Resource Directory

Everything You Ever Wanted to Know About…

…Guillain-Barré Syndrome (GBS)

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

Online Pamphlets

…Myositis

Websites
1. International Myositis Assessment and Clinical Studies Group is a coalition of healthcare providers and researchers with global approaches to improved treatments and understanding of myositis: https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main.
2. The Cure JM Foundation was created specifically to find a cure for Juvenile Myositis (JM), while also providing support and information for families affected by JM. http://curejm.com

…Peripheral Neuropathy (PN)

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

Support Groups
Click on the Member Services tab of the website, www.neuropathy.org, for listings of support groups across the nation.

…Primary Immune Deficiency Disease (PIDD)

Websites and Chat Rooms
1. The Immune Deficiency Foundation (IDF), www.primaryimmune.org, is dedicated to improving the diagnosis and treatment of PIDD through research and education. 800-296-4433
2. 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
3. The National Institute of Child Health and Human Development (NICHD), www.nichd.nih.gov/, is part of the National Institutes of Health. Go to the “Health Information and Media” tab on the website and do a search under “primary immunodeficiency.”
4. The American Academy of Allergy, Asthma & Immunology, www.aaaai.org, has a helpful Q&A section on its website, with resources and tips for those with various immune deficiencies.
7. The International Patient Organization for Primary Immunodeficiencies (IPOPI), www.ipopi.org, promotes the worldwide improvement in the care and treatment of PIDD patients.
8. To connect to a PIDD message board, go to www.jmfworld.com.
9. To chat with peers on IDF’s Forum, go to www.primaryimmune.org.

➢ The Neuropathy Association, www.neuropathy.org, is devoted exclusively to all types of neuropathy, which affects upwards of 20 million Americans. The Association’s mission is to increase public awareness of the nature and extent of PN, facilitate information exchanges about the disease, advocate the need for early intervention and support research into the causes and treatment of neuropathies. 212-692-0662
➢ 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 Jeffrey Modell Foundation, www.info4pi.org, is dedicated to early and precise diagnosis, meaningful treatments and, ultimately, cures for primary immunodeficiency. 212-819-0200
➢ The National Institute of Child Health and Human Development (NICHD), www.nichd.nih.gov/, is part of the National Institutes of Health. Go to the “Health Information and Media” tab on the website and do a search under “primary immunodeficiency.”
➢ The American Academy of Allergy, Asthma & Immunology, www.aaaai.org, has a helpful Q&A section on its website, with resources and tips for those with various immune deficiencies.
➢ Baxter’s website, www.immunedisease.com, offers in-depth information on immunology, PIDD and treatment with intravenous immune globulin.
➢ The Michigan Immunodeficiency Foundation, www.midf.org, seeks to improve the quality of life for Michigan residents affected by PIDD.
➢ The International Patient Organization for Primary Immunodeficiencies (IPOPI), www.ipopi.org, promotes the worldwide improvement in the care and treatment of PIDD patients.
➢ To connect to a PIDD message board, go to www.jmfworld.com.
➢ To chat with peers on IDF’s Forum, go to www.primaryimmune.org.
➢ Chat with parents of children affected by primary immune deficiency at http://health.groups.yahoo.com/group/PedPID/.
➢ Chat with peers with PIDD at http://health.groups.yahoo.com/group/PIDsupport/.

IG Living! www.igliving.com June-July 2006 45
Everything You Ever Wanted to Know continued…

### Online Pamphlets

1. Go to the National Institute of Allergy and Infectious Diseases site at [www.niaid.nih.gov](http://www.niaid.nih.gov) and search for “primary immune deficiency.”

### Books and Articles

2. “A Handbook for Care Givers,” by Helen Rummelsburg, gives an account of caring for her husband and offers helpful hints for patients and caregivers. Available at the GBS website bookstore at [www.gbsfip.com](http://www.gbsfip.com).
3. “Anatomy of an Illness,” by Norman Cousins, is a bestseller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body’s capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.
4. “Bed Number Ten,” by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.
5. “Coping With a Myositis Disease,” by James R. Kilpatrick, is written by a mother of a child with CIDP. Available at the GBS website bookstore at [www.gbsfip.com](http://www.gbsfip.com).
7. “Coping With a Myositis Disease,” by James R. Kilpatrick, is written by myositis patients telling their personal stories.
8. “If You’re Having a Crummy Day, Brush Off the Crumbs!,” by Mims Cushing, is a how-to book that offers more than 75 ways to help people get through the days when neuropathy (or other ailments) is particularly difficult.
9. “Inclusion-Body Myositis and Myopathies,” by Valerie Askanas (Editor), Georges Serratrice (Editor) and W. King Engel (Editor), is devoted to discussing the two forms of inclusion-body myositis.
10. “Living Creatively With Chronic Illness: Developing Skills for Transcending the Loss, Pain and Frustration,” by Eugenia G. Wheeler, is a self-help book specifically designed to help the chronically ill, their families, friends, counselors, medical personnel and the clergy.
11. “Managing Pain Before It Manages You,” by Dr. Margaret A. Caudill, is a wellspring of wisdom and practical approaches that can help transform your life and your pain.
12. “Medifocus Guide to Peripheral Neuropathy” is a guide to current and relevant PN research, organized into categories for easy reading.
13. “Myositis — A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References,” by ICON Health Publications, is a three-in-one reference book: a complete dictionary of terms relating to myositis, a list of bibliographic citations about the disorder and a guide to Internet resources.
14. “No Laughing Matter,” by Joseph Heller (the best-selling author of “Catch-22”), who teamed up with Speed Vogel, his best friend, to describe Heller’s battle with and triumph over GBS.
15. “Not Dead Yet: a Long Strange Trip From Doctor to Patient and Back Again,” by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.

### Other Organizations

1. For suggestions on how to deal with the medical and emotional impact of caring for an ill child, go to [www.kidshealth.org/parent/system/ill/seriously_ill.html](http://www.kidshealth.org/parent/system/ill/seriously_ill.html).
2. The National Committee for Quality Assurance provides free access to detailed report cards on health plans, clinical performance, member satisfaction, access to care and overall quality on its Health Plan Report Cards Online at [www.ncqa.org](http://www.ncqa.org).
3. The nonprofit Patient Advocate Foundation, [www.patientadvocate.org](http://www.patientadvocate.org), seeks to assure patient access to care, maintenance of employment and financial stability. 800-532-5274
4. The nonprofit Patient Services Incorporated, [www.uneedpsi.org](http://www.uneedpsi.org), specializes in health insurance premium, pharmacy co-payment and co-payment waiver assistance for people with chronic illnesses. 800-366-7741
5. WebMD, [www.webmd.com](http://www.webmd.com), is a handy medical reference that helps consumers take an active role in managing their health by providing objective healthcare and lifestyle information.
6. For a pediatrician’s guide to your child’s health and safety, visit [www.keepkidshealthy.com](http://www.keepkidshealthy.com).
7. The National Organization for Rare Diseases, at [www.rarediseases.org](http://www.rarediseases.org), provides links to numerous other organizations that have disease-specific support groups and virtual communities for patients and caregivers.
8. American Autoimmune Related Diseases Association (AARD) [www.aarda.org](http://www.aarda.org) brings national focus to autoimmunity through research, education and patient services. 800-598-4668.
9. The nonprofit General Resources

### Product Information

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

### General Resources

4. “Anatomy of an Illness,” by Norman Cousins, is a bestseller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body’s capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.
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15. “Not Dead Yet: a Long Strange Trip From Doctor to Patient and Back Again,” by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.
16. “Numb Toes and Aching Soles,” by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.

17. “Numb Toes and Other Woes,” by John Senneff, is the second in a series of three books. It focuses on clinical findings and treatment strategies for PN.

18. “Nutrients for Neuropathy,” by John Senneff, the third in the Numb Toes series, is focused exclusively on nutrient supplementation as a means for managing PN.

19. “The Official Patient’s Sourcebook on Inclusion Body Myositis,” by James N. Parker (Editor) and Philip M. Parker (Editor), is a reference manual for self-directed patient research.

20. “Pride and the Daily Marathon,” by Jonathan Cole, describes how Ian Waterman was suddenly struck down at work by a rare neurological illness that deprived him of all sensation below the neck, and how he reclaimed a life of full mobility.

21. “Pronoia Is the Antidote for Paranoia,” by Rob Brezsny, explores the best way to attract the blessings that the world is conspiring to give us.

IG Manufacturer Websites
Baxter: www.baxter.com
Grifols: www.grifolsusa.com
Octapharma: www.octapharma.com
Talecris: www.talecris.com
ZLB Behring: www.zlbbehring.com

Pump and Needle Websites
Intra Pump Infusion Systems: www.intrapump.com
Repro Med Systems, Inc: www.repro-med.com
Graseby Marcal Medical: www.marcalmedical.com
Norfork Medical: www.norfolkmedical.com

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

American Board of Physician Nutrition Specialists
http://www.ipnec.org

American Dietetic Association
http://www.eatright.org

American Gastroenterological Association
http://www.gastro.org

North American Society for Pediatric Gastroenterology Hepatology and Nutrition
http://www.naspgn.org/

...Scholarships
Immune Deficiency Foundation Scholarship
This award is available to individuals diagnosed with a primary immune deficiency disease. http://www.primaryimmune.org/services/scholarship.htm 800-296-4433

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

Bank of America Abilities Scholarship Program
These scholarships are awarded to students with disabilities who have a career interest in finance, business or computer systems.

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

Joyce Walsh Junior Scholarship for the Handicapped
This scholarship is awarded to disabled instrumentalists or vocalist members of National Federation of Music Clubs. http://www.mfmc.net/scholarships.html 317-638-4003

Panasonic Young Soloists Award
This award is given to vocalists or instrumentalists under age 25 who are permanently disabled and interested in studying music.

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

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

Through the Looking Glass
This nonprofit offers college scholarships for individuals with parents with disabilities. www.lookingglass.org 800-644-2666

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