Resource Directory

Ataxia Telangiectasia (A-T)

Websites
- A-T Children’s Project: www.atcp.org
- NINDS A-T Information Page: www.ninds.nih.gov/disorders/a_t/a-t.htm

Chronic Inflammatory Demyelinating Polyneuropathy (CIPD)

Websites
- GBS/CIDP Foundation International: www.gbsfi.com
- Neurology Muscular Dystrophy and Neuropathy Institute Illustration of a damaged myelin sheath on a nerve: www.beverlyhillsneurology.com/cidp

Online Peer Support Links
- The Neuropathy Association: www.neuropathy.org
- Barbara’s CIDP/GBS Site (This is a personal website) www.geocities.com/HotSprings/Falls/3420

Evans syndrome

Websites
- Evans Syndrome Research and Support Group: www.evanssyndrome.org
- Office of Rare Diseases (catalog of online resources) http://rarediseases.info.nih.gov/asp/diseases/diseaseinfo.asp?ID=6389

Guillain-Barré Syndrome (GBS)

Websites and Chat Rooms
- The GBS/CIDP Foundation International, www.gbsfi.com, has 23,000 members in 160 chapters on five continents. 610-667-0131
- 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
- The National Institute of Neurological Disorders and Stroke has an information page about CIDP: www.ninds.nih.gov/disorders/cidp/cidp.htm.

Online Peer Support

GBS Foundation Discussion Forums: www.guillain-barre.com/forums
Yahoo Support Group Discussion Board http://health.groups.yahoo.com/group/GBS_CIDP

Books and Articles
- “Bed Number Ten,” by Sue Baier, provides a view of long-term care through the eyes of a patient totally paralyzed with GBS.
- “Caring for a Child With GBS,” by Patricia Schardt, is a short guide written by a mother of a child with CIDP. Available at the GBS website bookstore at www.gbsfi.com.
- “No Laughing Matter,” by Joseph Heller (the best-selling author of Catch-22), who teamed up with Speed Vogel, his best friend, to describe Heller’s battle with and triumph over GBS.

ITP (Idiopathic Thrombocytopenic Purpura)

Websites
- ITP Support Association, UK: www.itpsupport.org.uk
- Platelet Disorder Support Association: www.pdsa.org

Online References

Kawasaki Disease

Websites
- Kawasaki Disease Foundation: www.kdfoundation.org
  PO Box 45 • Boxford, MA 01921
  Tel: 978-356-2070 • Fax: 978-356-2079 • Email: info@kdfoundation.org
- Overview from the American Heart Association focuses on how the disease affects the heart. www.americanheart.org/presenter.jhtml?identifier=4634

Mitochondrial Disease

Websites
- United Mitochondrial Disease Foundation promotes research and education for the diagnosis, treatment and cure of mitochondrial disorders and provides support to affected individuals and families. www.umdf.org
Resource Directory

• The Cleveland Clinic website provides many articles when searched by the topic, "mitochondrial disease."  www.clevelandclinic.org/health


Multifocal Motor Neuropathy (MMN)

Websites

• National Institute of Neurological Disorders and Strokes (NINDS) provides a Multifocal Motor Neuropathy Information Page:  www.ninds.nih.gov/disorders/multifocal_neuropathy/multifocal_neuropathy.htm

• Multifocal Motor Neuropathy Center at Johns Hopkins Department of Neurology  www.neuro.jhmi.edu/MMN/index.html

• The Neuromuscular Center at Washington University in St. Louis, Mo.  Neuromuscular Home Page  www.neuro.wustl.edu/neuromuscular

• The Neuropathy Association is dedicated to helping those with conditions affecting peripheral nerves.  www.neuropathy.org

Multiple Sclerosis (MS)

Websites and Chat Rooms

• The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS.  www.nationalmssociety.org/

• All About Multiple Sclerosis provides accurate and comprehensive medical information about MS written in plain English by people living with the disease and its symptoms.  www.mult sclerosis.org/index.html

• Multiple Sclerosis Foundation works for a brighter tomorrow for those affected by MS.  www.msfacts.org

• Multiple Sclerosis Association of America seeks to enrich the quality of life for individuals with multiple sclerosis.  www.msaa.com

• MSWorld’s Chat and Message Board features patients helping patients.  www.msworld.org

Online Peer Support

• Friends with MS:  http://friendswithms.com
  Forum:  http://health.groups.yahoo.com/group/FriendsWithMS

• My MSViews:  www.mymsvsviews.org
  Forum:  http://health.groups.yahoo.com/group/MSViews_Multiple_Sclerosis

• MS Support Group:  http://health.groups.yahoo.com/group/mscured

• The MS Carousel—A Place to Meet With People Who Understand MS!  http://health.groups.yahoo.com/group/thescarousel

Myasthenia Gravis (MG)

Websites and Chat Rooms

• The Myasthenia Gravis Foundation of America (MGFA) is the only national volunteer health agency dedicated solely to the fight against (MG).  www.myasthenia.org

• Myasthenia Gravis Fact Sheet prepared by National Institute of Neurological Disorders and Strokes.  www.ninds.nih.gov/disorders/myasthenia_gravis/myasthenia_gravis.htm

• Mayo Clinic’s overview of myasthenia gravis:  www.mayoclinic.com/health/myasthenia-gravis/DS00375

Online Peer Support

• MGFA’s Forum:  http://health.groups.yahoo.com/group/MGnet

• Bette’s Myasthenia Gravis Support:  http://health.groups.yahoo.com/group/bettesmyastheniagravisupport

• Maddy’s MG Support:  http://health.groups.yahoo.com/group/maddysmgsupport

• Autoimmune Information Network Inc.:  www.aiinc.org

• The California Myositis Symposium held in 2005 was captured on DVD. It presents offer valuable lessons in maintaining a positive attitude, exercises for physical therapy and innovative tools to aid in everyday activities. The DVD is available at no charge by sending an email to Richard Gay at rgay@socal.rr.com.

Myositis

Websites

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

• International Myositis Assessment and Clinical Studies Group is a coalition of healthcare providers and researchers with global approaches to improved treatments and understanding of myositis:  https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main

• The Cure JM Foundation was created specifically to find a cure for Juvenile Myositis (JM), while also providing support and information for families affected by JM.  http://curejm.com

• Johns Hopkins Myositis Center is a new patient treatment center that brings the expertise of rheumatologists and neurologists into a single clinic for patients with inflammatory (autoimmune) and toxic (drug induced) muscle conditions.  www.hopkinsmedicine.org/rheumatology/clinics/myositis_center.html

Online Peer Support

• Juvenile Myositis Family Support Network:  www.curejm.com/family_support/index.htm

• Myositis Association Community Forum:  www.myositis.org

• Myositis Support Group:  www.myosistisupportgroup.org

• Myositis Support Group UK:  www.myositis.org.uk

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

• The California Myositis Symposium held in 2005 was captured on DVD. It contains information about polymyositis, dermatomyositis and inclusion body myositis, including doctors’ discussions and detailed slides and explanations of muscle biopsies, skin rash, and tools used to diagnose these diseases. Other presentations offer valuable lessons in maintaining a positive attitude, exercises for physical therapy and innovative tools to aid in everyday activities. The DVD is available at no charge by sending an email to Richard Gay at rgay@socal.rr.com.

Books and Articles

• “Coping With a Myositis Disease,” by James R. Kilpatrick, is written by myositis patients telling their personal stories.

• “Inclusion-Body Myositis and Myopathies,” by Valerie Askanas (Editor), Georges Serratrice (Editor) and W. King Engel (Editor), is devoted to discussing the two forms of inclusion-body myositis.

• “Living With Myositis,” edited by Jenny Fenton, is an accessible, realistic and sympathetic guide to facts, feelings and future hopes.

• “Myositis — A Medical Dictionary, Bibliography, and Annotated Research Guide to Internet References,” by ICON Health Publications, is a three-in-one
reference book: a complete dictionary of terms relating to myositis, a list of bibliographic citations about the disorder and a guide to Internet resources.


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

**Pemphigus and Pemphigoid**

**Websites**
- The International Pemphigus and Pemphigoid Foundation provides information and support to people living with the autoimmune diseases. www.pemphigus.org

- Information from the National Institutes of Health: www.niams.nih.gov/hi/topics/pemphigus/pemphigus.htm

- Rare disease report: http://rarediseases.about.com/od/rarediseasesp/a/www.primaryimmune.org

- "If You’re Having a Crummy Day, Brush Off the Crumbs!," by Mims Cushing, The American Academy of Allergy, Asthma & Immunology, To chat with peers on IDF’s Forum, go to http://health.groups.yahoo.com/group/PIDsupport

**Peripheral Neuropathy (PN)**

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

- To learn about PN, how it is classified, the symptoms, causes and treatments, see the Peripheral Neuropathy Fact Sheet available at www.ninds.nih.gov/disorders/peripheralneuropathy/peripheralneuropathy.htm.

- The Neuropathy Action Foundation, at www.neuropathyaction.org, educates, empowers and informs patients and physicians about neuropathy.

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

**Online Peer Support**

- MSN Support Group Discussion Board: http://groups.msn.com/PNPARTNERS

- The Neuropathy Association Bulletin Board: www.neuropathy.org

- Yahoo Neuropathy Support Group Discussion Board: http://health.groups.yahoo.com/group/neuropathy

- Yahoo Support Group – Australia Discussion Board: http://au.groups.yahoo.com/group/LifeWithPN

**Books and Articles**
- "If You’re Having a Crummy Day, Brush Off the Crumbs!," by Mims Cushing, is a how-to book that offers more than 75 ways to help people get through the days when neuropathy (or other ailments) is particularly difficult.

- "Medifocus Guide to Peripheral Neuropathy," is a guide to current and relevant PN research, organized into categories for easy reading.

- "Numb Toes and Aching Soles," by John Senneff, discusses the symptoms, causes, tests, treatments and coping strategies for peripheral neuropathy.

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

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

- "Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won’t Stop" by Dr. Norman Latov, MD, PhD, published 2007, Weill Medical College, Cornell University, provides practical information on all the neuropathies, causes and treatments.

**Primary Immune Deficiency Disease (PIDD)**

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

- To learn about PN, how it is classified, the symptoms, causes and treatments, see the Peripheral Neuropathy Fact Sheet available at www.ninds.nih.gov/disorders/peripheralneuropathy/peripheralneuropathy.htm.

- The Neuropathy Action Foundation, at www.neuropathyaction.org, educates, empowers and informs patients and physicians about neuropathy.

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

**Online Peer Support**

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- The Neuropathy Association Bulletin Board: www.neuropathy.org

- Yahoo Neuropathy Support Group Discussion Board: http://health.groups.yahoo.com/group/neuropathy

- Yahoo Support Group – Australia Discussion Board: http://au.groups.yahoo.com/group/LifeWithPN

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Scleroderma

Websites
- Johns Hopkins Medicine Scleroderma Center: scleroderma.jhmi.edu
- Scleroderma Research Foundation: www.srfcure.org
- Scleroderma Foundation: www.scleroderma.org

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, is the only national organization dedicated to addressing the problem of autoimmunity. 800-598-4668 aarda@aarda.org
- Autoimmune Information Network Inc., www.aininc.org, helps patients and family cope with the disabling effects of autoimmune diseases. 732-262-0450 autoimmunehelp@aol.com
- National Association for Rare Disorders (NORD), www.rarediseases.org, promote awareness of rare diseases and the need for research. 800-999-6673 orphan@rarediseases.org
- National Institute of Neurological Disorders and Stroke (NINDS), www.ninds.nih.gov, offers treatment, diagnosis and research information for rare diseases. 800-352-9424 braininfo@ninds.nih.gov
- Diagnosed with SPS in 1994, Debra Kemery recounts her experience and offers practical information about coping with the disease at www.stiffman.org.

General Resources

Product Information
- Influenza and the influenza vaccine www.cdc.gov/flu or call 800-CDC-INFO (800-232-4636)
- IVIG Carimune NF www.carimune.com
- IVIG Flebogamma www.grifolsusa.com/flebogamma.htm
- IVIG Gammagard Liquid www.gammagardliquid.com
- IVIG Gamunex www.gamunex.com
- IVIG Octagam www.octapharma.com/corporate/03_products_and_therapeutic_areas/01_immunoglobulin_product_line/03_octagam.php
- SCIG (subcutaneous immune globulin) Vivaglobin www.vivaglobin.com

Other Organizations
- Alliance for Plasma Therapies is a unified, powerful voice of patient organizations, healthcare providers and industry to advocate for fair access to plasma therapies. www.plasmaalliance.org
- For suggestions on how to deal with the medical and emotional impact of caring for an ill child, go to www.kidshealth.org/parent/system/ill/seriously_ill.html.
- The National Committee for Quality Assurance provides free access to detailed report cards on health plans, clinical performance, member satisfaction, access to care and overall quality on its Health Plan Report Cards Online at www.ncqa.org.
- The nonprofit Patient Advocate Foundation, www.patientadvocate.org, seeks to assure patient access to care, maintenance of employment and financial stability. 800-532-5274
- WebMD, www.webmd.com, is a handy medical reference that helps consumers take an active role in managing their health by providing objective healthcare and lifestyle information.
- For a pediatrician’s guide to your child’s health and safety, visit www.keepkidshealthy.com.
- The National Organization for Rare Diseases, at www.rarediseases.org, provides links to numerous other organizations that have disease-specific support groups and virtual communities for patients and caregivers.
- American Autoimmune Related Diseases Association (AARD) www.aarda.org brings national focus to autoimmunity through research, education and patient services. 800-598-4668
- American Chronic Pain Association (ACPA) was founded in 1980 to provide resources for people coping with chronic pain. www.theacpa.org

Education and Disability Resources
- Social Security: www.ssa.gov/disability
- California State Disability Insurance (SDI): www.edd.ca.gov (Please note that each state has a different disability program.)
Additional Reading

- “Anatomy of an Illness,” by Norman Cousins, is a best-seller about overcoming illness and the triumph of the human spirit. The premise is that the human mind is capable of promoting the body’s capacity for combating illness and healing itself even when faced with a seemingly hopeless medical predicament.


- “The Confused Consumer’s Guide to Choosing a Health Care Plan: Everything You Need to Know,” by Martin Gottlieb, helps consumers through the confusing maze of choosing a healthcare plan.

- “The Everyday Guide to Special Education Law,” by Randy Chapman, Esq., makes the law accessible to parents so they can be more effective advocates for their children. Available at www.thegalcenter.org/thegalcenter-cgi-bin/shop?item=15.

- “Living Creatively With Chronic Illness: Developing Skills for Transcending the Loss, Pain and Frustration,” by Eugenia G. Wheeler, is a self-help book specifically designed to help the chronically ill, their families, friends, counselors, medical personnel and the clergy.

- “Managing Pain Before It Manages You,” by Dr. Margaret A. Caudill, is a wellspring of wisdom and practical approaches that can help transform your life and your pain.

- “Not Dead Yet: A Long Strange Trip From Doctor to Patient and Back Again,” by Dr. Robert Buckman, an oncologist and comic writer, is a witty account of his life as a doctor and autoimmune disease survivor.

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

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

- “When You’re Ill or Incapacitated” comprises one-half the booklet it shares with “When You’re the Caregiver,” both written by James E. Miller, suggesting 12 things to remember or do in each role.

- “YOU the Smart Patient: An Insider’s Handbook for Getting the Best Treatment,” by Michael F. Roizen, MD, and Mehmet C. Oz, MD, with the Joint Commission on Accreditation of Healthcare Organizations, shows you how to tackle such healthcare decisions as picking the best doctors and hospitals for you, knowing when to get a second opinion, and more.
The resources included in the NAMI National Resource Directory are not endorsed by NAMI, and NAMI is not responsible for the content or service provided by any of these resources. NAMI National Resource Directory as of August 2020. Updated August 2020.

Table of Contents. draft-ietf-core-resource-directory-05. Abstract. In many M2M applications, direct discovery of resources is not practical due to sleeping nodes, disperse networks, or networks where multicast traffic is inefficient. These problems can be solved by employing an entity called a Resource Directory (RD), which hosts descriptions of resources held on other servers, allowing lookups to be performed for those resources. I have the following directory layout: src. main. java. resources. sql (scripts for database). spring (configuration). webapp. Within a ServletContextListener class, I want to access the files under the SQL directory and list them. Basically my problem is with the path, because I know that listing files under a directory in a nutshell is: File folder = new File(path); File[] listOfFiles = folder.listFiles(); Maybe I could use the ServletContextEvent Object to try and build a path to resources/sql. I: Building resources W: invalid resource directory name: /home/Framework/debug/app-debug/res navigation brut.androlib.AndrolibException Â If you are trying to install a modified apk, did you resign it? no. Are you using the latest apktool version? yes. TamilanPeriyasamy changed the title invalid resource directory name: DoximityX/res navigation invalid resource directory name: app-debug/res navigation Jan 9, 2019. Copy link. Quote reply.