20 will be a new subcutaneous immune globulin treatment option for patients.
Education

“My Autoimmune Story” Video Series Launched by AARDA

The American Autoimmune Related Diseases Association (AARDA) has launched its new “My Autoimmune Story” video series on its YouTube channel, with the first story contributed by AARDA’s long-time spokesperson Emmy-nominated actress Kellie Martin. The series was part of AARDA’s 2013 March is National Autoimmune Awareness Month activities. Its goal is to give 50 million Americans afflicted with autoimmune disease, as well as their families and friends, a national voice and platform to share their personal story. AARDA hopes that collecting and featuring these short videos will help educate people about the widespread impact of autoimmune diseases, the difficulties of getting a diagnosis, the family or genetic component, and the financial and emotional burden of living with these chronic illnesses.

“Preparing and sharing our personal autoimmune stories will help build critical mass and focus national attention on a major disease category in this country that is often overlooked,” said Martin, who has served as AARDA’s spokesperson since 1999. “Imagine the impact we would have if just 1 percent of the 50 million Americans suffering from autoimmune disease uploaded a video. That’s 500,000 stories.”

Disease Awareness

Autoimmune Awareness Walk Dates Scheduled

The “Link for a Cure” autoimmune walks, hosted by the American Autoimmune Related Diseases Association (AARDA), were held this year in the Washington, D.C., metro area on June 22, and in Georgia on July 20. They will be held in the tri-state New York region on Aug. 25, in Kentucky on Sept. 21, in Missouri on Oct. 6, and in Michigan on Oct. 12. The main goal of the walks is to urge patients, their families and friends to join together in an effort to bring awareness to the more than 100 autoimmune diseases that plague Americans. This year's walks will feature a silent auction with donations from local retailers. The 50 million Americans who suffer from autoimmune disease who are unable to attend the planned walks also have the opportunity to get involved and raise funds to find a cure through virtual walks, which can occur any place and at any time. Participants in the planned walks or virtual walks can earn great prizes for their efforts.

Last year, “Army Wives” star and AARDA national spokesperson, Kellie Martin, attended the Washington, D.C., walk, and “American Idol” alum Leslie Hunt performed at the Midwest walk. “Autoimmune diseases run in families, and they have a common thread that links them all together,” says Martin. “This is an incredible opportunity for families touched by these diseases to ‘link together’ in support of autoimmune disease research and patient services.”

For more information about the walks, visit AutoimmuneWalk.org.
Octapharma USA President Flemming Nielsen has been named the Humanitarian Man of the Year by the Hemophilia Association of New Jersey (HANJ). Nielsen was honored during HANJ’s annual fundraising dinner.

Nielsen also is a member of the Management Board of Octapharma AG, the world’s largest independent human protein products manufacturer, and the parent company of Octapharma USA. He joined Octapharma AG in September 2003 at its headquarters in Lachen, Switzerland, holding several financial management positions, and then transferred to the U.S. in 2004 when Octapharma entered the American marketplace. Born and raised in Denmark, Nielsen earned a bachelor’s degree in business from the Copenhagen Business School.

“It is [a] great honor to be selected for this award,” said Nielsen. “Our partnerships with patient organizations like HANJ are very important to Octapharma USA because we are committed to providing patients with life-enhancing and [life-]saving therapies that will improve quality of life. Patient safety is always our first priority, so this is indeed a very special honor.”

Imagine caring for your child with hemophilia with no factor, refrigerator, running water, electricity, or transportation to a clinic. This is the reality for thousands of families in developing countries. For just $20 a month, you can help an impoverished child with hemophilia. Become a sponsor today!

www.saveonelife.net / contact@saveonelife.net
Caring for people with hemophilia around the world—one at a time.
Immunology 101:
Diagnosing an Antibody Deficiency: Case 4, Part 3:
How Delayed Immune System Maturation Can Mimic an Antibody Deficiency
By Terry O. Harville, MD, PhD

IN PART 1, we began the discussion of a 3-year-old boy with chronic/recurrent respiratory infections. Pertinent features of the history are: 1) He began having recurrent respiratory illnesses between 3 months and 6 months of age. 2) He was reported to have been given courses of antibiotics every four weeks to eight weeks. 3) He had been diagnosed with sinusitis and pneumonia, not merely upper-respiratory infections. However, he had not required hospitalization. Further, he had not been diagnosed with any other forms of infections.

In Part 2, we discussed that the history was worrisome for a possible diagnosis of antibody deficiency, but the physical examination was more typical of a child with allergic disease. Skin testing for allergic disease revealed the presence of numerous allergies. The white blood cell, lymphocyte and neutrophil counts were normal for age, as were the CH50 test and the serum IgG, IgA and IgM values. But, the serum IgE was elevated, as may be seen in allergic disease. Diphtheria and tetanus toxoid antibody titers were in the normal protective range.

Table. Results of the Pre-/Post-Immunization Study

<table>
<thead>
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<th>Pneumococcal Serotype</th>
<th>1</th>
<th>3</th>
<th>4</th>
<th>6B</th>
<th>7F</th>
<th>8</th>
<th>9N</th>
<th>12F</th>
<th>14</th>
<th>18C</th>
<th>19F</th>
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<td>1.75</td>
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<td>Protective? (&gt;1.3 μg/mL)</td>
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<td>Protective? (&gt;1.3 μg/mL)</td>
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<td>&gt;2x Increase</td>
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<tr>
<td>&gt;4x Increase</td>
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Titer values are in units of microgram/milliliter (μg/mL). By definition, this is a normal antibody immune response.
The one most critical testing procedure is the pre-/post-immunization comparison of antibody titers generated to pneumococcal polysaccharide vaccine. Blood was obtained at the initial visit for the pre-immunization titers, the boy was immunized with the pneumococcal vaccine, and in four weeks, post-immunization titers were obtained (see Table). To the great benefit of this boy, the functional antibody study revealed normal ability to respond to vaccination with good specific antibody production.

Treatment was begun with cetirizine, montelukast and PRN hydroxyzine, which led to dramatic improvement in symptoms by the return visit. This suggested that allergic disease likely was greatly contributing to the original symptoms. Further, we believe that the boost in his antibody responses associated with the vaccine immunization may have increased his immune response.

This is a case that may be more typical for many children with recurrent respiratory symptoms. It is common for people to believe that many of these children will outgrow the symptoms, especially around the age of puberty. But, not all children mature at the same rate, whether physically, mentally, socially or immunologically. Some children take longer than others for their immune system to fully mature, to be as active as the normal adult immune system. Further, common things are seen in both disorders; in fact, allergic disease would most likely result in respiratory symptoms in many children. Finally, this case illustrates the benefit of immunization and its use in testing the immune system. Indeed, many physicians, scientists and most immunologists believe that the biggest breakthrough in medicine occurred nearly 240 years ago when Edward Jenner performed the first successful vaccinations.

We will continue with more cases next time.

TERRY HARVILLE, MD, PhD, is medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences, and a consultant for immunodeficiencies, autoimmunities and transplantation.

Disclaimer: This case report is intended as an illustration for education purposes only. It does not necessarily represent an individual or precise information from patient files.
A Letter to Patients with Chronic Disease

By Rob Lamberts, MD

DEAR PATIENT,

You have it very hard, much harder than most people understand. Having sat for 16 years listening to the stories, seeing the tiredness in your eyes, hearing you try to describe the indescribable, I have come to understand that I, too, can’t understand what your lives are like. How do you answer the question, “How do you feel?” when you’ve forgotten what “normal” feels like? How do you deal with all of the people who think you are exaggerating your pain, your emotions, your fatigue? How do you decide when to believe them or when to trust your own body? How do you cope with living a life that won’t let you forget about your frailty, your limits, your mortality?

I can’t imagine.

But I do bring something to the table that you may not know. I do have information that you can’t really understand because of your unique perspective, your battered world. There is something that you need to understand that, while it won’t undo your pain, make your fatigue go away or lift your emotions, it will help you. It’s information without which you bring yourself more pain than you need suffer; it’s a truth that is a key to getting the help you need much easier than you have in the past. It may not seem important, but trust me, it is.

You scare doctors.

No, I am not talking about the fear of disease, pain or death. I am not talking about doctors being afraid of the limits of their knowledge. I am talking about your understanding of a fact that everyone else seems to miss, a fact that many doctors hide from: We are normal, fallible people who happen to doctor for a job. We are not special. In fact, many of us are very insecure, wanting to feel the affirmation of people who get better, hearing the praise of those we help. We want to cure disease, to save lives, to be the helping hand, the right person in the right place at the right time.

But chronic unsolvable disease stands square in our way. You don’t get better, and it makes many of us frustrated, and it makes some of us mad at you. We don’t want to face things we can’t fix because it shows our limits. We want the miraculous, and you deny us that chance.

And since this is the perspective you have when you see doctors, your view of them is quite different. You see us getting frustrated. You see us when we feel like giving up. When we take care of you, we have to leave behind the illusion of control, of power over disease. We get angry, feel insecure and want to move on to a patient we can fix, save or impress. You are the rock that proves how easily the ship can be sunk. So your view of doctors is quite different.

Then there is the fact that you also possess something that is usually our domain: knowledge. You know more about your disease than many of us do — most of us do. Your multiple sclerosis, rheumatoid arthritis, end-stage kidney disease, Cushing’s disease, bipolar disorder, chronic pain disorder, brittle diabetes or disabling psychiatric disorder — your defining pain — is something most of us don’t regularly encounter. It’s something most of us try to avoid. So you possess deep understanding of something that many doctors don’t possess. Even doctors who specialize in your disorder don’t share the kind of knowledge you can only get through living with a disease. It’s like a parent’s knowledge of their child versus that of a pediatrician. They may have breadth of knowledge, but you have
depth of knowledge that no doctor can possess.

So when you approach a doctor — especially one you’ve never met before — you come with a knowledge of your disease that they don’t have, and a knowledge of the doctor’s limitations that few other patients have. You see why you scare doctors? It’s not your fault that you do, but ignoring this fact will limit the help you can get only from them. I know this because, just like you know your disease better than any doctor, I know what being a doctor feels like more than any patient could ever understand. You encounter doctors intermittently (more than you wish, perhaps); I live as a doctor continuously.

So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship:

1. Don’t come on too strong — Yes, you have to advocate for yourself, but remember that doctors are used to being in control. All of the other patients come into the room with immediate respect, but your understanding has torn down the doctor-god illusion. That’s a good thing in the long run, but few doctors want to be greeted with that reality from the start. Your goal with any doctor is to build a partnership of trust that goes both ways, and coming on too strong at the start can hurt your chances of ever having that.

2. Show respect — I say this one carefully, because there are certainly some doctors who don’t treat patients with respect — especially ones like you with chronic disease. These doctors should be avoided. But most of us are not like that; we really want to help people and try to treat them well. But we have worked very hard to earn our position; it was not bestowed by fiat or family tree. Just as you want to be listened to, so do we.

3. Keep your eggs in only a few baskets — Find a good primary care doctor and a couple of specialists you trust. Don’t expect a new doctor to figure things out quickly. It takes me years of repeated visits to really understand many of my chronic disease patients. The best care happens when a doctor understands the patient and the patient understands the doctor. This can only happen over time. Heck, I struggle even seeing the chronically sick patients for other doctors in my practice. There is something very powerful in having understanding built over time.

4. Use the ER only when absolutely needed — Emergency room physicians will always struggle with you. Just expect that. Their job is to decide if you need to be hospitalized, if you need emergency treatment or if you can go home. They might not fix your pain, and certainly won’t try to fully understand you. That’s not their job. They went into their specialty to fix problems quickly and move on, not to manage chronic disease. The same goes for any doctor you see for a short time: They will try to get done with you as quickly as possible.

5. Don’t avoid doctors — One of the most frustrating things for me is when a complicated patient comes in after a long absence with a huge list of problems they want me to address. I can’t work that way, and I don’t think many doctors can. Each visit should address only a few problems at a time; otherwise, things get confused, and more mistakes are made. It’s OK to keep a list of your own problems so things don’t get left out — I actually like getting those lists, as long as people don’t expect me to handle all of the problems. It helps me to prioritize with them.

6. Don’t put up with the jerks — Unless you have no choice (in the ER, for example), you should keep looking until you find the right doctor(s) for you. Some docs are not cut out for chronic disease, while some of us like the long-term relationship. Don’t feel you have to put up with docs who don’t listen or minimize your problems. At the minimum, you should be able to find a doctor who doesn’t totally suck.

7. Forgive us — Sometimes I forget about important things in my patients’ lives. Sometimes I don’t know you’ve had surgery or that your sister comes to see me as well. Sometimes I avoid people because I don’t want to admit my limitations. Be patient with me — I usually know when I’ve messed up, and if you know me well, I don’t mind being reminded. Well, maybe I mind it a little.

You know better than anyone that we docs are just people — with all the stupidity, inconsistency and fallibility that goes with that — who happen to doctor for a living. I hope this helps, and I really hope you get the help you need. It does suck that you have your problem; I just hope this perhaps decreases that suckishness a little bit.

ROB LAMBERTS, MD, is a practicing primary care physician in Augusta, Ga.

Reprinted with permission from Doctor-Rob.org at more-distractible.org/2010/07/14/ a-letter-to-patients-with-chronic-disease.
School Site Programs for K-12 Health-Impaired Students

The school performance of students with chronic illnesses often suffers because of missed days due to illness and treatments. However, there are programs that can help these students succeed.

By Ronale Tucker Rhodes, MS
Approximately 17 percent of all students under age 18 suffer from a chronic illness to the degree that it affects their performance in school. Performance is hindered mainly because these kids miss numerous days of school due to sickness that requires them to go to the hospital, recover at home or attend regular medical appointments. As a result, they experience decreased academic performance, and they have difficulty completing work on time or taking part in exams, participating in some school activities (for example, physical education or excursions), and they often feel less confident and less motivated, which can affect self-esteem. Fortunately, there are two laws designed to protect the educational rights of children with disabilities who wish to remain in school site educational programs.

The Laws

The first law that protects chronically ill kids' educational rights is Section 504 of the Rehabilitation Act of 1973. That Act was amended with the Americans with Disabilities Act Amendments Act of 2008 (ADAAA), effective Jan. 1, 2009, which broadened the interpretation of a disability. The second is Public Law 94-142 (Education of All Handicapped Children Act), which was passed by Congress in 1975 and has been revised many times over the years, with the latest revision published in 2006. That law is now codified as the Individuals with Disabilities Education Act (IDEA). Section 504 is not tied to any type of funding, which means schools are not provided any federal funds for the programs and services they must provide to comply. IDEA, however, is a grant statute and provides schools with additional, although limited, financial support. Both laws require school districts to provide children with a free appropriate public education (FAPE), meaning that accommodations and/or modifications must be made for children whose disabilities impede their ability to learn. It's important to note that Section 504 and IDEA do not apply to private schools. However, private schools are public accommodations under Title II of the Americans with Disabilities Act, which means students are entitled to reasonable accommodations in private schools, too.

The Office for Civil Rights (OCR) in the U.S. Department of Education (ED) enforces Section 504 of the Rehabilitation Act, while the Office of Special Education and Rehabilitative Services (OSERS), also a component of the ED, administers IDEA. Section 504 is an anti-discrimination law enacted to “level the playing field” to eliminate impediments to full participation by persons with disabilities compared with those without disabilities. As such, accommodations are made for educational opportunities that meet the needs of all students. IDEA, on the other hand, is remedial, often requiring the provision of programs and services in addition to those available to persons without disabilities. This means it focuses on the “unique” educational needs of the student. In short, Section 504 precludes hurdles to participation, whereas IDEA is similar to an affirmative action law that provides additional benefits for underrepresented groups such as those with disabilities.

Children with a chronic illness may qualify for protection under Section 504 and/or IDEA. The definition of a disability is much broader under Section 504 than it is under IDEA. Section 504 protects children with a disability who 1) have a physical or mental impairment that substantially limits one or more major life activities; 2) have a record of such an impairment or 3) are regarded as having such an impairment. With the ADAAA's broadened interpretation of a disability, a major life activity includes the operation of a major bodily function, including but not limited to functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions. Under IDEA, children are defined as having a disability if their educational performance is adversely affected due to the disability. There are 14 disability categories included in IDEA, including other health impairment under which children with a chronic health condition may qualify for services if the condition adversely affects their educational performance. What's critically important to chronically ill children is that under these laws, episodic illnesses — those that come and go — are disabling even when students are in remission if they would be disabling when active.

The programs available to children with disabilities who qualify include a 504 plan under Section 504 of the Rehabilitation Act and an Individual Education Program (IEP), alternatively called an Individual Education Plan (IEP), under IDEA. See Table 1 for a list of differences between a 504 plan and an IEP.

Obtaining a 504 Plan

Children who do not qualify for an IEP may qualify for a 504 plan. To be eligible for a 504 plan, students do not need to receive special education services, and they will still remain in their regular classrooms. What the written plan entails is determined individually based on the nature of the disabling condition and what each child needs in order to have an equal opportunity to compete with those without disabilities.
Some examples of what accommodations are required to be provided to students with a chronic illness under a 504 plan include, but are not limited to, extended time on tests or assignments, peer assistance with note taking, frequent feedback, an extra set of textbooks for home use, computer-aided instruction, rearranging class schedules, taping lectures and individual contracts (see also Sample Accommodations for Chronically Ill Students Under a 504 Plan and IEP).  

To obtain a 504 plan, it must be proved that a student has a disability. A detailed letter from a doctor will often suffice; however, in some situations, schools request copies of medical records. The law does not require that school officials be able to obtain an unlimited release of medical records or that they be able to speak to a student's doctors whenever wanted. Once it is determined a student has a disability, a request for a 504 plan must be made to someone in authority at the school such as the principal, a guidance counselor or the coordinator of 504 plans for the district. Present at the meeting should be the student (depending on his or her age), the student's parent(s), the student's teachers and a school administrator.

The purpose of the meeting is to develop a plan of accommodation for the student. Parents, if appropriate, should have a list of things the student needs. For instance, if a child is repeatedly absent due to illness, the items needed may be copies of notes and/or handouts and homework assignments sent home each day, the ability of teachers to waive homework assignments if they are otherwise convinced the student has mastered the subject matter, and tutoring. With budget constraints, getting tutoring is often difficult. However, teachers may be willing to help a student via email or to spend extra time with a student, and that should be deemed an important supplement to tutoring that should be asked for. Once a plan is agreed upon and written, it requires yearly re-evaluations or periodic reviews.  

Under Section 504, the school cannot require parents of students with disabilities to pay the costs associated with necessary accommodations or services, but fees charged to all parents of the general student population may also be collected from parents of students with disabilities.  

**Obtaining an IEP**

An IEP trumps a 504 plan. Therefore, children who qualify for an IEP do not require a 504 plan. For students to qualify for an IEP, they must be found eligible for special education. IDEA defines the term “special education” as “specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings, and instruction in physical education.” Specially designed instruction means “adapting, as appropriate, to the needs of an eligible child under this part, the content, methodology or delivery of instruction to address the unique needs of the child that result from the child’s disability and to ensure access of the child to the general curriculum, so that the child can meet the educational standards within the jurisdiction of the public agencies that apply to all children.”

How an IEP is obtained is similar to a 504 plan. However, there are differences. First, a full multifactored evaluation is required using a variety of assessment tools and strategies to gather relevant functional and developmental information, including information provided by parents that may assist the team in determining whether the child has a disability and how it affects the child’s educational program. Second, because the student is eligible for special education, the school district is required to assign a case manager (special education teacher) to the student. Third, how an IEP is written differs. The IEP document contains very specific language and parts such as goals and objectives that are not included in the 504 plan. Timelines for an IEP are also very specific, whereas there are no timelines written into the 504 plan. And, a minimum number of IEP participants and who they are, such as an administrator, general education teacher and special education teacher, are required, whereas there are no requirements stating who must attend the 504 plan meeting.  

After an IEP is finalized, it requires a re-evaluation every three years by the IEP team to determine if services are still needed to address the student’s disability unless the parents and other members of the IEP team agree it is not necessary. Should a student require a change of placement, re-evaluation may not be required.

Finally, under IDEA, all services included in a student’s IEP must be provided at no expense to the student or the parents, including those that are charged to the general student population.  

**Handling a Dispute**

If parents believe their child has been discriminated against under Section 504 or ADAAA, or the school is not complying with an IEP, the parents have the right to file a complaint. For a 504 plan, a complaint should initially be filed with the school’s or school district’s Section 504
compliance officer. Should there not be such a position, that is a violation of Section 504. Unfortunately, there is no Section 504 requirement that says state education agencies must establish state complaint systems for Section 504 and ADAAA noncompliance allegations (as there is under IDEA). However, a complaint may also be filed with the OCR (usually the regional office).

The scope of Section 504 complaints with OCR is very broad. The complaint may be filed by any individual or organization, and it may address individual student, class or systemic issues. And, it must be filed within 180 days of the alleged discriminatory action, although the regional director is authorized to waive the time limit. The OCR will conduct an investigation of the complaint through data collection and written responses to questions, and it may conduct an onsite review. In individual complaints, an informal process known as early complaint resolution is available.

Once the complaint is reviewed, the OCR will issue a letter of finding either with a no-violation conclusion or identifying violations and specifying corrective actions. If the school fails to implement the corrective actions, there may be an administrative hearing with the possibility that federal educational funds may be terminated.

It’s important to note that the OCR states that its compliance monitoring generally focuses on whether a school district has followed the policy and procedural requirements of the law and regulations; it does not see its role as second-guessing substantive decisions. According to the OCR: “It is not the intention of the department except in extraordinary circumstances to review the result of individual placement and other educational decisions, so long as the school district complies with the ‘process’ requirements of [the identification and location, evaluation and due process procedures].”

When a child has an IEP and the parents have concerns about their child’s rate of progress, the appropriateness of the services provided to the child or the child’s educational placement, these issues can be resolved either informally

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<th>Table 1. Differences in the Details of the Law Between the 504 Plan and the IEP</th>
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<td><strong>504 Plan</strong></td>
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<td>• Offers all children with disabilities equal access to an education. In some cases, may include special education services, but for a child in a wheelchair it may mean a ramp or elevator to access the classroom</td>
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<td>• Documented in a written plan</td>
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<td>• No specific timelines</td>
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<td>• No requirements stating who must attend the plan meeting</td>
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<td>• Reports of noncompliance and the request for a hearing are made to the Office for Civil Rights</td>
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<td>• Does not offer as many specific procedural safeguards</td>
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Source: Education Center. 504 Plan vs. IEP. Accessed at www.ed-center.com/504
In the classroom, the student may:
- Use the bathroom at any time, without delay.
- Keep a water bottle at the desk at all times.
- Keep hand sanitizer at the desk at all times.
- Alter the location of personal or classroom supplies for easier access or to minimize distraction.
- Have a preferential locker location that is centralized.
- Have preferential seating and be allowed to move seats if students around the student are ill.
- Go to the nurse’s office when unwell, regardless of tests or lesson plans taking place.
- Have “stop the clock” breaks during state testing (only available under an IEP in some school districts) and classroom testing.
- Self-monitor energy levels, fatigue and pain to determine if he or she feels capable of participating in gym or other physical activities. Should be allowed to take breaks whenever he or she feels it is necessary, and rejoin the activity after the break.

The student will:
- Only miss class when necessary due to illness or medical appointments (every effort will be made to schedule appointments outside of school hours).
- Work toward handing in assignments on time and only request deadline extensions when his or her illness makes it necessary.
- Attend before- and/or after-school tutoring as needed to make up any missed work and assignments.

When away from class due to illness or medical appointments, teachers will:
- Make sure all PowerPoints, handouts, homework assignments and class materials are available, to the extent possible, for the student to complete the work from home.
- Reschedule tests and extend deadlines for submitting projects and homework assignments when the student requests the extension because of illness. The student will not be penalized for handing in work late or missing tests due to illness.

Additional provisions under an IEP:
- Provides the student with a case manager who is the point person who communicates between the student’s family and his or her teachers regarding any absences and who meets with the student when he or she returns after an absence to help organize and prioritize missed assignments and tests.
- Provides the student with a private location and alternate time to perform any special procedures.
- Involves the school nurse, teachers and staff by establishing a health alert (the school provides training for every staff member involved with the student so that they are aware of the health issues and of proper procedures).
- Provides education and support for peers.
- Provides for modifications to recesses, physical education and transportation.

or formally. It is advised that both sides first discuss their concerns and try to compromise. This can happen through an IEP review in which the parents and the IEP team discuss the parents’ concerns and work toward an agreeable solution. Solutions can be temporary in which a particular plan of instruction is tried for a period of time. In those circumstances, after the trial period, the team reconvenes for an additional IEP review.

A second informal approach is an IEP facilitation. While this is not one of the dispute resolution options described in the law’s procedural safeguards, its use is on the rise; however, there is no requirement in IDEA for school systems to provide an IEP facilitation. An IEP facilitation includes an impartial facilitator who is not a member of the IEP team, but who is there to keep the team focused on developing the child’s program while addressing conflicts as they arise. When disagreements arise, the facilitator can model effective communication and listening for team members, can encourage members to identify new options and, most important, will ensure the meeting remains focused on the child.

Some large school districts also have information dispute
resolutions (IDRs). An IDR is an optional, voluntary and informal process to resolve disputes regarding a child’s IEP. Under IDR, the parents identify issues in dispute, and the district attempts to work with the parents to quickly and informally resolve the identified issues. Although the process is quick and informal, it may result in a formal, binding agreement between the district and the parents. This agreement will include a waiver of certain claims, including all special education claims the parents may have against the district up to the time of the agreement, meaning that the parents will no longer be able to file a request for formal due process or state mediation for anything occurring prior to the agreement. Accordingly, parents should be sure they understand all of the terms of the agreement before signing. If the IDR process is unsuccessful, parents may still initiate formal proceedings.

Formal approaches include filing a state complaint, a resolution meeting, mediation and due process. A state complaint can be filed by an organization or individual, including those from another state. Complaints must be written directly to the state education agency (SEA) and must describe what requirement of IDEA the school has violated, among other specific things. A resolution meeting is then held between the parents and the SEA director, after which the SEA must either resolve the complaint or have a system in place in which complaints are filed with the school district. In the latter circumstance, complainants can have the district’s decision reviewed by the SEA. When the SEA makes a ruling, the school system must be given the opportunity to respond to the complaint, including making a proposal to resolve the complaint. In most cases, the SEA must resolve the complaint within 60 calendar days and must issue a written decision. If the SEA finds the school system has failed, the SEA must address the failure and include corrective action.

Also, after a state complaint is filed, parents can opt for mediation. In mediation, parents and school personnel sit down with an impartial third person called a mediator to talk openly about the areas where they disagree and try to reach agreement. Mediation must be voluntary on the part of both parties; it must use a qualified and trained mediator who is selected by the state on a random, rotational or other impartial basis; all discussions must remain confidential; it can’t be used to deny or delay parents’ right to a due process hearing; and any agreement must be put in writing.

The final formal approach is due process. When due process is used, an impartial third person, called a hearing officer, decides how to resolve the problem. First, a due process complaint must be filed by providing a copy to the other party and forwarding a copy to the SEA. This includes the child’s name, the address where the child resides, the name of the school the child is attending, a description of the conflict and a proposed resolution of the conflict. The information in the complaint must be kept confidential. Within 15 days of a complaint being filed, the SEA must convene a resolution meeting with the goal of giving the parties an opportunity to resolve the issues without holding a hearing. If the resolution doesn’t
succeed, a due process hearing is held in which each party presents its views in a formal legal setting using witnesses, testimony, documents and legal arguments. Within 45 days of the resolution period expiring, a final decision must be reached. If the hearing officer's decision is not appealed, it is final.

For IEPs, each state also has specific ways for parents and schools to resolve differences. The state’s guidelines can usually be obtained at the local department of special education. Parents may also wish to visit CADRE, the National Center on Dispute Resolution in Special Education, at www.directionservice.org/cadre.10

Other Resources

In addition to Section 504 and IDEA, there are other resources available for parents with chronically ill children. In some circumstances, it may be best for children to utilize the Home & Hospital Instruction Program, which serves students who incur a temporary disability that makes attendance in the regular day classes or alternative education program impossible or inadvisable. The district in which the home or residential health facility is located is responsible for instructing and educating pupils who must be hospitalized or remain at home due to a temporary but extended illness or disability. There is no provision in statute that specifically addresses instructional content; however, the goal of home or hospital instruction should be maintenance of the students' former level of performance while recovering. Once students have recovered, they may return to the school to continue their education.11

There also are other laws that parents should be aware of. The No Child Left Behind (NCLB) Act, Public Law 107-110, is the nation's latest general education law. The law, which focuses on accountability for results, and emphasizes doing what works based on scientific research, has increased parental options and increased local control and flexibility. Information about the NCLB Act is available at www.ed.gov/nclb.

The Family Educational Rights and Privacy Act (FERPA), a federal law that protects the privacy of student education records, applies to all schools that receive funds under any program administered by the U.S. Secretary of Education. FERPA gives parents certain rights with respect to their child's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Information about FERPA is available at www.ed.gov/policy/gen/guid/fpco/ferpa/index.html.5

Setting Students Up for Success

It's critical for parents to utilize the school site programs to ensure their chronically ill children succeed in school. School districts want their students to succeed, and they work with each and every one to ensure they get the modifications and/or accommodations they need. But, which program is best for a child depends on his or her unique academic needs. According to Erin Vanderwood, program specialist/pupil services at Riverside Unified School District, Riverside, Calif., “The team actually discusses at what level support is needed. If a student has a medical condition that requires him or her to have some kind of special education services, like a resource teacher or a special classroom, then an IEP is needed. However, if it's determined that the student doesn’t need extra help, just accommodations, then a 504 plan is needed. The 504 keeps a student in the least restrictive environment.”

RONALE TUCKER RHODES, MS, is the editor of IG Living magazine.

Arianna’s Need for an IEP

Arianna Kazemi was diagnosed at age 2 with primary immunodeficiency. When she was in kindergarten, the teacher called Arianna’s mother, Annaben, to tell her that Arianna was sleeping at her desk every day. “She said, ‘I don’t think this is normal,’ and she was concerned,” explains Annaben. In addition to being overly tired, Arianna was getting a lot of colds and picking up every illness. It was then that Arianna was retested and began treatment with intravenous immune globulin, which made a difference, but because it was such a shift in Arianna’s routine, she needed special accommodations. So Arianna was placed on a 504 plan.

Arianna had a 504 plan throughout elementary and middle school. “The elementary school was very accommodating,” says Annaben. She had preferential seating, which meant if someone was sick, she was able to switch desks to be seated farther away. Because she was prescribed so many antibiotics, Arianna was allowed to get up and go to the bathroom or get a drink when she wanted. And, she could go to the front office, where they had a cot that Arianna could lie on to rest. “The teacher in kindergarten started washing Arianna’s desk every day,” says Annaben. “And, the school secretary would call me to let me know what was going on and to ask if what Arianna was doing was OK. In first grade, the teacher washed all the desks.”

But, in middle school with six or seven teachers, Annaben started to find it harder to obtain accommodations for Arianna. So, in eighth grade, before transferring to high school in another district, Annaben decided to fill out the necessary paperwork to obtain an IEP for Arianna. Unfortunately, in the fall, when Arianna started high school, the IEP was met with resistance. “They felt a 504 would suffice because she wasn’t behind in her academics,” explains Annaben. “But, we were bumping into a lot of problems like 15 days of missed school in the first quarter.” Arianna had always been a straight-A student, yet with so many missed school days, she had a B in physical education, which was precluding her from being on the dance team (even though Arianna’s PE teacher expressed that she was her best dancer). She also was in advanced English, and that teacher wouldn’t allow Arianna the extra time to make up work. “The 504 plan just didn’t carry enough weight,” says Annaben. “She was a straight-A student, but they didn’t understand the stress she was under to keep up those grades.”

What Arianna really needed was a flexible schedule to allow her to complete her work. “An IEP is a legally binding document that would force the situation,” explains Annaben. So, she fought for an IEP and obtained one with the help of a letter from Arianna’s immunologist. As part of the IEP, they requested a free block period at the beginning or end of the day so if Arianna was tired, she could go in later or come home early. But, the school denied that. “Even with an IEP, we couldn’t adjust her schedule. She had to be a regular student with the same attendance policy,” says Annaben. That was when Annaben discovered Arianna could instead be enrolled in independent study. “Now, if she misses school, she can make it up in a different way,” explains Annaben. “If she’s not feeling well on Tuesday, she can go in on Thursday and make up the hours. Or, she can do it online.” The IEP also provided Arianna with a case manager who advocates for her. According to Annaben, a case manager often helps because he or she can approach the situation in a more neutral manner, whereas a parent might often get frustrated. “Many parents aren’t knowledgeable when they go in to ask for things, or they don’t know how to get what they want to help their child, so it becomes very adversarial,” says Annaben.

With the IEP, Arianna has managed to stay a straight-A student and her stress level is greatly reduced. “I get a lot more rest and am more energized,” says Arianna. “I feel like I can finish something without having to take a nap or get an incomplete.”
When parents are diagnosed with a chronic illness, they must find ways of helping their children cope to ensure they live a full life in the present.

By Annaben Kazemi
nder the best circumstances, parenting is a demanding job. But, parents with a chronic illness face additional challenges. Besides having their own pain to deal with, they must help their children adjust to the illness. Common questions are: “Is my mom/dad going to be OK?” “Who will take care of me?” and “Can I catch this disease?”

Although the situation is life-altering for a family, it is possible to turn it into an opportunity to strengthen family bonds and create resiliency. The ways parents can help their children deal with the uncertainty of illness and to help their children become secure and well-adjusted include being honest, revising expectations, keeping a positive attitude and teaching them to cope.

Be Honest About What’s Going On

One of the most difficult things for parents to do after one is diagnosed with a chronic illness is to tell others, especially their own children. Yet, experts agree that parents shouldn’t try to shield their children by hiding the illness, because it is impossible to keep such a secret over time. Children are highly perceptive and notice the smallest nonverbal cue or change in routine. Very young kids tend to sense when something is going on. And, older children may overhear conversations, find medications or notice symptoms, and jump to the wrong conclusions.

While some parents worry that talking with their children may cause fear, honest communication is a key factor in creating security because it builds trust. Most children want to handle crisis in a positive way, and they have the potential to cope and grow through difficult times. But, careful planning is needed. The information must be communicated to them on their developmental level; otherwise, children won’t be able to make sense of it, and they will be alone in their worry.

Having an open and honest conversation about the parent’s illness is a good place to start. Children should be told the name and symptoms of the disease. They should be asked what they already know or what they have heard, and any wrong information they may have should be corrected.

Younger children need reassurance that their parent’s illness is not a punishment for their bad behavior, it is not a monster that comes to get them, and it is not contagious. Most important, they need to know that they will still be loved and taken care of. Older children may want to be included in what the ill parent is going through. Kathleen McCue, MA, child life specialist at the Cleveland Clinic Foundation, recommends taking the children along to watch the parent’s routine medical treatment. This will help to give them a realistic view of the illness, and it will make them feel involved in the parent’s care in a nonthreatening way.

Revising Expectations of Family Life

When parents share the diagnosis of a chronic illness, family life doesn’t cease. Parenting continues, but some adjustments have to be made. The family may no longer look the way their children imagined it would, which is a loss that can hurt a lot. Therefore, children need to be able to express their negative feelings of anger or sadness, and parents need to acknowledge those feelings.

Even if children don’t admit to having negative feelings, they should be assured that they are not to blame. And, while the illness doesn’t mean they will be alone, parents must be honest in telling them things may have to change. Kids should also be told that the illness doesn’t mean they are loved any less and that it is not contagious, so they cannot catch it by spending time with the sick parent or by hugging or kissing that parent. Instead, it should be emphasized that the parent really wants to be as much a part of their life as possible.

Postponing or missing events and activities will be inevitable because of the unpredictability of their illness. Yet, while parents can’t protect their children from the disappointment, it is possible to ease their feelings of being let down. Parents can let them know how proud they are of their accomplishments and find creative ways to share in them. For example, if parents have to miss a spring recital, another adult can videotape the performance, and then the parents and children can watch the tape together and allow the children to narrate the experience.

“To help a child grow from this experience, it’s not necessary for an ill parent to be strong as a rock,” explains Elliot Rosen, EdD, medical family therapist at the Family Institute of Westchester in Mount Vernon, N.Y. “It’s important for kids to know that their parents are human. And, a parent who readily admits that she can’t do it all — and reaches out for help from others in her community — sets a great example for her child.”

Attitude Matters

One of the most difficult parts of coping with chronic illness is for parents to take care of themselves so that they can continue to actively parent, especially when that means saying no — to the baseball game, holiday pageant or family gathering — when the heart wants to say yes.
And, children can learn a valuable lesson from parents who are able to explain their limits yet still function with pride and confidence. They will realize that having an illness doesn’t affect a person’s worth. “The single most important factor is the parent’s attitude,” emphasizes Manuel D. Reich, DO, director of the Center for Pediatric Psychiatry and Medicine at the University of Pittsburgh Medical Center. “If the parent is depressed, complains a lot and acts needy, the child is at risk for having more problems — or may even develop his own disability, such as headaches, stomachaches or a breathing difficulty. But if the parent is taking care of herself and leading as normal a life as possible, the child will be secure in the fact that Mom is doing the best she can do to accommodate his needs. In fact, many of these children become responsible and well-organized early on. They may have a somewhat less idyllic sense of childhood, but the trade-off is that they may also be more mature. Many go to work in one of the helping professions, such as medicine or advocacy law.”

Coping with Hospital Stays

When a parent has to stay at the hospital, fear of separation is a crucial issue for children; even the youngest infants are sensitive to their parent’s absence. They want to know who will care for them while the parent is away, what will happen while the parent is gone and when the parent can return home. Older children may question why the hospital stay is needed and how long it will take. Therefore, it’s important to help reassure children and to answer their questions honestly and directly.

Many of the worries that parents and children have about hospitalizations can be alleviated with preparation. Developing a plan is crucial. Keeping a routine and setting expectations make the daily routine predictable and safe. For example, Grandma will pick the children up from school each day, and homework will get done in the hospital lounge while everyone takes turns visiting the ill parent. Or a neighbor will walk the children to school, and Mom will Skype after school to hear about the day. The key is to help the children stay informed and connected.

Unless there are extreme logistical obstacles or health-related reasons to postpone visits, families should support children of all ages coming to the hospital. Any apprehension the children may be feeling can be eased by explaining to

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them what it will be like at the hospital: the building, the hallway, the room, how Mom or Dad will look, etc. Also, it should be planned how long the children will stay, but the time should be flexible, and there should be alternatives if the children want to step out of the room.

Some children may say that they don’t want to visit their parent in the hospital. In this case, patience is required. Younger children may be frightened of what might happen there, while older children may not want to see their parent looking very ill. Or, they may just be uncomfortable in a hospital environment. Talking through some of these worries can help.

Sometimes, a visit is just not possible. Phone calls are good alternatives, but technology can allow for video chat, texting, email and photo communication. Even being able to send a drawing, note or small token and then receiving feedback about how much the hospitalized parent appreciated it often feels gratifying to children.

**Tweens**

Tweens alternate between their family and peer relationships for support. Their emotions are heightened by the onset of puberty. Yet, their emotions are often perceived as a threat that the pre-adolescents are struggling to overcome. How the parent can help:

- Expect a child of this age to be in battle with emotions (be respectful of the child’s efforts to control or conceal their vulnerability; let them know the parent is there for them).
- Understand that the tween’s emotions may manifest in feeling physically ill (i.e., headaches, stomachaches, colds).
- Look for peer support groups, and encourage peer relationships and involvement.

**Striving for a Full Life**

Growing up in a household where a parent has a chronic illness can place added stress on children. They are impacted by the diagnosis of a parent’s serious illness in many ways.

Frequently, their emotional needs and concerns can go unaddressed. Therefore, it’s important for parents to find ways of caring for their children’s needs while also caring for themselves. And, if parents are able to demonstrate a positive attitude, their children will mirror it.

Ultimately, parents need to explain to their children that they will need to learn to move on and to embrace a new family dynamic, which means they will have to let go of what may have been. They can’t cling to: “What would my life have been like if my mom/dad wasn’t sick?” Otherwise, they will miss the opportunity to live a full life in the present.

**ANNABEN KAZEMI** is the patient advocate for IG Living magazine.

**References**

The Role of an IG Infusion Nurse

By Cindi Vokey, RN, BSN

The infusion nurse is both a caregiver and an educator who must be experienced in the administration of IVIG and SCIG.

Immune globulin (IG) therapy has been prevalent in the medical field for many decades. In recent years, the use of IG therapy has increased due to the identification of multiple disease states that respond to therapy. A drug that was once primarily used for patients as a replacement therapy is now used to treat many autoimmune diseases. The evolving use of IG has created new dosing guidelines and administration schedules, requiring special consideration and training for the infusion nurse and his or her patient.

When caring for a patient, an infusion nurse is responsible for working collaboratively with other healthcare professionals. In addition, he or she must use the process of assessment, problem identification, intervention and evaluation to strive for safe, high-quality patient outcomes. By constantly monitoring patient and process outcomes, the nurse is able to identify areas that will benefit from performance improvement, thereby improving the quality of care.¹

IG Replacement Therapy for PIDD Patients

One of the largest patient populations treated with IG therapy is immune-deficient patients. Mostly referred to as primary immunodeficiency disease (PIDD), this disorder refers to the inability of a person’s immune system to create an adequate quantity or quality of antibodies to fight off infection. In effect, PIDD patients’ immune systems are either absent or hampered in their ability to function.²

When treating PIDD patients, an infusion nurse can administer IG in two ways: intravenously (IVIG) and subcutaneously (SCIG). The average patient receiving IVIG replacement therapy will receive a dose of 0.4 to 0.6 mg/kg every month. The dosing of SCIG is determined by the brand of IG administered. Some brands administered by IV can be given subcutaneously. Other brands, which are infused only subcutaneously, are dosed by conversion of IV to SC.
If you are a Hizentra patient or caregiver
Sometimes talking to someone who "gets it" is KEY.

Voice2Voice
Your key to explore Voice2Voice online

Voice2Voice is a peer-to-peer support program from CSL Behring, "the maker of Hizentra.
Voice2Voice connects Hizentra patients and caregivers with advocates™ who have direct experience with Hizentra and know what it's like to live with primary immunodeficiency disease (PIDD), as well as advice from experts.

Sign up for Voice2Voice.
You can visit us online at Voice2Voice.com/V2V or call 1.877.644.2933 for assistance.

Voice2Voice advocates are not healthcare professionals or medical advisors. For medical advice, please contact your physician.
Information appearing on Voice2Voice sites is not editorially endorsed by CSL Behring but is their own personal opinions.

Important Safety Information
Hizentra contains excipients of primary immunodeficiency disease (PIDD) patients 2 and 10 yr.
Hizentra should not be used in patients with a history of severe allergic reactions.

Important: If Hizentra is used to treat PIDD patients with excipients, the product should not be used for routine prophylaxis.

For people with PIDD
Hizentra is the Ig therapy that's deliberately designed for SubQ use

Backed by the expertise of CSL Behring, Hizentra 20% is currently being used by more than 10,000 patients and providers, a number that's growing every day.
Hizentra helps keep Ig levels stable with low-volume cell injections.

Individuals doing more can have confidence that you are getting the dose that's right for you.

Important Safety Information (Continued)
For your doctor's advice about any side effects that concern you, your doctor will monitor for potentially serious reactions that have been seen with hGH in patients, including thromboembolic events (blood clots), anaphylaxis (allergic reactions), and anaphylactoid reactions (non-allergic reactions) resulting in potentially life-threatening outcomes.

The most common side effects are injection site reactions such as pain and redness, numbness, and tingling.
Hizentra should be taken on an empty stomach, at least 1 hour before or 2 hours after eating.

Hizentra is made from components of human blood. The risk of transmission of infectious agents, including viruses and, theoretically, infections, is extremely low. (See section 12.4.)

Vacation plans can include, ramps and rolling right on the track as you're using Hizentra. Below, we outline a掠atour.

For the healthcare professional you are being selected with Hizentra. Also food diet. If you are pregnant or nursing, if you plan to breastfeed a lactating.

Please see brief summary of full prescribing information for Hizentra on adjacent pages.

You are encouraged to report adverse effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch/ or call 1-800-FDA-1088.

If you are a Hizentra patient or caregiver
Sometimes talking to someone who “gets it” is KEY.

Voice2Voice
Your key to explore Voice2Voice online

Voice2Voice is a peer-to-peer support program from CSL Behring, the maker of Hizentra,
Voice2Voice connects Hizentra patients and caregivers with advocates who have direct experience with Hizentra and know what it’s like to live with primary immunodeficiency disease (PIDs), so you can share stories, gain advice and feel supported. Learn more at Voice2Voice.com.

Sign up for Voice2Voice.
You can enroll online at Voice2Voice.com/V2V or call 1-877-944-4061 (Ext. 5307) for assistance.

Hizentra.com/V2V

For people with PIDD
Hizentra is the Ig therapy that’s deliberately designed for SubQ use

Backed by the expertise of CSL Behring, Hizentra 20% is currently being used by more than 10,000 patients and providers,* a number that’s growing every day
Hizentra helps keep IgG levels stable with low-volume cell injections — the first and only 20% Ig concentration delivering a consistent level of protection against infection.
Individually dosing means you can have confidence that you are getting the dose that’s right for you

Important Safety Information (continued)
Tell your doctor about any side effects that concern you. Your doctor will monitor for potentially serious reactions that have been seen with other Ig products, including infusion-related reactions (including hypersensitivity reactions, headache, chest pain, flushing, hypotension), palpitations, chills, nausea, vomiting, respiratory distress, and/or angioedema.

Hizentra is made from plasma obtained from healthy donors. The risk of transmission of infectious agents, including viruses and, theoretically, the PrP27-30 (BSE) agent, cannot be completely eliminated.

Please see full prescribing information for Hizentra on adjacent pages.
You are encouraged to report adverse effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.
Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid

Initial U.S. Approval: 2010

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use Hizentra safely and effectively. See full prescribing information for Hizentra.

INDICATIONS AND USAGE

Hizentra is an Immune Globulin Subcutaneous (Human) (IGSC), 20% Liquid indicated for the treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years of age and older.

DOSAGE AND ADMINISTRATION

For subcutaneous infusion only. Do not inject into a blood vessel.

Start treatment with Hizentra 1 week after the patient’s last Immune Globulin Intravenous (Human) (IGIV) infusion, when the patient has received IGIV infusions at regular intervals for at least 3 months.

Dosage

- Calculate the initial weekly dose of Hizentra needed to achieve a systemic serum IgG concentration (area under the concentration-time curve [AUC]) not inferior to that of the previous IGIV treatment.

  Initial dose = Previous IGIV dose (in grams) x 1.53

  No. of weeks between IGIV doses

  To convert the dose in grams to milliliters (mL), multiply the calculated dose (in grams) by 5.

- Adjust the dose of Hizentra over time based on clinical response and serum IgG trough levels.

  Measure the serum IgG trough level during IGIV therapy prior to switching to Hizentra and again after 2 to 3 months of treatment with Hizentra. Adjust the dose to achieve a serum IgG trough level that is approximately 290 mg/dL higher than the last trough level during prior IGIV therapy.

Administration

- Infusion sites – Abdomen, thigh, upper arm, and/or lateral hip. Use up to 4 injection sites simultaneously, with at least 2 inches between sites.

- Infusion volume – For the first infusion, up to 15 mL per injection site. This may be increased to 20 mL per site after the fourth infusion and to a maximum of 25 mL per site as tolerated.

- Infusion rate – For the first infusion, up to 15 mL/hr per site. This may be increased, to a maximum of 25 mL/hr per site as tolerated. However, the maximum flow rate is not to exceed a total of 50 mL/hr for all sites combined.

DOSAGE FORMS AND STRENGTHS

0.2 g/mL (20%) protein solution for subcutaneous injection

CONTRAINDICATIONS

- Anaphylactic or severe systemic reactions to human immune globulin or components of Hizentra, such as polysorbate 80
- Hyperprolinemia (Hizentra contains the stabilizer L-proline)
- IgA-deficient patients with antibodies against IgA and a history of hypersensitivity

WARNINGS AND PRECAUTIONS

- IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions. Discontinue use if hypersensitivity reaction occurs.
- Thrombotic events have been reported with the use of immune globulin products, including Hizentra.
- Aseptic meningitis syndrome has been reported to occur with IGIV or IGSC treatment (5.3).
- Monitor patients for reactions reported to occur with IGIV treatment that may occur with IGSC treatment, including renal dysfunction/failure, thrombotic events, hemolysis, and transfusion-related acute lung injury (TRALI).
- Products made from human plasma can contain infectious agents, e.g., viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

ADVERSE REACTIONS

The most common adverse reactions, observed in >5% of study subjects, were local reactions (i.e., swelling, redness, heat, pain, and itching at the injection site), headache, diarhea, fatigue, back pain, nausea, pain in extremity, cough, rash, pruritus, vomiting, abdominal pain (upper), migraine, and pain.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

DRUG INTERACTIONS

The passive transfer of antibodies may:
- Lead to misinterpretation of the results of serological testing.
- Interfere with the response to live virus vaccines.

USE IN SPECIFIC POPULATIONS

- Pregnancy: No human or animal data. Use only if clearly needed.
- Pediatric: No pediatric-specific dose requirements are necessary to achieve the desired serum IgG levels.

Storage and Handling

When stored at room temperature (up to 25°C [77°F]), Hizentra is stable for up to 30 months, as indicated by the expiration date printed on the outer carton and vial label. DO NOT FREEZE. Do not use product that has been frozen. Do not shake. Keep Hizentra in its original carton to protect it from light.

Revised: December 2012
IVIG Therapy for Autoimmune Diseases

IVIG therapy is used as an immune modulator to treat many autoimmune diseases such as chronic inflammatory demyelinating peripheral neuropathy, myasthenia gravis, Guillain-Barré syndrome, multiple sclerosis, polymyositis and dermatomyositis. The complete mechanism of IG is not fully understood; however, it is believed that through the administration of higher doses of IG, the immune system is able to reverse the autoimmune process. Although dosing can be different for several diseases, treatment is commonly given every three to four weeks, and it is usually administered at a high dose (generally 1 to 2 grams of IVIG per kg of body weight) to attempt to decrease the severity of the autoimmune disease. It is important for an infusion nurse to be familiar with the common scheduling of IVIG for each disease.

When preparing the IG, maintaining aseptic technique is important.

The Nurse’s Role in Administering IVIG Therapy

When administering IVIG, an infusion nurse must assess the patient’s health history and perform a risk assessment prior to each infusion. Special consideration needs to be taken in regard to the patient’s history of exposure to IVIG. For instance, patients are categorized in the following manner:

- IVIG naïve: patients who have never received IVIG
- IVIG initial infusions: patients who have received IVIG but may have changed brands or have not received therapy within six weeks
- IVIG subsequent infusions: patients who will receive therapy after they have received their first dose from a new brand, after the first lifetime dose or after having received the same drug within a six-week time frame (subsequent infusions are also defined as infusions that are well-tolerated without a reaction or significant change in vital signs)

The nurse must also be familiar with each brand of IVIG, its label and specifications and its titration guidelines.

Prior to preparing IG for administration, IV access (either peripherally or through a vascular access device) must be obtained. Infusion nurses receive specialized training for peripheral IV insertion. When accessing peripherally, a thorough assessment of the patient’s ease for access should be made. Should there be any previous difficulties with IV access, the nurse should report that to the prescribing physician.

Patients who have been receiving therapy for a prolonged period of time or who have been diagnosed with poor peripheral IV access will have a vascular access device for IV administration. The infusion nurse must have extensive experience with these devices, which include:

- PICC lines (must be experienced with dressing changes, flushing requirements and cap changes)
- Port-a-caths (must be experienced with accessing and de-accessing)
- Tunneled catheters such as Hickman or Groshong (must be able to identify which tunneled catheter the patient has and what the flushing requirements are)

Central lines should always be assessed for signs of infection, and the nurse should educate the patient in the proper identification of central line infections.

When preparing the IG, maintaining aseptic technique is important. To maintain a sterile infusion, antiseptic can be used on rubber stoppers.

For proper IG administration, the nurse must be familiar with the necessary equipment. Most infusions require the use of several glass vials that will need a vented spike adapter to be added to the tubing. In addition, the use of infusion pumps is recommended. Therefore, knowledge of common infusion pumps is required.

Both prior to and throughout the infusion, the nurse should assess the patient’s vital signs (pulse, blood pressure, respirations and temperature). The nurse also should ensure the patient has taken premedications as ordered by the physician and that the patient is adequately hydrated.

Once IVIG therapy has been initiated, careful assessment of the patient for infusion-related reactions is crucial. The nurse should understand the initial intervention for rate-related reactions, including stopping the infusion and assessing the patient’s status, as well as decreasing the rate of infusion. All side effects should be documented and reported, including mild to moderate rate-related reactions such as headache, nausea and vomiting, chills, rigors and flushing.

While anaphylaxis is rare, it can occur during IVIG and SCIG administration. As such, the nurse’s knowledge of the management of anaphylaxis is crucial. The nurse must
know where the anaphylaxis kit is located and should be familiar with the administration of an EpiPen and other medications included in the kit. Should anaphylaxis occur, IG administration should be immediately stopped, and the appropriate anaphylaxis medications should be administered. The patient should then be evaluated by emergency medical services personnel, and the prescribing physician should be notified.

Following the infusion, the nurse should discuss important patient interventions such as staying well-hydrated, continuing premedications and monitoring urine output.

**The Nurse’s Role in Administering SCIG Therapy**

The use of SCIG administration has been increasing over the past few years, and there are now several products on the market. SCIG offers several advantages for the patient. IV access is not needed because the drug is administered in the subcutaneous tissue. A steady state of IgG is maintained, providing better long-term coverage from potential infections. And, the patient tends to have less systemic side effects. Ultimately, the goal is to allow the patient to become independent in therapy and to self-administer his or her infusion on a weekly basis, and the nurse plays an essential role in this.

The nurse administering or teaching the patient to administer SCIG should be knowledgeable about the drug’s clinical indication and implementation and should demonstrate competency in clinical judgment and practice. Patient education is a crucial element to the success of SCIG therapy. The nurse should always maintain and educate the patient regarding infection control practices and aseptic technique. And, he or she must understand how to manage patient side effects and to recognize the most common ones.

Site selection and needle selection play an important role in the proper administration of SCIG. Often, the nurse will educate the patient regarding needle comfort. If the patient is new to SCIG, the nurse can explain the use of different needle lengths and the option of choosing multiple sites. In some situations, the nurse may encourage the patient to use several sites at once, thereby administering less volume of IG into each site.

When teaching the patient to self-administer, there are two essential points. First, the patient should be taught to prime the drug but to not allow the drug to flow toward the end of the needles. Allowing a “dry stick” (when the drug does not reach the end of the needles) helps decrease skin reactions. Second, once the needles have been inserted, checking for proper placement is crucial. The nurse and/or the patient must draw back on the plunger to check for a blood return. If a blood return occurs, the needles may be entering a vascular area. When this happens, the needles should be discarded and a new set should be primed and inserted as instructed.

Site reactions, which include swelling, itching and redness, occur frequently in patients. These reactions should decrease over 24 to 48 hours as the drug is slowly absorbed after the infusion, and they should decrease in occurrence over time. For instance, reactions occur more often in patients who are initiating therapy, and they usually decrease over the first eight to 10 weeks of therapy. It’s important for the nurse to educate the patient regarding local reactions and symptomatic treatment of them, including warm or cool compresses (whichever is preferred by the patient). But the patient should be instructed not to use hot compresses, as they can cause the drug to absorb too quickly.

Even after the patient becomes independent with SCIG, ongoing patient education is important. And, while the nurse’s responsibilities may decrease compared with those of IVIG, his or her responsibilities are still vastly important.

**Ensuring Expert Care**

The infusion nurse plays an important role in the proper administration of IG therapy. To ensure expert care, the nurse must maintain the necessary qualifications and education. And, he or she must understand that a key component of both IVIG and SCIG administration is patient education. Throughout the infusion process, the goal is to instill trust and confidence in the patient and to maintain professionalism in the patient-nurse relationship.

**CINDI VOKEY, RN, BSN, is the clinical educator at NuFACTOR Specialty Pharmacy.**

**References**

“My life turned around and improved when…”: This was the leading sentence we asked IG Living readers to finish when writing their entries for our third annual essay contest. These words sparked entrants to share heartwarming and inspirational stories about their personal journeys of living with a chronic illness. From dozens of entries, the first-, second- and third-place winners were chosen. Featured here is the winning entry. The second- and third-place winners’ essays will be published on IG Living’s blog in August at www.IGLiving.com/blogengine.

A Father’s Pride

MY LIFE TURNED around and improved when I pierced my daughter’s skin for the first time. She was 5 years old. Due to her immune deficiency, she had received hundreds of needles by that point, always from nurses, and always in hospitals or doctors’ offices. For a dad with no medical background (I never even took high school biology), leaving the responsibility with the professionals felt appropriate. Piercing her skin myself seemed the reverse of everything I had hoped to be as a parent, and I wept the first time I did it.

Since her diagnosis of common variable immune deficiency, we had been driving an hour to the hospital once a month for her intravenous immune globulin (IVIG) infusions. The infusion room nurses were experts, and we loved them, but we were not their only patients. After slogging through traffic, we had to wait for a blood draw, and wait again for the IG to be prepared and the pump to be programmed. Then, after hours of VHS videos, fluorescent lights and vending machine snacks, we stumbled, exhausted, back to our car in time for evening traffic. Those were long days, a monthly interruption that we accepted because we had no other options.

When our immunologist brought up the possibility of shifting to weekly subcutaneous IG (SCIG) infusions that we could administer at home, we were skeptical. Did we want to think about infusions that often? Maybe it was better to keep our daughter’s treatments in the hands of the professionals. Maybe it was better to keep her infusions separate from the rest of our lives.

Continued difficulty with finding a vein settled the question. To avoid installing a port in my daughter, we opted for the SCIG route and found ourselves being trained in our own kitchen by a wise and patient home health nurse. Soon, I was flicking a syringe to get the air bubbles out. Soon, I knew the tricks to getting the last precious drops of IG from the vials (injecting air makes it easier to get the fluid out). Soon, I was programming our own pump, adjusting the speed and monitoring the volume on a device I had previously ignored. Soon, I was doing what I never wanted to do: piercing the skin of my child.

And instead of taking over our lives, SCIG gave us our lives back. Our daughter, now 11, gets her infusions every week, but at whatever hour is convenient for her. She programs her own pump, and carries it with her in a small purse. She does not visit hospitals much — the occasional checkup with her immunologist is all. Instead, she gets infused while doing homework, going shopping or watching a movie. What was once a chore has become routine, even mundane.

The change is profound. Instead of something being done to her, an infusion is now something our daughter does to take care of herself. The difference was never more striking than during the holidays, when a big party was scheduled on an infusion night. Our daughter wore her pump, and halfway through the party stepped away from the kids’ table so I could disconnect it. When I returned to the party after putting it away, I found her back at the kids’ table, surrounded by a ring of girls, all listening open-mouthed to her explanation of her pump and what it does. “Aren’t you scared to get poked?” “Nah, it’s no big deal.” And I wept again for my little girl whose infusions are a part of her life, but not what defines her — something that makes her brave and keeps her healthy, instead of sick.

BENJAMIN R. KARNEY is a professor of social psychology at the University of California, Los Angeles.
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After living for years with the life-altering symptoms of chronic inflammatory demyelinating polyneuropathy (CIDP) and the equally debilitating treatment side effects, Mary Busch made a brave and, some would say, radical decision: She applied for a stem cell transplant trial.

**Trudie**: Tell us about your journey to CIDP diagnosis.

**Mary**: My symptoms started about a year before my CIDP diagnosis in 2004. I had intermittent pins and needles in my fingers and toes. Over the next few months, the pins and needles continued to spread throughout my arms and legs. Eventually, I started having numbness, pain, muscle weakness and extreme fatigue. After I took a fall, my primary care doctor immediately sent me to a neurologist. By the time I was diagnosed, I was unable to walk independently or lift my arms, and my limbs were completely numb.

**Trudie**: What were the most significant lifestyle changes you experienced after developing your illness?

**Mary**: I wasn’t able to do all the physical things I loved such as running, volleyball and taking care of my family. Sometimes, I couldn’t even take care of myself. The prescribed treatment for my disease made things worse. High-dose steroids were the first treatment, and though they helped with my symptoms, the side effects were terrible. I started gaining weight, developed high blood pressure, and my joints swelled. Later, I was switched to intravenous immune globulin (IVIG), but also developed side effects, including severe headaches, nausea and vomiting. I usually spent four eight-hour days a month being infused and a week after that recovering from the side effects. I was barely functioning and, before long, was not able to work. Eventually, I was diagnosed with aseptic meningitis syndrome from the infusions. The last 10 years have taken quite a financial, emotional and physical toll on me and my family.

**Trudie**: Tell us about your decision to pursue a stem cell transplant.

**Mary**: I decided to pursue other options after a bad relapse two years ago. I was in a wheelchair unable to take care of my own basic needs and in constant burning pain. My health was progressively getting worse, despite treatment. I found a website called www.clinicaltrials.gov in the back of *IG Living* magazine. I always thought trials were a last-ditch effort and never felt my disease was severe enough to enter a clinical trial. My view changed after the last relapse. I decided to search the site and found a stem cell transplant trial for CIDP at Northwestern University headed by Dr. Richard K. Burt. I decided to apply last June and was accepted.

**Trudie**: What was the procedure like?

**Mary**: The stem cell process is pretty grueling. The first step was pre-transplant testing to make sure my body could handle the transplant process. Then, I was admitted for an initial dose of chemo to start conditioning my immune system for transplant. Following the chemo, I started self-injections of Neupogen to stimulate stem cell growth for harvest. About a week later, my stem cells were harvested by a procedure called apheresis. After harvest, the main part of the transplant began with seven days of chemo to send my white blood counts down to zero. At that point, my stem cells were given back to me. The chemo made me really nauseous, and I developed fevers, but the staff was right on top of every complication. Nine days later, my stem cells engrafted (repopulated), and I started producing enough white blood cells to go home. I spent about two months in Chicago for the whole process.
Trudie: What is your prognosis now? Are you “cured”?  
Mary: My short-term prognosis is good since I have shown improvement without treatment. Long-term is unknown at this point because the study is not finished. However, many previous CIDP stem cell patients are still doing well years later without any treatment. The doctors will not say cure, but they will say long-term remission. I like to think this is a cure. 

Trudie: How has your lifestyle improved since the transplant? 
Mary: My lifestyle has improved greatly. I have been walking two to three miles every other day. I have been swimming, starting to bike and even went kayaking. Household chores, grocery shopping and cooking meals no longer totally wipe me out after an hour or two. These things seem small, but I haven’t been able to do that in years. 

Trudie: What were the risks going into this, and how did you balance them against the potential benefits? 
Mary: The transplant can have risks from chemotherapy. Infection is the greatest risk, especially when you are neutropenic (a critically low white blood count) in the hospital, but the staff really takes every precaution to avoid any problems. I knew my health was declining with each relapse, so I decided that it was worth the risk. The hard part of chemo was short compared with getting my life back. Even knowing I would get sick and lose my hair, I would do it again in a heartbeat. 

Trudie: Were there any out-of-pocket expenses for participating in this trial? 
Mary: The stem cell transplant is in Phase II and is not funded by any pharmaceutical company, so it is expensive. My insurance company paid for the medical part of the transplant but not other expenses such as lodging, transportation, food, etc. I had to cash out some of my retirement and had help from my parents to pay for all the out-of-pocket expenses, but it was worth having my health back. Some patients have paid for it by fundraising, so it can be done. 

Trudie: What has this experience taught you? 
Mary: The stem cell experience has taught me that I can make it through anything and, hopefully, in the process inspire others that they can make it too. My advice to other patients is to never give up on themselves or on medical science. You never know when the next breakthrough will come.

If your life depends on immune globulin and you have a unique experience to share, we want to feature you in this column! Email us at editor@IGLiving.com.
TEEN TALK!

Preparing Ourselves for the Future

By Tyler Carlsen

TRANSITIONING THROUGH the years from grade school to college is a very big leap for everyone. But for people like me with chronic health conditions such as immune deficiencies, the leap can feel larger than it is. Our level of independence is raised along with our responsibility. We’re solely in charge of our own fate, and we have to make choices that will yield the best outcome.

Think back to a normal day in grade school. Healthy kids woke up early, rushed out the door to catch the bus to school and sat in their classes and saw their friends. Although they may not have liked school, and they may have sometimes been bored by it, they always looked forward to going.

For me and others with chronic illness, our experience was a little different. On an average morning, my day would start with daily aches and pains; oftentimes I had a sinus infection that I’d been fighting for weeks; and I was frequently tired because I didn’t get as much sleep as I wanted since I was anxious thinking about the future. I would get up, push myself out the door and, most of the time, leave school early due to how I felt.

For those who experienced the first situation, thinking about what the future holds is exciting and even a little thrilling. For those like me, the future is a very unpredictable thing. For years, we’ve been at home getting our treatments, seeing our family and friends and just feeling safe. Now, we’re going to be in a brand-new place on our own, and we have to figure out how to regain the sense of comfort and stability we had at home.

Fortunately, there are some things we can do to ease the transition. Here’s what I did. I started by visiting my local doctor’s office to set up an infusion schedule and form a relationship with the staff. I also began making friends in my new location to build a support system, but I remembered and used my support system back home as well. And, I created a routine to help balance my life. In short, I planned my schedule in a way that gave me time to stop and breathe while still allowing me to accomplish all my daily goals.

Although some of my advice may seem a little frightening to those like me, my point is that we have the ability to begin and maintain a completely normal and happy life no matter what the circumstances may be. We just have to be prepared to face any challenges that we may encounter and stand strong, knowing that those challenges are only temporary. I am happy to say that I am no longer afraid of what the future holds, and I am ready for what comes next.

TYLER CARLSEN was diagnosed with common variable immune deficiency at age 8. He is currently a student at Cape Cod Community College, where he is an aspiring filmmaker studying video production. Tyler also enjoys writing and has been a past contributor to IG Living.

Check out the IG Living Teen page at IGLiving.com/IGLTeen.aspx

Teens with a chronic illness who rely on IG therapy have unique life experiences. This column is an opportunity for them to share their stories and to connect with other teens. Teens are invited to submit their stories of 600 words or fewer to editor@IGLiving.com.
THOSE OF US with a chronic illness should know that nothing is ever textbook. There is no plan to count on, and we are usually forced to be the most spontaneous people alive because our bodies never tell us ahead of time about the wild ride we are about to take! But we learn to just go on and cope with the unexpected in the best way we can.

I thought I was as educated about childbirth as almost any doctor or midwife. I scavenged blogs written by moms. I read books and articles written by so-called experts. I asked my team of specialists all the questions for every hypothetical event I could think of. I made sure to compile a directory of their phone numbers in case I needed anything.

My bag was packed to go to the hospital weeks before my due date. The car seat was installed, and I had the cutest little outfit picked out to dress my little boy in when it was time to take him home. I was so excited to not only meet the little man that had been living inside me for the last 39 weeks, but also to put into action all that I had learned.

The moment that was going to change my life forever was upon me, and yet the stress of the unknown was distracting and even a bit scary. I listened to calming music, did a little meditation and envisioned a smooth, complication-free delivery. I left no stone unturned!

It’s laughable now, but at the time, I found very little humor in what happened. The moment I arrived at the hospital, all of my preparation went out the window. I knew I was going to be induced, but I had no idea that being induced could take up to five days! I guess I was lucky to have to sit in that hospital room for only two-and-a-half days before labor finally started. And, I had no clue that, once the contractions started, my son would be delivered six short hours later and in the middle of the night — when everyone else was sure I had at least another 12 hours.

Never for a second did I imagine that my baby would have the umbilical cord wrapped around his neck, or that I would have to wait almost 45 minutes to hold him because of my own complications. I never planned on spending six days in the hospital because my bladder didn’t want to function on its own. And, I certainly never planned for a return trip to the emergency room with a raging infection and having to leave my newborn baby for the first time after just five days.

I also never expected to be so emotional. I had heard about the hormone crash after delivery, but for some strange reason, I never thought it would happen to me. Boy, was I wrong. If anyone mentioned sleep, milk, diapers, food, medication or even told me what time it was, I would start to cry. If someone had told me nine months earlier that the sight of a breast pump would turn me into a sloppy, sobbing mess, I would have told them they were nuts. But, that’s what happened. My reality was so far off from what I had anticipated.

I am happy to report, however, that after two months, I was out of the thick of the chaos and unknown. I know there are many more adventures to come. And, I feel I have gained some perspective and have a slightly better grasp on reality. I realize that what I went through wasn’t typical, but most of us chronically ill people know not to expect the textbook version of anything. And, I have learned firsthand that the greatest struggles often bring the greatest joy. Now, when I hold my baby, I feel like I have accomplished something profound — not just by creating a life, but creating one with my compromised and disabled body. I’m blessed.

EVER FECSKE MAZZA was diagnosed with CVID and interstitial lung disease in 2004. She is a new mom of a sweet little boy named Boston, and loves every minute of it! She lives in Los Angeles, Calif., with her husband, and when she isn’t changing diapers and playing with her son, she enjoys wedding planning, baking, flower arranging, cooking, shopping and anything that sparkles!
Somehow, it always comes down to the mother.

The first person a teacher asks to speak to when a problem arises. The first person a physician discusses a medical issue with. The person the other mothers — at soccer and baseball practice, at Scout meetings — whisper about when she leaves the room.

That child is too thin!
That child is too heavy!
That child is too short!

And then…
What is she doing wrong? Why doesn’t she do something to fix this? Surely, she must see The Problem.
Surely.
Surely, the mother sees the problem. She drops off her child with a smile and a wave, heads back to her SUV to rest her head on the steering wheel. She closes her eyes tight, unable to un-see the differences. The Problem. The fact that her child is unlike his peers; there are glaring discrepancies in the size of her child and the size of the others.

What have I done wrong? Why can’t I fix this?
Surely, she sees what the other mothers see.

And she sees the other mothers. She notices the way they turn their heads — just slightly — when her child joins the group. Are they checking? Checking to make sure their children are still superior? That The Problem hasn’t somehow affected the perfection of their offspring?
She sees them catch one another’s eye, each in turn. A fraction of a second — barely that — but still. Enough.
She hears the artificial coating in the invitation that comes just a little too late; the unnecessary volume in the equally unnecessary reassurances: “He’s just a late bloomer” or “He’ll slim down once he hits that growth spurt.”
She hears the words that are implied, but not stated out loud.
“He’ll be fine, as soon as you figure out where you went wrong, and fix it.”
Judge and jury.
They cannot understand how desperately she loves him. How completely she would sacrifice to be able to fix The Problem.
Mother love equals mother guilt.
She knows something isn’t quite right. This isn’t her first child; she knows what is normal, average — and she just knows something is off.
Not quite sure what it is. Just — something. But, how could that be? She was so careful. No drinking, no smoking, no caffeine. Forty weeks of carefully measured actions. Vegetables. Milk. No undercooked meats. Never missed a prenatal appointment. No drugs during the birth.
Not quite sure what it is. Just — something. But, how could that be? She was so careful. No drinking, no smoking, no caffeine. Forty weeks of carefully measured actions. Vegetables. Milk. No undercooked meats. Never missed a prenatal appointment. No drugs during the birth.
She breast-fed. They said that would be better. Safer.
Well-child checkups are passed with flying colors. Hesitantly, she voices concern to the physician.
Her worries are blown off, like an insignificant kite detached from a string.
All mothers worry. You’re just overly tired. All babies are different. Nothing is wrong.
Nothing is wrong.
Nothing.
Except … she knows there is something. But she lies to herself. She convinces herself to believe all is well. When the worry rears its head in her throat, lodging there like a child’s bouncy ball, too big to move either up or down, just … stuck — she busies her mind. Turns up the TV. Calls a friend to gossip about nothing. Furiously cleans. Invents extra errands. Pushes the worry down, down, deep into her gut, where it belongs.

Until The Event. The Dreaded Something that changes the minds of those who dismissed her initial concerns.

The day the doctor sits her down and speaks to her in slow, easy-to-understand words. Do you understand? Yes, she understands. She looks him in the eye, forces herself to listen. She listens, but the pain in her chest makes her hold her breath. Oddly, she remembers another time when she felt this way. When was it? She searches her memory.

First grade. On the playground, standing on the swing with daring. Clutching tight at the chains biting into her fingers, she calls fearlessly to her friends, “Underdog me!” and sails away, up, up, up into the sky.
She falls. Hits the ground with a sickening thwack. She lies there, so
much pain in her chest and back she cannot breathe. She wants to cry out, but the air in her chest sits heavy as a block of ice. Unmoving. She is frozen.

This feels like that.

Labs. Tests. Appointments. Precriptions. Journals. Journals! Logging every bite that passes the child’s lips; every new symptom; every night that passes without rest; every unusual behavior. Furiously, she scribbles into the journals — here, she is certain, the answer will appear. A pattern will emerge, and whatever it is that has caused the Dreaded Something will show itself. She will eliminate it, and everything will be OK again.

She will be able to breathe again. She misses the way it used to feel, back when she could breathe without even thinking about it.

She cannot find the pattern. She cannot find the answer.

Sitting in the tiny exam room that has become far too familiar, she waits. The door creaks open, the physician enters and takes a seat on the little spinning stool. Small talk. She eyes the folder in his hand. She does not want to talk. She only wants the magical answer, the sword that will slay the Dreaded Something. She considers snatching the folder out of his hands. She smiles. She waits.

Finally, the answer comes. The block of ice in her chest somehow spreads to her shoulders, arms, head. She feels the slow freezing of her entire being. Her teeth begin to chatter.

It is her fault. The doctor says it jokingly. “Isn’t it always the mother’s fault?” He chuckles. It lingers in the air, like hot breath on a frigid day.

Here it is, then. The answer. She has done this to her child; her body, her genetics, have caused the Dreaded Something. She cannot take it away. She cannot fix it.

Doesn’t he see how much this hurts? He laughs and says he should create a frequent-flier parking spot just for her family. Does he understand she would willingly give her home, her arm, her leg — her life — anything, anything to fix this?

Mother love equals mother guilt.

Sometimes at night, she hears the muffled strains of guitar strings being plucked and closes her eyes, listening, a smile on her lips. Her child has struggled so much, lost so much, grown so much. Still, her child finds beauty in small things: a brightly colored bead, an unusual sunset, a new song.

She hurries dinner in order to make it on time to school conferences. The teacher laughs as the report card is handed over: “If only I had a classroom of kids like this one, I’d be happy to come to work every day!” She feels a warmth, a melting in her icy chest. She straightens her shoulders and takes a deep breath.

Her heart constricts, her chest hurts as she watches the IV insertion. She rubs her child’s back, watches as his eyes follow the hands of the nurse. Alcohol rub, gauze pad, syringe, bandage. He knows the routine; he knows once every item is in its own place, the poke will come. He sits up tall, back and tiny shoulders straight. He does not blink or turn away. He watches with detached curiosity; he holds his breath, scrunches his nose — there, it’s over. All done. He smiles and cracks a joke; his nurse laughs. She kisses his little head and tells him he is brave. She thinks to herself he is stronger than most grown men.

A child is bullied on the playground. A new child, and something about him makes him stand out. Something isn’t quite right. He has a Problem. She watches as her child leaps in front of him, arms outstretched. Chin up, eyes blazing, her child protects him. The bullies back off. Arm slung about the new child’s shoulder, her son offers to play with him, introduce him to some nice kids. Her eyes water with liquid pride. He has endured great pain, but he is such a compassionate boy. The Champion of the Underdog — he will not stand for hateful words or unkind actions.

She looks at the children she is raising. Kind-hearted, compassionate. Honest, cheerful. Funny. Creative. Loyal. These things are also her fault. She loves them with an intensity that burns the ice.

Mother love equals mother guilt.

VALARIE KINNEY is the mother of four children, three of whom are diagnosed with common variable immunodeficiency.

Patients who rely on IG therapy have unique life experiences. If you have a story you’d like to share about your adventures, experiences, relationships, reminiscences, self-portrayals, etc., for publication in this column, submit it to editor@igliving.com. All submissions must be 600 words or fewer and can be accompanied by high-resolution photos.
“BUT I DON’T WANNA do homework, Mom!” my primary immune deficiency disease kid Caleb whined.

Nurse Nancy, our better-than-wonderful homecare nurse, gave me “the look” she had been giving for the past eight years. It’s a “stand-your-ground, you’ll-both-survive-this” look that has gotten us through many infusion-day battles.

Caleb had just gotten hooked up to his lifesaving, life-sustaining intravenous immune globulin (IVIG) and had been pre-warned to bring the morning’s assignments he’d be missing during his infusion. He had, yet again, “forgotten” to bring them home the day before.

“I just, well … I dunno, forgot, Mom,” Caleb tried to explain in his best eighth-grade studentese.

We had just recently changed his 504 educational plan’s language to read that unless Caleb was physically unable or sick, infusions created an opportunity for him to make up missing and/or current school assignments. We, “the educational plan committee,” thought it to be a brilliant move; Caleb considered our bold changes to his 504 plan a call to arms.

“So, what are we going to do about this? You know you’ll have to make up your missing work eventually, Son,” I nagged.

“Caleb, all they are doing is setting you up for success,” Nurse Nancy cooed, turning both Caleb and me into human puddles of goo.

“How about we make a deal, Mom,” Caleb chimed in with earnest grit.

“What kind of a deal?” I asked, skeptical of Caleb’s 14 years of deal-making experience. Nurse Nancy gave me “the look” for a shot of self-assuredness. She strategically took Caleb’s vitals to see if it would throw his confidence off. No such luck, as Caleb dove right into the rules of engagement.

“Mom, I understand that you expect me to do my missing assignments while I’m infusing. I get it. But I’d like to respectfully agree to disagree with you.”

I’m impressed with my inexperienced challenger, but a sweeping inferiority complex feeling grips me. All I can muster is, “Ohhhh-kaaaaay,” as if I was trying to save myself from certain annihilation.

“Think about it. I’m hooked up to a machine that interrupts my thoughts every few minutes, not to mention how important it is for Nurse Nancy to take my vitals every half an hour or so,” Caleb reasoned. “You also know Benadryl makes me sleepy, and for whatever reason, I’m constantly hungry, and the Military Channel always seems to be running a special while I’m getting my IVIG — all very good reasons why I can’t seem to get any work done.”

Caleb looked my way and waited for a response, and all I was able to spit out of my mouth was “Ohhhhh-kaaaaay.” He had me in a trance; his strategy was working.

“I propose that I will, at my next infusion, do schoolwork if you agree to put yourself in my boots and make your brain work at your next infusion,” Caleb challenged.

I couldn’t think. He had me at Benadryl. But after I snapped to attention, I realized he wasn’t making an impossible request. Sure, this is easy! I reasoned. I’m on deadline for the magazine, and my five-hour Remicaid infusion makes for perfect time to pull a good article out of my, uh, brain. Yes! This is a slam dunk!

“Challenge accepted, Son!” I announced with General Patton-esque resolve. “I will work on my next article while infusing if you agree to do your schoolwork at your next IVIG infusion. Agreed?”

“AAAAAbsolutely!” Caleb concurred with equal determination.

“We’re on!” I announced.

“What a smoker this will turn out to be,” Nancy chimed in. Caleb looked at his nurse cockeyed. “It’s a type of boxing match, youngin. See, you can be taught,” Nurse Nancy scolded.

“Yeah, but who’s gonna school who?” Caleb mocked.

Nancy looked at my calendar and whispered into my ear: “Your infusion
is tomorrow.” I waited for “the look,” but it was nowhere to be found.

My infusion started off like clockwork: Port-a-catheter accessed, good blood flow, heparin, saline flushed, and then joint-preserving fluid began to fill the maze of tubing that hung from my CADD pump. I was at least a good five hours in the comfy chair my infusion company provided, so I thought I’d take advantage of the quiet and started to write. I placed my laptop onto my lap, put my fingers on the keyboard and, just when I was about to spill my brains out, my reimbursement specialist knocked on the door and asked, “Yooou Whoooo! Is there anybody in here?”

Geri and I spoke for a while about my co-payments and how the new calendar year was affecting my infusion coverage, and then she made her way to the next patient. A hush of silence filled the room as I resumed my task at hand.

A few paragraphs later, I noticed that all I had written was zzzzzzzzzzzzzzzzzz. I woke up with my mouse dangling by my side. Two hours gone in a Benadryl-induced coma! I tried shaking off my sleepy existence as my nurse made her way in.

“Did you have a nice nap, Cheryl?” Tamber asked in her sing-songish, nursey slang. She poked a thermometer under my tongue, disabling my ability to answer her, then wrapped the blood pressure cuff around my arm, filling it with ample air, or so I thought, and then gave the bulbous ball a few more squeezes. Turns out, my vitals were pretty perfect, as I expected them to be after a nice two-hour siesta.

My grouchy stomach told me we were dangerously close to lunchtime and, sure enough, in walks my husband, Mark, with our traditional infusion-day fare: takeout from Yu Nied Sum Luk. Mark stayed through an hour of ESPN, then decided, “Well, I’d better get going. The kids will be home soon, so give me my marching orders.”

Mark’s good-bye tour included 15 minutes of talking with the infusion center staff and 10 giving me an unsolicited back rub that threw me into another Benadryl- and Chinese takeout-coma. I woke to Tamber’s gentle voice saying, “Cheryl, it’s time to de-access you, then 45 minutes of observation. Cheryl, can you hear me?” Oh, I heard her. I just wanted her to float away on the imaginary cloud she inhabits.

Mark was asleep in a chair next to me, a fortune cookie was strategically placed on his chest, which rose up and down with every breath he took. I looked down at my blank computer screen and decided I might as well concede defeat. With about 30 minutes left, all I could do was hope for a few tidbits of new information learned from cable TV to share with our three kids whom Mark was sorely late in picking up.

“So, Mom, what did you write about this time?” Molly asked with a mouthful of mashed potatoes.

“Uh, you know. The same ol’ stuff, another day,” I said, ducking my innocent daughter’s question and then filling my mouth with meatloaf to avoid answering another. Then, it happened. I just couldn’t dodge another bullet from my family. I had run out of excuses, and I had to face the music.

“Well, guys, instead of writing my article, I decided to learn at least five new things while I was infusing today. Don’t you think that’s clever?” I tried to sell it to them, but nobody was buying.

“So, what did you learn, Mom?” Caleb sneered.

His older brother, Calvin, added an empathetic, “Yeah, whaddidja learn there, Mommy Dearest?”

Mark buried his face in tapioca pudding as if he was an ostrich; it was his only parental salvation.

“Well, you’d be surprised what I learned, Momma’s Little Darlings,” I shot back with Momma moxie. “I learned that sex can sell a bottle of barbecue sauce; garlic is Greek for “scent from heaven”; Tiger Woods is dating U.S. Ski Team’s Lindsey Vonn; there is something called a fish pedicure where a tank of carp nibble dead skin off your feet; and, finally, I’m only about a level-two hoarder.”

Our dinner table was in silent awe of my report. In all honesty, I had to be the bigger one to say it’s quite difficult to get anything done on infusion day other than watching bad cable. “So, I’ll go lighter on you from here on out, Caleb. I still expect some sort of work completed, but not the load we wrote into your 504. I’m so sorry.”

“Don’t worry ‘bout it, Mom,” Caleb said, forgiving me for being so hard on him.

“So, who schooled who?” Calvin asked.

“According to the Entertainment Channel your mom was watching, the only person getting schooled today was Kim Kardashian!” Mark interjected. “She’s the one who got ‘schooled’ by the carp eating the dead skin off her feet!”

We all agreed that night that sometimes no news is good news.

CHERYL L. HAGGARD is a stay-at-home mom and has three children, two of whom have CVID. She and her husband, Mark, also operate Under the Hood Ministries at www.underthehoodministries.org.
Parenting:

Losing the IV Pole: What to Do While Infusing

Infusing IVIG or SCIG doesn’t have to interfere with all the good things in life.

By Mark T. Haggard

I HAVE spent a few hours coaching basketball during my career. Some years ago, I was coaching a team of girls that was better than some teams, but not as good as others. We were playing against one of those teams with which we were not equal, getting beaten by 10 points. I looked down the bench and called for Marissa to go into the game. The first time she touched the ball, she drilled a three-pointer from the corner. The next time, three-pointer. Third time, she faked the three-pointer and drove the baseline for two. Then, she asked to come out of the game. I shook my head incredulously.

“I have to come out,” she mouthed.

“No,” I demanded. “Keep shooting the ball!”

“I really have to come out.”

“We’re down by four points. You could win the game for us.”

“Put Shelly in for me.”

“Time out!”

I got my team together, slightly disgruntled, and planned out our strategy for the rest of the quarter without my hot-shooting guard. Out of the corner of my eye, I watched Marissa take out a needle and put it into her belly. “What are you doing?” I asked.

“Infusing myself.”

“Infusing?”

“Yeah, insulin.”

I was mesmerized as I watched her click the pump. Then I looked at the scoreboard and saw that we trailed by 10 points again. “Get me some tape,” I growled. “I can strap the pump to you and get you back in the game!”

Marissa smiled and shook her head. “Sorry, Coach.”

Infusions sometimes interfere with the great things in life, but kids don’t have to be completely debilitated by them. Their lives do not have to end for hours at a time while they infuse. Certainly, no doctor would recommend strenuous activity like a high school basketball game, but kids can still find ways to be active and not be robbed of their lives.

When asked on the IG Living Facebook page what immune globulin (IG) patients do while infusing, most respondents said that they sleep, read or watch TV or a DVD. Laurie, who receives subcutaneous IG (SCIG) to treat her common variable immune deficiency, enjoys her “Do Not Disturb” time, relaxing and enjoying her peace and quiet, reading, watching TV and going for an occasional walk; she has even gone shopping while infusing. Sandy said that if she does not have paperwork to do for her job, she pulls out her iPad and reads, surfs the Internet, or catches up with her Facebook friends. Many primary immune deficiency disease patients are finding
that they need not be tied down by an IV pole.

**Intravenous IG (IVIG)**

When my kids were first diagnosed with an immune deficiency, they received IVIG infusions at Central California Children’s Hospital. We packed a picnic basket with lunch and brought it with us to the Ambulatory Infusion Clinic. After our kids took a nap, we would eat our picnic lunch. Then, we would put our kids in one of the wagons provided by the hospital and go sightseeing. Once, I turned my back near the outdoor play area only to turn around in time to see my son ascending the monkey bars while fully infusing; the needle in the back of his hand would not stop him. That was the last time he saw the outside play area while his needle was in. The hospital had its own school on site, and we would go see the teacher and have him show off the stuff in his classroom, which had an Amazon River bullfrog living in a terrarium. When the bullfrog wasn’t active, he would lie still and flat like a pancake. Afterward, we scheduled our kids’ infusions for the days the bullfrog was fed a huge cricket. Except for the needle poke, it was a fun trip for our children.

Now, both of my children are older, and they receive their IG at home. My son still gets IVIG. Every fourth Thursday, “Nurse Nancy” comes to the house, accesses his port and starts his IVIG. While infusing, his first responsibility is to do classwork that he is missing from the school day. If that gets done, he goes upstairs to play on the gaming system. (We don’t have an Amazon River bullfrog.) He enjoys the time off from school, but the needle stuck in his clavicle definitely limits his activity.

My wife now receives intravenous Remicade for her ankylosing spondylitis and reactive arthritis. Every four weeks, I take a day off from work and spend time with her while she infuses at the local infusion center. We discuss our goals and dreams. We look over our family’s calendar and our budget. Around lunchtime, I go out to fetch lunch at the nearest Taco Bell or Chinese takeout. We then have lunch together: It’s a Date Day.

**Subcutaneous IG (SCIG)**

The proliferation of subcutaneous infusions has opened many doors for those who are treated with IG. No longer are patients bound to an IV pole and limited in what they can do. My daughter is treated with SCIG, and since it is less cumbersome, she sometimes forgets that she is infusing. She is intent on not letting a couple of small needles in her stomach stand in her way. I was horrified one afternoon when I pulled back the curtains and saw her jumping on the trampoline in the backyard while infusing.

SCIG does allow my daughter to continue activities that are off limits to my son while being treated with IVIG. Between the pump and needles in my daughter’s SCIG setup is 18 inches of “spaghetti” line. As long as those are tucked up, my daughter can be quite active. She has discovered that her infusions are a minor hindrance to her otherwise active life. She takes walks with her family. She rides her bicycle, sometimes meeting her friends at the library for video games and a good book. As long as there is no possibility of her needles dislodging, SCIG will not slow her active life.

**The proliferation of subcutaneous infusions has opened many doors for those who are treated with IG.**

**Leaving the IV Pole**

Infusion time does not need to be downtime; patients need not crawl into a hole while receiving their IG. The IG Living Facebook page and the recently launched IGL Teen page on Facebook are great outlets for those getting their infusions — to find friends, give and take advice and to communicate with others who understand what they are going through. The advent of SCIG infusions frees patients from the IV pole and allows them to continue the activities that enrich their lives. Whether Facebooking with others, shopping, going on bike rides or watching kids play at the beach, patients need not let an infusion rob them or their loved ones of their active lifestyles.

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FOR PATIENTS who receive immune globulin (IG) therapy, a four- to six-hour infusion can seem endless. That’s why experts recommend patients bring portable entertainment projects and comfort items to their treatments to help them pass the time.

According to Healthcare Architect Michael Pukszta, “Researchers discovered a very strong correlation between a patient’s emotional well-being and receiving treatment in an environment that offers positive distractions. Positive distractions are elements in the environment that offer patients a means of mitigating stress. These distractions can be visual or auditory and are often interactive.”

Activities to Occupy Time

Various activities can help IG patients occupy their time during treatments. One activity is to catch up on what blog readers call a blogroll, which is a list of blog links that bloggers recommend to their readers. Blogrolls are offered in a wide assortment of interests ranging from chronic disease and fitness to photography, music, wedding and travel. Educational, inspirational and humorous blogrolls also are available.

For those who wish to tune out the world during treatment, a good pair of noise-cancelling headphones can help. These multitasking headphones use active noise control to neutralize unwanted sound, which can provide silence for patients seeking repose as they sleep. They also are wonderful for patients wishing to read a book, work on a mind game, or listen to movies, audiobooks or music without outside sound interruption.

Handiwork projects are a way for patients to keep their hands busy during infusions. These projects can include anything from knitting, crocheting and sewing, to scrapbooking and photo album creation. Many IG patients find this form of activity especially gratifying because it gives them something to show for their time in the infusion chair.

Patients who simply want to relax and decompress can find solace through prayer and meditation. This form of mental relaxation can help patients refresh their minds, maintain a positive outlook, and enable them to weather the trials that come with living with a chronic health condition. According to a study conducted by Dr. Andrew Newberg, director of the Center for Spirituality and the Mind at the University of Pennsylvania, “Prayer and meditation increase levels of dopamine that are associated with states of well-being and joy.”

Comfort and Privacy Tips

Pukszta also mentioned that researchers discovered many patients who undergo infusions prefer to have control over their environment. “Providing patients with options for controlling light, temperature, sound and glare can give patients a sense that — while they may not be in control of their disease — they can have some control over their treatment environment and make themselves as comfortable as possible,” he says.

But, large, public-style treatment rooms make privacy and temperature control a challenge. One possible solution is to pack a heated throw. Heated throws are large, warm, come in a variety of fun colors and patterns, and give patients an opportunity to have more control over their environment and their privacy. Favorite blankets also offer many patients, particularly children, the ability to bring a little piece of home to the infusion suite. Memory foam travel pillows are another element that can provide patients with a comfortable and secure place to rest their heads during treatment. In addition, these pillows offer a more relaxed sleeping posture for those who become drowsy.

Another way to make the infusion experience more enjoyable is with a portable reading light. Small transportable lights can help patients read, play games or write in well-lit comfort without disturbing others nearby. And, a sturdy lap desk can serve many purposes, including providing a stable surface for a computer, iPad, needlework and scrapbooking, as well as a convenient place for snacks and beverages.

Power to Enjoy

Whether patients are catching up on a blogroll, listening to music, praying for their well-being or getting cozy under a heated throw to take a well-deserved nap, the IG infusion room can become a diverting and relaxing environment.

CARLA SCHICK is a staff writer for IG Living magazine.

References

Sunbeam Microplush Heated Throw
The Sunbeam microplush heated throw features ThermoFine technology that senses and adjusts to deliver consistent warmth. The throw measures 50 inches wide by 60 inches long, is machine washable and dryer safe. The controls offer a low, medium and high heat setting and will automatically turn off after 10 hours.

Cabeau Evolution Travel Pillow
The Cabeau Evolution Travel Pillow is made with responsive memory foam to provide long-lasting head and neck support and comfort. The raised side supports prevent the head from falling to the side, and the adjustable sliding toggles can be fastened to hold the pillow in place. The pillow also features a media pouch to hold a cell phone or MP3 player, and the cover is machine washable.

Hug Reading Light
The Hug Light includes two strong, flexible, foam-covered steel alloy arms with two high-intensity, independently operated LEDs on each end. It offers hands-free capability, a 40-hour battery life, extra-wide and precise illumination and a rubber grip neck pad. The pliable material can be bent to hold any shape.
(800) 997-6971, www.huglight.com

Levenger Laplander Lap Desk
The Levenger Laplander is a flat lap desk that offers a removable poly-bead-filled cushion. Removable elastic cloth straps keep items like pens, books, eyeglasses and small electronics in place. The lap desk measures 23 inches wide by 15¾ inches deep by 2½ inches high and weighs 2 pounds, 8 ounces. It is available in natural cherry veneer with a cream cushion or dark cherry with a black cushion, and features a convenient carrying handle.

Beats Executive Noise-Cancelling Headphones
The Beats Executive Noise-Cancelling over-ear headphones use battery-powered noise cancellation to block out unwanted sound. The headphones also deliver clear, high-quality music. Designed for travel, they are lightweight, comfortable to wear and fold flat for easy storage. They come with a 3.5 mm audio cable, ¼-inch adapter cable, airline adapter, in-line control and microphone cable, hard shell carrying case and cleaning cloth.

Directory of Infusion Entertainment and Comfort Products
These organizations provide information about various disease states, which can be found by conducting a search of the disease state name.

- Advocacy for Patients with Chronic Illness: www.advocacyforpatients.org
- The Alliance for Biotherapeutics (fair access to plasma therapies): www.bioalliance.org
- American Autoimmune Related Diseases Association (AARDA): www.aarda.org
- American Chronic Pain Association (ACPA): www.theacpa.org
- Band-Aides and Blackboards: www.lehman.cuny.edu/faculty/jfleitas/bandaides
- eMedicine from WebMD: emedicine.medscape.com
- FamilyDoctor.org: www.familydoctor.org
- Johns Hopkins Medicine: www.hopkinsmedicine.org
- KeepKidsHealthy.com (pediatrician’s guide to children health and safety): www.keepkidshealthy.com
- Mayo Clinic: www.mayoclinic.com
- National Committee for Quality Assurance (detailed report cards on health plans, clinical performance, member satisfaction and access to care): www.ncqa.org
- National Heart, Lung and Blood Institute: www.nhlbi.nih.gov/health/health-topics/by-alpha
- National Institutes of Health: health.nih.gov/see-all-topics.aspx
- National Organization for Rare Disorders (disease-specific support groups and virtual communities for patients and caregivers): www.rarediseases.org
- Office of Rare Diseases Research: rarediseases.info.nih.gov
- Patient Advocate Foundation (patient access to care, maintenance of employment and financial stability): www.patientadvocate.org
- WebMD (medical reference): www.webmd.com
- Baxter: www.baxter.com
- Bio Products Laboratory: www.gammaphex.com
- CSL Behring: www.cslbehring.com
- Grifols: www.grifolsusa.com
- Kedrion: www.kedrionusa.com
- Octapharma: www.octapharma.com
- United Mitochondrial Disease Foundation: www.umdf.org
- MitoAction: www.mitoaction.org

For a more comprehensive list of resources, visit the Resources page at www.IGLiving.com.
Multifocal Motor Neuropathy (MMN)

**WEBSITES**
- Neuromuscular Disease Center at Washington University: neuromuscular.wustl.edu
- The Neuropathy Association: www.neuropathy.org

Multiple Sclerosis (MS)

**WEBSITES**
- All About Multiple Sclerosis: www.mult-sclerosis.org/index.html
- Multiple Sclerosis Association of America: www.msaa.com
- National Multiple Sclerosis Society: www.nationalmssociety.org

**ONLINE PEER SUPPORT**
- Friends with MS: www.FriendsWithMS.com
- MSWorld’s Chat and Message Board: www.msworld.org

Myasthenia Gravis (MG)

**WEBSITES AND CHAT ROOMS**
- Myasthenia Gravis Foundation of America (MGFA): www.myasthenia.org

**ONLINE PEER SUPPORT**
- Genetic Alliance: www.geneticalliance.org

Myositis

**WEBSITES**
- The Myositis Association, www.myositis.org, is devoted exclusively to all types of myopathy, 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, and advocate the need for early intervention and support research into the causes and treatment of myopathies. (202) 887-0088
- International Myositis Assessment and Clinical Studies Group: www.niehs.nih.gov/research/resources/collab/imacs/main.cfm

Peripheral Neuropathy (PN)

**WEBSITES**
- Neuropathy Action Foundation: www.neuropathyaction.org
- Calgary Neuropathy Association: www.calgaryneuropathy.com
- Texas Chapter of the Neuropathy Association: www.handsfeetheart.org

Online Peer Support

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)

**WEBSITES**
- P.A.N.D.A.S. Network: pandasnetwork.org

**ONLINE PEER SUPPORT**
- The Myositis Association, www.myositis.org, is to find a cure for inflammatory and other related myopathies, while serving those affected by these diseases. (202) 887-0088
- The Cure JM Foundation www.curejm.com (760) 487-1079
- Michigan Immunodeficiency Foundation: www.facebook.com/groups/108048062584350
- Myositis Association Community Forum: tmacommunityforum.ning.com
- Myositis Support Group: www.myosistissupportgroup.org
- Myositis Support Group – UK: www.myositis.org.uk

Primary Immune Deficiency Disease (PIDD)

**WEBSITES**
- The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. (800) 296-4433

**ONLINE PEER SUPPORT**
- The National Institute of Child Health and Human Development (NICHD): www.nichd.nih.gov/health/topics/Primary_Immunodeficiency.cfm
- American Academy of Allergy, Asthma & Immunology: www.aaaai.org
- International Patient Organisation for Primary Immunodeficiencies (IPPO) — UK: www.ipopi.org
- New England Primary Immunodeficiency Network: www.nepin.org
- Rainbow Allergy-Immunology: www.uhospitals.org/rainbow/services/allergy-immunology
- Team Hope (for families and patients in New England): www.teamhope.info

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

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

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

WEBSITES
- Scleroderma Foundation: www.scleroderma.org
- Scleroderma Research Foundation: www.srfcure.org
- Scleroderma Center: www.hopkinsmedicine.org/rheumatology/clinics/scleroderma_center.html

ONLINE PEER SUPPORT
- International Scleroderma Network: www.sclero.org/support/forums/a-to-z.html

Stiff Person Syndrome (SPS)

WEBSITES
- American Autoimmune Related Diseases Association Inc.: www.aarda.org
- Genetic Alliance: www.geneticalliance.org
- Living with Stiff Person Syndrome (personal account): www.livingwithspss.com
- Stiff Person Syndrome: www.stiffpersonsindrome.net

Other Resources

Education and Disability Resources
- Americans with Disabilities Act of 1990: www.ada.gov Provides protection for people with disabilities from certain types of discrimination, and requires employers to provide some accommodations of the disability.
- Individuals with Disabilities Education Improvement Act of 2004: idea.ed.gov/explore/home
- National Disability Rights Network: www.ndrn.org This website offers a search tool to find resources in your state to assist with school rights and advocacy.
- Social Security: www.ssa.gov/disability
- U.S. Department of Education Website: www2.ed.gov/parents/landing.html?exp=4 This federal government website offers a parents section titled “My Child’s Special Needs.”
- World Allergy Organization: www.worldallergy.org

Product Information
- Influenza and the influenza vaccine: www.cdc.gov/flu or call (800) CDC-INFO: (800) 232-4636
- IVIG Flebogamma 5% DIF and 10% DIF: www.grifols.com/portal/en/US/bioscience/?div=8883
- IVIG/SCIG Gammagard Liquid: www.gammagardliquid.com
- IVIG Gammagard S/D: www.baxter.com/patients_and_caregivers/products/gammagard_sd_5.html
- IVIG/SCIG Gammaked: www.gammaked.com
- IVIG Gammaplex: www.gammaplex.com
- IVIG Privigen: www.privigen.com
- SCIG Hizentra: www.hizentra.com

Pump and Infusion Sets Websites
- EMED Technologies: www.emedtc.com
- Marcal Medical Inc.: www.marcalmedical.com
- Intra Pump Infusion Systems: www.intrapump.com
- Micrel Medical Devices: www.micrelmed.com
- Norfolk Medical: www.norfolkmedical.com
- RMS Medical Products: www.rmsmedicalproducts.com
- Smith Medical: www.smiths-medical.com/brands/cadd

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The **Products** you need when **you need** them.

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