



By Ronale Tucker Rhodes, MS

**IT WAS 10** years ago when we asked “Yoo-hoo! Anybody Out There?” in the February-March 2006 debut issue of *IG Living* magazine that mailed to nearly 16,000 specialty physicians, including allergists, immunologists, neurologists, hematologists-oncologists and pediatric allergists, as well as to members of the U.S. Congress. The decision to publish this magazine was based on our recognition that there was a great need among immune globulin (IG) patients for information and a sense of belonging to a community. Our goal was to provide support for underserved and isolated patients by first informing legislators and providing doctors with a resource for education, communication and advocacy to recommend to their patients.

In just a decade, *IG Living* has grown and is now read by upwards of 30,000 patients, physicians and others tied to the IG community. We’ve heard back from a great number of you over the years. We know that the majority of our readers have a common variable

immunodeficiency (CVID) diagnosis; however, diagnoses span all of the primary immunodeficiency (PI) diseases, as well as autoimmune and neurological disorders. Most of you also infuse IG intravenously (IVIG) in the home setting, but the number of individuals infusing subcutaneously (SCIG) is slowly gaining ground. We’re proud that most readers have been receiving *IG Living* for more than five years and report reading each issue cover to cover. What’s more, you are active on our IGLiving.com website and Facebook page.

It’s so rewarding to see how much the magazine and the landscape of the IG community have continued to evolve, especially in how you now support each other! While many of the challenges affecting our community in 2006 still remain today, in this special anniversary issue, we want to share with you some snippets of community developments reported on in *IG Living* over the past decade in the areas of diagnosis, treatment, safety, reimbursement and legislation.

# Diagnosis

2006



According to Immune Deficiency Foundation (IDF) surveys, the average time to diagnose a PI was 9.2 years, during which time 37 percent of patients developed permanent impairments such as loss of hearing, pulmonary function, digestive function, mobility, vision or neurological function. This delay in diagnosis resulted in delay of treatment for 21 percent, an inability to see a specialist as often as needed for 11 percent and treatment denial by insurance carriers for 17 percent.

2007



To increase awareness and speed diagnosis of PI in children, the American Academy of Pediatrics, the Jeffrey Modell Foundation and Talecris Biotherapeutics announced a new continuing medication education series titled "Immunodeficiency in Pediatrics." The program, which featured a panel discussion, addressed the concern that PI may be more common than previously thought, and that pediatricians need to have a high degree of suspicion when evaluating certain key signs and symptoms such as recurrent or resistant infection in patients.

2011



At the national level, Secretary of Health and Human Services Kathleen Sebelius announced the addition of SCID to the core panel of 29 genetic disorders, as part of her recommendations to adopt the national Recommended Uniform Screening Panel. SCID was the first nominated condition to be added to the core panel of disorders.

In the same year, a pilot program was launched in Wisconsin to see if it's possible to detect severe combined immune deficiency (SCID) in children within days of birth. The program used a blood test that accurately measures the number of T cells, based on genetic material called T cell receptor excision circles (TRECs), to predict how well the body will manufacture T cells that fight infection.

During that year, five states and one territory (California, Louisiana, Massachusetts, New York, Wisconsin and Puerto Rico) began offering SCID screening. Seven other states — Colorado, Delaware, Iowa, Michigan, Minnesota, North Carolina and Rhode Island — also voted to recommend the addition of SCID to their newborn screening panels to begin at a later date. And, proposals to add SCID screening were made in Connecticut, Nebraska, Ohio and Pennsylvania.



2013

It took two years after Florida Governor Rick Scott's veto in 2011 for the state to add SCID screening to its uniform set of newborn screening tests.



Following Florida's decision were Iowa and Texas. Texas added SCID screening to its standard newborn panel, while Iowa launched a pilot screening program to ensure the screening process met all necessary standards.

2014

Eighteen states were now screening for SCID, and another dozen states were slated to start screening by the end of the year.



2015

As more forms of PI have been identified over the years, the International Union of Immunological Societies Expert Committee on Primary Immunodeficiency published an updated classification of human primary immunodeficiencies (PIs), the most current and complete catalog of known PIs. The report serves as a reference for these conditions and provides a framework to help in the diagnostic approach to patients suspected of having a PI.



# Treatment



2006

There were two administration options for IG, intravenous (IVIG) and port access, until the U.S. Food and Drug Administration (FDA) expanded the options to three with its approval of the first subcutaneous immune globulin (SCIG) therapy, Vivaglobin 16%. Still, IVIG was the preferred method of treatment except in cases where physicians determined that patients didn't tolerate IVIG well.



With the addition of Vivaglobin, there were 10 FDA-approved IG products manufactured by five companies. Further, these products were determined only to be "definitely useful" by the primary immunodeficiency committee of American Academy of Allergy, Asthma and Immunology to treat five diseases: PI, idiopathic thrombocytopenic purpura (ITP), Graves' ophthalmopathy, demyelinating polyneuropathies and Kawasaki disease.

Yet, for every FDA-approved indication for IG therapy, it was estimated there were 10 non-FDA-approved indications. In fact, there were 18 clinical trials being performed in the U.S. by both manufacturers and clinical researchers to determine the safety and efficacy of IG therapy for PI, multiple sclerosis, ITP, chronic inflammatory demyelinating polyneuropathy (CIDP), hemolytic disease, myopathy, severe C. diff, West Nile encephalitis and others.



2008

The next IG product to be approved by FDA in the U.S. was CSL Behring's Privena, a new IVIG that requires no refrigeration or reconstitution.



2010

FDA approved yet another IVIG product, Gammaplex ready-to-use 5% for the treatment of PI.

Shortly thereafter, CSL Behring received approval from FDA for its Hizentra SCIG 20% liquid for treating patients diagnosed with PI.

The once-weekly IG replacement therapy is the first 20% SCIG approved in the U.S.



2007

Most IG patients were receiving infusions in hospital outpatient clinics, infusion suites or doctor offices, but a growing number had started receiving infusions at home. It was estimated that as many as one million people across the U.S. were receiving home infusions.



The success of IG in treating patients led to publication of a paper by Dr. Jeffrey Ravetch, Theresa and Eugene M. Lang professor and head of Rockefeller's Laboratory of Molecular Genetics and Immunology, that explains what makes IG effective. According to Dr. Ravetch, a small fraction of the IgG antibodies in the IG solution carry a sugar called sialic acid that is required for its protective ability. The discovery, he said, paved the way to generate a recombinant form of IgG that, by virtue of a sialic acid molecule attached in the right place, would be anti-inflammatory and could act as a novel treatment for autoimmune disorders.

But, IG therapy came with side effects. So, researchers at the University of California, Los Angeles, Medical Center and David Geffen School of Medicine began studying ways to minimize those effects. In their studies that used already approved IG products, they discovered ways in which patients were able to remain on their routine IG therapy schedule and dosage.



2009

Then, FDA approved Gamunex as a treatment for CIDP, the first and only therapy approved to treat CIDP and the only IVIG approved to treat a neurological disorder in the U.S.



Researchers then began wondering about the clinical efficacy of SCIG versus IVIG in treating CIDP. In two different studies, they found a sustained effect of SCIG in CIDP in a 1:1 dose ratio compared with IVIG, which is corroborated by another case report describing effective treatment with SCIG in a patient with multifocal motor neuropathy (MMN).

Four more case studies described how PI patients successfully switched from IVIG to SCIG therapy. Those patients, who were diagnosed with CVID and agammaglobulinemia, were treated weekly with Vivaglobin, then the only approved SCIG therapy.

# Treatment



FDA then approved Talecris Biotherapeutics' Gamunex-C 10%, the third SCIG therapy for the treatment of PI in the U.S.

And, with the approval by FDA of Flebogamma 10% DIF IVIG to treat PI, Grifols became the first company in the U.S. to offer patients and clinicians two concentrations of liquid IVIG (5% and 10%).

There were then 11 IG products FDA approved (with some removed and new products added) for five indications: PI, ITP, CIDP, B-cell lymphocytic leukemia and Kawasaki syndrome. While all IG products carried an indication for PI, no one product carried an indication for all five. In addition, the number of off-label uses for IG had greatly expanded, far exceeding that of labeled indications. Diseases most commonly treated off label were Guillain-Barré syndrome, polymyositis, dermatomyositis, MMN, stiff person syndrome, relapsing-remitting multiple sclerosis and pemphigus. What's more, there were a number of studies being conducted to look at the efficacy of IG in other non-FDA-approved indications, including Alzheimer's disease, secondary recurrent miscarriage and chronic regional pain syndrome.

Due to delays in supply, CSL Behring discontinued distribution of Vivaglobin in the U.S. market, once again reducing the number of approved IG products to 10.



The number quickly returned to 11 with FDA approval of Kedrion Biopharma's Gammaked 10% for intravenous treatment of PI, ITP and CIDP, and for subcutaneous treatment of PI.

Since IG is a lifetime therapy for CVID, a group of physicians at the 37th annual meeting of the European Group for Blood and Marrow Transplantation in Paris, France, reported that they believed hematopoietic stem cell transplants (HSCTs) were feasible in CVID patients and would result in an improvement of the condition. Their conclusion was based on a cohort of four CVID patients who underwent HSCTs with peripheral stem cell grafts, all of whom presented with a host of other medical issues in addition to CVID and in whom no graft failure occurred.



2011

2013

The approval of Biotest Pharmaceuticals' Bivigam 10% IVIG liquid to treat PI brought the number of IG products in the U.S. market to 12.



2014

Two additional IG products were added to the market when FDA approved Octapharma's Octagam 10% IVIG for the treatment of chronic ITP and Baxter's HYQVIA SCIG with recombinant human hyaluronidase for the treatment of PI. HYQVIA became the first SCIG treatment approved for PI patients with a dosing regimen requiring only one infusion up to once per month (every three to four weeks) and one injection site per infusion to deliver a full therapeutic dose of IG.

In other treatment news developments, an international consortium of scientists perfected gene therapy in promising clinical trials that they said might lead to an eventual long-term cure for X-linked SCID. The mechanism used to deliver the gene therapy was designed to prevent the serious complication of leukemia that developed in one-quarter of boys treated a decade ago in a similar trial in Europe.



2015

A different study showed that patients with SCID have improved survival when they undergo HSCT within a few months after birth, before the onset of infection or after the infection resolves. It was hoped that this would put pressure on states that have resisted adding SCID to their newborn screening programs.

And, according to another study, HSCT could be considered in some instances for patients with CVID, specifically "in patients in whom there has been extensive characterization of the immunologic and/or genetic defect underlying the CVID diagnosis."

With four SCIG products now on the market, CSL Behring sought a new dosing option for Hizentra SCIG 20% that was approved by FDA to allow PI patients to individualize therapy with flexible dosing, meaning treatment at regular intervals from daily to once every two weeks.



2016

Today, several clinical trials are underway that are examining the efficacy of SCIG treatment for neuromuscular conditions. These include the PATH (polyneuropathy and treatment with Hizentra) study for CIDP patients and another evaluating SCIG for the treatment of patients with dermatomyositis.

# Safety



2006

Grifols set the stage for deterring adulterated and mislabeled IG products with its laser-etched vial technology. With laser etching, each vial of IG was laser inscribed with the product's lot number that includes such information as date of production, expiration of product and vial size. Grifols also took additional protective steps by etching a filling sequence number on each vial that corresponds with a recording of the entire filling sequence.

Focus on the safety of the drug supply chain at this time was heightened. The Prescription Drug Marketing Act (PDMA), the federal drug pedigree requirement that called for documentation of every entity that had possession of a vial or bottle of medication handled by a distributor, was an effort to secure the supply channel and prevent drug counterfeiting and diversion, but it was on hold due to a constitutional challenge. In response, states began considering their own legislation, and Florida became the leader in the nation with its passage of the Prescription Drug Protection Act (PDPA), which required all distributors of prescription drugs to prepare, authenticate and distribute drug pedigrees whenever they transacted prescription medicine. However, the pharmaceutical industry neutralized the Act by supporting legislation that eliminated the pedigree requirements.



2008

Unfortunately, the U.S. Court of Appeals for the Second Circuit affirmed the preliminary injunction issued by a federal district court against the PDMA. In response, FDA said it didn't "intend to initiate any enforcement actions against any wholesaler solely for failing to include lot numbers, dosage, container size or number of containers on a pedigree; or failing to provide a pedigree that goes back to the manufacturer so long as the pedigree otherwise identifies the last authorized distributor of record that handled the drugs."

In the IG arena, a study conducted by Octapharma, manufacturer of Octagam, broke new ground in understanding the long-term safety profile of IVIG. It found that Octagam produced few side effects, and those were almost always minor and confined to certain groups of patients. The largest study of its type that compiled information from 6,357 people receiving Octagam, it found that only 0.35 percent of the approximately 93,000 infusions received during the study resulted in some type of adverse event. The study authors acknowledged that the results didn't mean all IVIG drugs would perform the same way, but they did generally bode well for IVIG patients.

2011

Unfortunately, after the publication of that study, Octapharma USA initiated a voluntary withdrawal of all lots of Octagam IVIG 5% from the U.S. marketplace due to an unusually high number of thromboembolic events that were associated with people being administered the drug. The withdrawal followed an initial announcement earlier in the year of a voluntary withdrawal of selected lots of Octagam 5%.

2012

Through examination, it was determined that the increase of thromboembolic events was due to FXIa procoagulant activity. Following this discovery, Octapharma removed FXIa through corrective and preventive measures in the manufacturing process, and FDA and the Committee for Medicinal Products for Human Use in Europe approved the return of Octagam 5% to the market.



2015

Due to concerns about the Ebola virus outbreak, especially among persons with immunodeficiencies who are more vulnerable to infections, the Plasma Protein Therapeutics Association endorsed the recommendation by the EU Center for Disease Prevention and Control that travelers or residents returning from Ebola virus disease-affected areas be deferred for donation of plasma for fractionation two months after return.

To help increase the availability of plasma therapies to treat immune disorders, autoimmune disease, neuropathies and others, Plasma Tech Biopharmaceuticals reported it developed a new and innovative method to extract plasma proteins from pooled human plasma samples.

An additional improvement in the fractionation process came with FDA approval of the Intercept Blood System for plasma, the first pathogen-reduction system for use by blood establishments in the preparation of plasma to reduce the risk of transfusion-transmitted infections. The system can be used to reduce pathogens in plasma derived from whole blood and plasma obtained by apheresis, a collection process that separates red blood cells from plasma and then returns the red cells to the donor.

# Policy / Legislation

## 2008



Because of the genetic link to many diseases that respond to IG therapy, the importance of genetic testing to the IG community was determined likely to grow, resulting in concerns about losing health benefits or having to pay more for coverage as a result of information found by genetic testing. In response, President Bush signed the Genetic Information Nondiscrimination Act, popularly known as GINA, into law. GINA prohibits health insurers and employers from discriminating against individuals based on their genetic information.

Protections for people with disabilities expanded again when Congress passed the Americans with Disabilities Act Amendments Act (ADAAA). The portions of the amendment's changes that apply specifically to patients treated with IG include 1) the phrase "major life activity" now includes operation of major bodily functions, including but not limited to functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions; 2) an impairment that is episodic or in remission is a disability if it substantially limits a major life activity when active; and 3) the question of whether an impairment is disabling must be made without regard to whether medication, equipment, prosthetics, assistive technology or other treatment, devices and supplies improve the impairment.



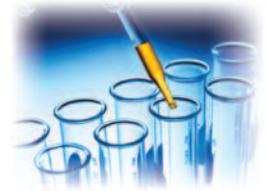
## 2014

And, with concern about which vaccines immunocompromised individuals should receive, the Infectious Diseases Society of America issued the "Clinical Practice Guideline for the Vaccination of the Immunocompromised Host" to recommend that individuals with compromised immune systems get the flu shot and other vaccinations.



## 2011

To encourage more participation in clinical trials, President Obama signed into law the Improved Access to Clinical Trials Act, which amends the Social Security Act to provide for an exclusion under the Supplemental Security Income (SSI) program and Medicaid for certain compensation of individuals who participate in clinical trials for rare diseases and conditions. The law excludes "the first \$2,000 received during a calendar year by such individual (or spouse) as compensation for participation in a clinical trial involving research and testing of treatments for a rare disease or condition, and the first \$2,000 received by an individual (who has attained 19 years of age) as compensation for participation in a clinical trial meeting the requirements of section 1612(b)(26) for purposes of determining the income eligibility of such individual for medical assistance under the state plan or any waiver of such plan."



## 2012

The ADAAA of 2008 was also expanded upon when the Equal Employment Opportunity Commission published final regulations that protected many more employees from disability discrimination in the workplace than had previously been the case under the courts' narrow interpretations of the ADA and ADAAA. Specifically favorable for the IG community were that an "impairment need not prevent or severely or significantly restrict performance of a major life activity to be considered a disability," that "impairments that are episodic or in remission are disabilities if they would be substantially limiting when active" and that "major life activities" includes "major bodily functions" such as immune system, normal cell growth, and brain, neurological and endocrine functions.

With the growing use of IVIG for neuromuscular disorders, the American Academy of Neurology (AAN) released an evidence-based guideline on the efficacy of IVIG for neuromuscular disorders, based on a comprehensive review of the literature by the AAN Therapeutics and Technology Assessment Committee in the 43-year period between 1966 and 2009.



# Reimbursement



2006

Changes established in 2005 for Medicare reimbursement of IG therapy threatened the care and lives of many patients in the U.S. A congressionally mandated reduction in Medicare Part B reimbursement rates and the two-tier rates for liquid and lyophilized IG established two different rates for administering IG, depending on where treatment was received. This new reimbursement methodology significantly lowered the rate paid to physician offices and homecare companies, creating a dangerous situation for seriously ill, low-income patients with PIs or neuropathies. The reduced rate at which physicians were reimbursed was so devastating that many had no choice but to refer patients to hospitals where co-pays were as high as \$649 per treatment. And, what many people predicted would happen did: One patient unable to receive his IG treatments died.

Another issue also prevented many patients with autoimmune diseases such as Guillain-Barré syndrome and neuropathies from receiving coverage for IG therapy. Even though these diseases were discovered more than 100 years ago, and the use of IVIG to treat these disorders was known to be beneficial, insurance companies mandated evidence from controlled medical clinical trials, which didn't exist, versus experimentation and observation. This made getting reimbursed extremely difficult.



2009

Effective Jan. 1, the final rules for reimbursement changes issued by CMS went into effect. The changes included 1) the elimination of the preadministration fee for the hospital outpatient setting and the physician's office that was established to help locate product for patients who had shifted to other treatment sites because of earlier reimbursement changes; and 2) a reduction in the reimbursement for the hospital outpatient setting from ASP plus 5 percent to ASP plus 4 percent.



2007

Patient access to IG therapy in states across the country was further reduced when the majority of Medicare carriers (private insurance companies that implement Medicare benefits at the local level) implemented local coverage determinations. The determinations varied by state and carrier, and were not based on accepted medical guidelines for treatment and dosing.

In the private healthcare sector, some insurance companies transitioned the management of chronically ill patients' homecare and delivery of their specialty pharmaceutical products and services to a single, company-designated specialty pharmacy and/or homecare company. Under this new policy, patients started receiving product from a specialty pharmacy either owned or designated by the insurance company and nursing services from the homecare company selected by the insurer, rather than by the patient. While the effects of the policy were not yet known, analysts predicted that patients would have increased cost barriers to out-of-network providers.



2008

But a report titled "Specialty Pharmacy Management Insights" indicated that specialty pharmacies were becoming more important as insurance companies, managed care providers and other payers sought ways to streamline specialty pharmaceutical dispensing and cut costs. According to the report by Wyeth Healthcare Systems, more specialty pharmacies would be acquired by larger companies and would offer more services. What wouldn't change is their role: providing the special needs of patients that are peripheral to the actual administration of their medicine.

Also that year, the Centers for Medicare and Medicaid Services (CMS) reduced reimbursement for all drugs offered in the hospital outpatient setting, including IVIG, from the manufacturer's average sales price (ASP) plus 6 percent to ASP plus 5 percent, as well as reduced the IVIG hospital outpatient preadministration fee by 50 percent — at a time when IVIG patients were shifted to hospitals as the site of care of last resort. CMS was also scheduled to eliminate coverage for treatment of certain infections that are acquired while patients are hospitalized, which would have severely affected immune-compromised patients, many of whom have no other site-of-care option.



# Reimbursement



2010

Then, insurance companies, including private healthcare plans, Medicare Part D plans, Tricare and the Federal Employees Health Benefit Program, announced that patients who need chronic lifesaving therapies such as IG may have to pay for them under Tier IV and Tier V categories. Previously, these therapies that were covered by a health insurance company's major medical plan were switched to be covered only under Tier 1, II and III categories; the higher the tier number, the higher the co-pay. Under Tiers IV and V, patients would be required to pay a 10 percent to 30 percent co-pay for their therapy.

2011

In response, the state of New York passed a law that prohibits commercial health insurance plans from creating specialty tiers within their prescription drug formularies. According to New York law, specialty tiering is contrary to the original purpose of insurance, which is to spread the cost; instead, it creates a structure where those who are most sick pay more, which is an unlawful discriminatory practice.

California joined New York by passing a bill that protects patients with life-threatening diseases from escalating insurance costs for medication.

It placed a \$150 co-payment cap for a one-month supply of medication, prohibited health plans and insurers from using co-insurance and placed an annual out-of-pocket limit on prescription drug costs if a plan or insurance policy maintains an annual limit. Many other states were considering similar legislation.

The Department of Health and Human Services also sought to protect consumers from exorbitant insurance costs when it issued a regulation to ensure that large health insurance premium increases would be thoroughly reviewed and consumers would have access to clear information about those increases. The rule requires independent experts to scrutinize any proposed increase of 10 percent or more for most individual and small group health insurance plans.



2013

Access to IVIG therapy continued to be a concern due to Medicare reimbursement changes, prompting President Obama to sign into law the

Medicare IVIG Access Act, a demonstration project to assess whether adding coverage for nursing services and supplies to administer IVIG for patients with PI in the home will impact issues currently faced by Medicare patients. Under current law, Medicare Part B covers IVIG treatment only in the home for some PI patients.

2014

With the Medicare IVIG Access Act underway, the Centers for Medicare and Medicaid Services held an open-door forum to get input from key stakeholders on questions related to the design and implementation of the demonstration project. The main questions under discussion during the forum were:

- Should billing for demonstration-covered nursing services and supplies be permitted by organizations that are not supplying the drug?
- What types of organizations should be eligible to participate in the demonstration?
- Who should CMS reach out to to inform about this demonstration?
- How can CMS best reach out to beneficiaries and their providers?
- Should CMS have an open enrollment period during which applications would be submitted on an equal basis for consideration, rolling enrollment or some combination?
- Should a patient's physician be required to sign a beneficiary's application to confirm the diagnosis and awareness of the demonstration and locus of service?
- Should the beneficiary's application specify a particular drug or supplier?

The outcome of this initiative is still being awaited.

*Editor's note: The above information is what was reported on in IG Living magazine during the past decade, and is not meant to be representative of all events that occurred in the highlighted areas.*

# IGLiving Top Educational Picks!

*IG Living* is indeed unique. Not only does each issue provide insight on the issues of greatest importance to our readers, but it is an educational resource chock-full of information that cannot be found elsewhere. Over the years, we have teamed with talented writers, dedicated healthcare professionals, patients and caregivers in the IG community who have dedicated countless hours during the past decade to write articles to help you better understand your diseases and cope with the many issues you face living with chronic illness. The sheer number of articles published in *IG Living* totals in the thousands, many of which detail how diseases treated with IG are diagnosed and treated. Here, though, we list our picks for the top educational articles on disease management, lifestyle management, parenting/caregiving, communication, insurance/reimbursement and research — all of which (and much more!) you can find on our website at [www.IGLiving.com/magazine/archive.html](http://www.IGLiving.com/magazine/archive.html).

## Communication



- Improving Patient-Doctor Communication, by Ronale Tucker Rhodes, MS  
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- Paging Dr. Right!  
by Trudie Mitschang  
October-November 2011, p22



- Telling It All: How to Share the News of Your Diagnosis, by Dana Martin  
June-July 2015, p18

## Insurance/Reimbursement



- A Review of Medicare and Disability Programs, by Jennifer Kester  
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- How the ACA Impacts the Chronically Ill, by Ronale Tucker Rhodes, MS  
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- How to Write an Effective Appeal Letter, by Kris McFalls  
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- Transitioning IG Coverage to Medicare, by Michelle Greer, RN, and Leslie J. Vaughan, RPh  
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## Lifestyle Management



- Exercise Success, by Matthew D. Hansen, DPT, MPT, BSPTS  
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- Financial Planning for Patients with Chronic Illness, by Trudie Mitschang  
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- GI Problems for IG Patients, by Jill Weisenberger, MS, RD, CDE  
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- How Exercise Benefits the Immune System, by Matthew D. Hansen, DPT, MPT, BSPTS  
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- How to Cope, by Erika Lawrence, PhD  
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- How to Successfully File for Disability, by Cynthia Perry  
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- Job Interviewing Strategies for the Chronically Ill, by Dana Martin  
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- Patient Advocacy: How Patients Can Gain Control, by Annaben Kazemi  
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## Parenting/Caregiving



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- The Impact of Chronic Illness on the Family, by Erika Lawrence, PhD  
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- Treating PIDD Kids — Post-Diagnosis, by Amy Scanlin, MS  
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## Research



- Funding Research to Find Cures/Treatments, by Matthew D. Hansen, DPT, MPT, BSPTS  
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- Gene Therapy: The Cutting-Edge of PI Treatment, by Caroline Y. Kuo, MD, and Roger H. Kobayashi, MD  
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- Individual IG Dosing Strategies, by Ronale Tucker Rhodes, MS, and Kris McFalls  
December-January 2012, p18



- Long-Term Effects of PIDDs, by Annaben Kazemi  
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- Screening for Severe Combined Immunodeficiency Disease, by Amy Scanlin, MS  
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- Severe PIs: Cutting-Edge Science Turns Tragedies to Cures, by Keith Berman, MPH, MBA  
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## Disease Management



- An Overview of Immune Globulin Dosing, by Kris McFalls  
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- Diagnosing PIDD: Problems and Solutions, by Kris McFalls  
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- Fungal Infections in PIDD Patients, by Alexandra F. Freeman, MD, and Anahita Agharahimi, MSN, CRNP  
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- Overcoming SCIG Needle Anxiety, by Amy Ehlers, BS, PharmD, BCPS  
April-May 2013, p16



- Preventive Healthcare for Patients with Chronic Illness, by Ronale Tucker Rhodes, MS, and Kris McFalls  
August-September 2010, p16



- Routine Primary Immunodeficiency Lab Reports: What Do They Mean? by Bob Geng, MD, MA  
October-November 2015, p36



- The ABCs of Tracking Healthcare Treatment, by Ronale Tucker Rhodes, MS, and Kris McFalls  
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- Understanding and Treating IG Side Effects, by Ronale Tucker Rhodes, MS, and Kris McFalls  
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