RARE DISEASE RESOURCE LIST

National and State Resources for Patients, Families and Professionals

The Foundation for Children with Atypical HUS

A Public Service sponsored by the Atypical HUS Community at [www.atypicalhus.org](http://www.atypicalhus.org)

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SOCIAL SECURITY / DISABILITY

This national Rare Disease Resource List was compiled by Linda Burke, founder of [www.atypicalhus.org](http://www.atypicalhus.org). A dynamic resource list, it serves only as a starting point for your information search. Entries will be added, modified, and updated on a regular basis. State Rare Disease Resource Lists can be found after the national entries – volunteer to create your state’s resource list if it is not already present. Resource information and links to be considered for inclusion should be submitted to linda@atypicalhus.org.

This Rare Disease Resource List was created Feb. 2013 to honor global Rare Disease Day. (Revised Oct. 2013)
RARE DISEASE ORGANIZATIONS

The National Organization for Rare Disorders (NORD) is dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

The Office of Rare Diseases Research (ORDR) at the National Institutes of Health (NIH) coordinates research and information on rare diseases at the NIH. The ORDR website aims to answer questions about rare diseases and the activities of the ORDR for patients, their families, healthcare providers, researchers, educators, students, and anyone with concern for and interest in rare diseases. The site provides information about ORDR-sponsored biomedical research, scientific conferences, and rare and genetic diseases. It also serves as a portal to information on major topics of interest to the rare diseases community.

Genetic and Rare Diseases Information Center (GARD) is a collaborative effort of two agencies of the National Institutes of Health, The Office of Rare Diseases Research (ORDR) and the National Human Genome Research Institute (NHGRI), committed to helping people find useful information about genetic conditions and rare diseases.

The National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the nation’s medical research agency — making important discoveries that improve health and save lives. NIH is made up of 27 Institutes and Centers, each with a specific research agenda that often focuses on particular diseases or body systems, and is the largest source of funding for medical research in the world. They have a comprehensive listing of publications and clinical trials, and offer resources by topic, disease, and age groups not limited to rare diseases.
**EURORDIS**, the voice of 30 million people affected by rare diseases throughout Europe, is a non-governmental patient-driven alliance of patient organizations representing 561 rare disease patient organizations in 51 countries. Rare disease patients are able to access new developments regarding their disease throughout the world.

**Canadian Organization for Rare Disorders (CORD)** is Canada’s national network for organizations representing patients with rare disorders works with governments, researchers, clinicians, and industry to promote research, diagnosis, treatment, and services for all rare disorders in Canada.

**Orphanet** is the reference portal for information on rare diseases and orphan drugs, available in 6 languages. Orphanet’s aim is to help improve the diagnosis, care and treatment of patients with rare diseases. Orphanet has teams in more than 30 countries.

**RARE DISEASE ADVOCACY**

**RareConnect** is a multilingual site that connects rare disease patients globally. Living with a rare disease can be an isolating experience. RareConnect was created by EURORDIS (European Rare Disease Organization) and NORD (National Organization for Rare Disorders) to provide a safe space where individuals and families affected by rare diseases can connect with each other, share vital experiences, and find helpful information and resources. Connect to join existing patient communities, or contact them to explore creation of a new disease-specific community for your rare disease group.

**Genetic Alliance** a leading health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities. Their **Advocacy ATLAS** (launched Oct. 2013) is an online toolkit created by Genetic Alliance, Parent to Parent USA, and Family Voices that provides individuals with special healthcare needs and their families with tools and strategies to advocate for whatever they may need.

The **Global Genes: the R.A.R.E. Project** is a rare and genetic disease patient advocacy organization that promotes the needs of the rare and genetic disease community under a unifying symbol of hope — the Blue Denim Genes Ribbon. Their mission is centered on increasing rare disease awareness, public and physician education, building community through social media, and supporting research initiatives.
ORGANIZATIONS FOR UNDIAGNOSED OR UNNAMED SYNDROMES

**In Need of Diagnosis (INOD)** provides help and support to individuals with undiagnosed conditions.

Some patients wait years for a definitive diagnosis. Using a unique combination of scientific and medical expertise and resources at the **National Institutes of Health (NIH)**, the **Undiagnosed Diseases Program (UDP)** pursues two goals. It strives to provide answers to patients with mysterious conditions that have long eluded diagnosis, and it is committed to advance medical knowledge about rare and common diseases.

** Syndromes Without A Name USA (SWAN USA)** is a non-profit tax exempt organization that offers support, information, and advice to families of children living with a syndrome without a name. SWAN also has organizations in other countries, too.

**CAREGIVERS – ADVOCACY AND SUPPORT**

**The Caregiver Action Network (CAN)** is a family caregiver organization working to improve the quality of life for the more than 65 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN is a nonprofit organization providing education, peer support, and resources to family caregivers and serves a broad spectrum of family caregivers and care situations.

**National Family Caregivers Association** 1-800-896-3650
The National Family Caregivers Association (NFCA) educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age.

National Family Caregivers Association (NFCA) **Resources for Caregivers** offers a virtual library of information and educational materials ranging from national educational campaigns to Tips and Tools for family caregivers to information on agencies and organizations which provide caregiver support.

**Family Caregiver Alliance** provides a public voice for caregivers, offering assistance through education, services, research, and advocacy.

**Patient Advocate Foundation** 1-800-532-5274
National non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis.
Empowering Caregivers site provides a safe, nurturing site for all caregivers with emotional and spiritual support and a vast amount of both online and offline resources for caregivers.

The Invisible Disabilities Association (IDA) encourages, educates, and connects people and organizations touched by illness, pain, and disability around the globe. IDA also offers resources for information about various illnesses, help with costs of medications, disability benefits, and more.

HealingWell.com features a thriving support community, blog, videos, a newsletter, articles, and resources to help patients actively manage the challenges of living with chronic illness.

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Family Voices utilizes affiliate organizations in each state, with a list at http://www.familyvoices.org/states. Resources include special topic areas such as workplace issues, benefits, and considerations for families with special needs. Others include information regarding health care and insurance, Title V, and family-centered care.

Parent to Parent - USA. Emotional & Informational support for families of children who have special needs. Parent to Parent USA (P2PUSA) is a national non-profit organization committed to promoting access, quality and leadership in parent to parent support across the country.

PATIENT ASSISTANCE PROGRAMS

Patient Access Network (PAN) Foundation provides co-payment assistance to underinsured patients with chronic diseases, including breast cancer. Qualified patients will be granted up to $7,500 per year to cover out-of-pocket expenses associated with their treatment.

Patient Advocate Foundation (PAF) is a national nonprofit organization that provides professional case management services to Americans with chronic, life-threatening, and debilitating illnesses. PAF case managers serve as active liaisons for you and your insurers, employers, or creditors to resolve insurance, job retention, and debt crisis matters as they relate to your diagnosis.

State Pharmaceutical Assistance Programs
Many states and the U.S. Virgin Islands offer help paying drug plan premiums and/or other drug costs, as part of the Medicare program.

UnitedHealthcare Children’s Foundation is a 501(c)(3) non-profit charity dedicated to facilitating access to medical-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child and that are not fully
covered by available commercial health benefit plans. This support is in the form of a medical grant to be used for medical services not covered or not completely covered by commercial health benefit plans.

The First Hand Foundation is a not-for-profit, 501(c)(3) organization that provides funding so individual children may have access to health care that would otherwise be impossible. Our mission is to directly impact the health status of a young life. Since our inception in 1995, First Hand has distributed more than $14 million to impact 134,000 lives in 76 countries.

Team Continuum is dedicated to helping cancer patients of all ages and with all types of cancer. They help cancer patients minimize the burdens of everyday life by providing immediate and vital assistance for non-medical essentials — such as paying their rent and utility bills — so they can focus on crucial medical care.

BrightHand understands that hearing your child has a rare or undiagnosed disease is like entering an alternate universe. You still have work, family, financial, and other obligations while trying to find the best possible care for your child. When a child’s medical costs exceed a family’s ability to pay, BrightHand can help by assisting with co-payments for children with rare or undiagnosed diseases.

(NHGRI) at the National Institutes of Health (NIH) has information about financial assistance resources for people who need help paying for medical care.

Partnership for Prescription Assistance  1-888-477-2669
This organization helps uninsured or low-income patients obtain low-cost or free brand-name medications.

National Fuel Funds Network  (202) 824-0660
NFFN (National Fuel Funds Network) members such as community-based organizations, local government agencies, and utility partners raise and distribute money for bill-payment assistance in neighborhoods across the country.

NeedyMeds is a 501(c)(3) non-profit information resource devoted to helping people in need find assistance programs to help them afford their medications and costs related to health care.
HOME HEALTH CARE

**Visiting Nurse Agency (VNA)**  VNA home health care services include assisting those persons who are recovering, disabled, chronically or terminally ill and are in need of medical, nursing, social, or therapeutic treatment and/or assistance with the essential activities of daily living.

The **National Association of Healthcare Advocacy Consultants (NAHAC)** is a professional organization for people working in the field of health care advocacy. They seek to ensure consumer protection through development of professional standards and best practices in the field of health care advocacy.

INSURANCE ASSISTANCE

**Patient Advocate Foundation**  1-800-532-5274
National non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis.

**Children’s Health Insurance Program (CHIP)**  1-877-543-7669
The Children’s Health Insurance Program (CHIP) is a state and federal partnership that provides low-cost health insurance coverage for children in families who earn too much income to qualify for Medicaid but cannot afford to purchase private health insurance.

**Insure Kids Now**  1-877-543-7669
Your state, and every state in the nation, has a health insurance program for infants, children, and teens. The insurance is available to children in working families, including families that include individuals with a variety of immigration status.

AGE SPECIFIC RESOURCES

**CHILDREN**  (see also Education)

**National Institutes of Health (NIH)**  Their category ‘Child & Teen Health’ offers a comprehensive listing of information and issues affecting children and teens. Explore the wide spectrum of physical, emotional, and social growth topics for children of all ages.

**The American Academy of Pediatrics (AAP)** and its member pediatricians dedicate their efforts and resources to the health, safety, and well-being of infants, children, adolescents, and young adults.
The Department of Pediatrics at National Jewish Health gives detailed information and suggested steps to help families cope with a child’s chronic illness.

The AACAP (American Academy of Child and Adolescent Psychiatry) is a national professional medical association dedicated to treating and improving the quality of life for children, adolescents, and families affected by various disorders. This article about children with long-term illness is part of a Family Fact section.

Sensory Processing Disorder Checklist. Many children with special health needs may have sensory issues (muscle coordination or overly/under-sensitive to certain sounds, smells, tastes, visual input) that affect functioning in both home and school environments. This simple checklist for parents is a good starting point to begin discussion with physicians, therapists, and school personnel. The link above is from the book The Out-of-Sync Child by Carol S. Kranowitz (1995).

Learning disability concerns at school or in the workplace? The Interactive LD Checklist can be utilized for preschool age through high school and with specialized adult surveys.

The Family Center on Technology and Disability is a resource designed to support organizations and programs that work with families of children and youth with disabilities.

Family Voices believes that children with special health needs face common problems. With a focus on children's health care, they offer information on family-centered care, health care financing, and other resources.

Social Security Administration — Children and Social Security. A resource booklet for parents, caregivers, or representatives of children younger than age 18 who have disabilities that might make them eligible for Supplemental Security Income (SSI) payments. It is also for adults who became disabled in childhood and who might be entitled to Social Security Disability Insurance (SSDI) benefits. (This SSDI benefit might be considered a “child’s” benefit because it is paid on a parent’s Social Security earnings record.)

The National Association of School Nurses (NASN) – Parents of children diagnosed with a rare disease often rely on the school nurse as a vital member of their child’s care team. Enlist the aid of the school nurse for assistance in such areas as creating an IHP (Individualized Heath Plan) or 504 plan (for children with special health care needs). School nurses are positioned to offer valuable insight into how chronic illness might impact the P.E.T. (Pupil Evaluation Team) process. The National Association of School Nurses offers SCHLRN-L, an online discussion group that promotes networking among school nurses to share information, insights, and resources.

Members of the National Association of School Nurses (NASN) recognize that there are students whose health care needs affect or have the potential to affect safe and optimal
school attendance and academic performance. The professional school nurse can create an **Individualized Healthcare Plan (IHP)**, in collaboration with the student, family, educators, and health care providers.

Part of the Social Security Act, **Title V** is the state program For Children and Youth with Special Health Care Needs (CYSHCN). Federal law mandates that Title V/CSHCN programs serve these children.

“Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” This definition can include physical conditions or children with disabilities. The Association of Maternal & Child Health Programs (AMCHP) works to improve the health of women, children, youth, and families, including those with special health care needs. AMCHP’s [resource page](http://www.amchp.org) with a detailed overview of Title V:

FMI see an [overview of Title V at Family Voices](http://www.familyvoices.org) or visit HRSA, an agency of the U.S. Department of Health and Human Services [www.hrsa.gov/orgchart.htm](http://www.hrsa.gov/orgchart.htm).

**Shadow Buddies**  **1-913-642-4646**
Shadow Buddies are condition-specific dolls designed to be a friend "just like me" for seriously ill or medically challenged children. This provides comfort to children, as well as effective method for educating newly-diagnosed children.

**Camp Sunshine** provides respite, support, joy, and hope to children with life-threatening illnesses and their immediate families through various stages of a child’s illness. The year-round program is free of charge to all families and includes 24-hour onsite medical and psychosocial support.

**Starlight Children's Foundation**  **1-310-479-1212**
Starlight Children’s Foundation is dedicated to improving the quality of life for children with chronic and life-threatening illnesses and life-altering injuries by providing entertainment, education and family activities that help them cope. Contact [info@starlight.org](mailto:info@starlight.org)

**Super Sibs**  **1-888-417-4704**
Super Sibs mission is to honor, support and recognize brothers and sisters of children with cancer and their goal is to reach out to the brothers and sisters of over 12,600 children in the U.S. and Canada who are diagnosed with cancer each year. Contact [info@supersibs.org](mailto:info@supersibs.org)
National Institutes of Health (NIH) ‘Child & Teen Health’ category offers a comprehensive listing of information and issues affecting children and teens. Explore the wide spectrum of physical, emotional, and social growth topics for children of all ages.

Chronic Illness Resources for Teens These resources are the result of a collaboration between the Koop Institute (C. Everett Koop in partnership with Dartmouth Medical School) and the S.T.A.R. Program for teens with chronic illness.

The Family Center on Technology and Disability is a resource designed to support organizations and programs that work with families of children and youth with disabilities.

Family Voices believes that children with special health needs face common problems. With a focus on children's health care, they offer information on family-centered care, health care financing, and other resources.

Focus Adolescent Services is a clearinghouse on information and resources regarding teen and family issues. They strive to empower individuals to help their teens and heal their families through education and support.

TeensHealth is part of the KidsHealth family of websites, and is a place for teens who need honest, accurate information and advice about health, emotions, and life. These sites, run by the nonprofit Nemours Center for Children’s Health Media, provide accurate, up-to-date health information that's free of “doctor speak.” (The Nemours Foundation is a nonprofit organization, created by philanthropist Alfred I. DuPont, devoted to improving the health of children.) Written especially for the teen with a health condition, this resource outlines, in teen terms, issues involved in living with a chronic illness.

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SENIORS

NIH SeniorHealth makes aging-related health information easily accessible for family members and friends seeking reliable, easy to understand online health information. This site was developed by the National Institute on Aging (NIA) and the National Library of Medicine (NLM), both part of the National Institutes of Health (NIH), offering a wide range of topics, videos, and tools for older adults.

The American Geriatrics Society (AGS), a not-for-profit organization of health care providers, dedicated to improving the health and well-being of all older adults.

ART Therapy for Seniors: The Assisted Living Federation of America (ALFA) is the largest national association exclusively dedicated to professionally operated senior living communities for seniors. Click here to view the Art Programs: Enhancing the Lives of Older Adults Toolkit.

VETERANS

US Department of Veterans Affairs Veterans of the United States armed forces may be eligible for a broad range of programs and services provided by the VA. As the nation’s largest integrated health care system, the VA’s health care offers a variety of services, information, and benefits, and they operate more than 1,400 sites of care.

The Disabled American Veterans (DAV) is a non-profit 501(c)(4) charity dedicated to building better lives for America’s disabled veterans and their families. They provide free help with earned VA benefits, transportation and advocacy

VA Library Network (VALNET) A compilation of consumer health websites, not limited to rare diseases.

The Department of Health and Human Services (HHS) is the United States government’s principal agency for protecting the health of all Americans and providing essential human services. HHS and its operating divisions offer a variety of resources and programs specifically designed to support military families.

Angel Flight Veteran Arranges flights for veterans and active-duty military personnel and their families in need of compassionate medical air transportation.
The Office of Special Education Programs (OSEP) is dedicated to improving results for infants, toddlers, children, and youth with disabilities ages birth through 21 by providing leadership and financial support to assist states and local districts.

Serving the nation as a central source for information on disabilities, the National Dissemination Center for Children with Disabilities provides a wealth of information and resources for early intervention for babies and toddlers as well as children from ages 3 to 22 years old. Check the ‘State Resource Sheets’ that connect parents with the disability agencies and organizations for their particular state.

The Family Center on Technology and Disability is a resource designed to support organizations and programs that work with families of children and youth with disabilities. Funded by the U.S. Department of Education's Office of Special Education Programs, the Family Center on Technology and Disability provides a wide range of resources on assistive technology, from introductory fact sheets and training materials to in-depth discussion of best practices and emerging research.

U.S. Department of Education (Office of Special Education Programs) — IDEA: Individuals with Disabilities Education Act This site was created to provide a "one-stop shop" for resources related to IDEA and its implementing regulations, with access to cross-referenced content from other laws (e.g., the No Child Left Behind Act (NCLB) and the Family Education Rights and Privacy Act (FERPA), etc.). Among a variety of other information sources, you'll find video clips on selected topics, links to OSEP’s Technical Assistance and Dissemination (TA&D) Network and a Q&A Corner where you can submit questions. (URL above)

The National Center for Learning Disabilities (NCLD) focuses on fostering success for all individuals with learning disabilities in school, at work, and in life. Below are some excellent resources regarding the impact of learning disabilities on all ages.

Learning disability concerns at school or in the workplace? The Interactive LD Checklist can be utilized for preschool age through high school and with specialized adult surveys.

Learning Disabilities in Adulthood:

Learning Disabilities in the Workplace:

Post-High School Options and Learning Disability Issues:

Information regarding the Americans with Disabilities Act, with links to associated topics of interest (such as Employment, Education, and Healthcare) as well as an overview of rights/laws.

**Sensory Processing Disorder Checklist** Many children with special health needs may have sensory issues (muscle coordination or overly/under-sensitive to certain sounds, smells, tastes, visual input) that affect functioning in both home and school environments. This simple checklist for parents is a good starting point to begin discussion with physicians, therapists, and school personnel. From the book *The Out-of-Sync Child* by Carol S. Kranowitz (1995).

**Grahamtastics Connection** A non-profit program that provides laptops and Internet access to connect chronically ill children to their world, particularly vital for those missing school due to hospitalization or treatment schedules.

**The National Association of School Nurses (NASN)** Parents of children diagnosed with a rare disease often rely on the school nurse as a vital member of their child’s care team. Enlist the aid of the school nurse for assistance with such areas as creating an IHP (Individualized Health Plan) or 504 plan (for children with special health care needs). School nurses are positioned to offer valuable insight into how chronic illness might impact the P.E.T. (Pupil Evaluation Team) process. The National Association of School Nurses offers SCHLRN-L, an online discussion group that promotes networking among school nurses to share information, insights, and resources.

Members of the **National Association of School Nurses (NASN)** recognize that there are students whose healthcare needs affect or have the potential to affect safe and optimal school attendance and academic performance. The professional school nurse can create an Individualized Healthcare Plan (IHP), in collaboration with the student, family, educators, and healthcare care providers.
**SOCIAL SECURITY / DISABILITY**

**Disability.gov** is an award-winning federal Web site that contains disability-related resources on programs, services, laws and regulations to help people with disabilities lead full, independent lives.

**Disability Claims**
Common Social Security questions answered, and explanation of the [Social Security Claims](#) process provided.

General website for the [Social Security Administration](#), it contains multiple resource lists and a wide variety of information.

(800) 772-1213

**The Social Security and Disability Resource Center** website provides information on the federal government’s two disability benefit programs, title II social security disability benefits and title 16 SSI disability benefits.

**SocialSecurityDisability.ws** is a national service with Social Security Disability attorneys, lawyers and advocates helping individuals apply for Social Security benefits in each state.

**Social Security - CAL**

**Compassionate Allowances (CAL)** Compassionate Allowances is a specialized program to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards. Compassionate Allowances (CAL) are a way of quickly identifying diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal objective medical information. Compassionate Allowances allow Social Security to target the most obviously disabled individuals for allowances based on objective medical information that we can obtain quickly.
U.S. GOVERNMENT RESOURCES

Information regarding the Americans with Disabilities Act, with links to associated topics of interest to aHUS adults (such as Employment, Education, and Healthcare) as well as an overview of rights/laws.

The Department of Health and Human Services (HHS) is the United States government’s principal agency for protecting the health of all Americans and providing essential human services. HHS’s Medicare program is the nation’s largest health insurer, and together Medicare and Medicaid provide health care insurance for one in four Americans. HHS works closely with state and local governments, and many HHS-funded services are provided at the local level by state or county agencies. The Department’s programs are administered by 11 operating divisions, including eight agencies in the U.S. Public Health Service and three human services agencies. This link brings you to the Family page offering a variety of resources for patients and their families.

U.S. Social Security Administration — Children and Social Security. A resource booklet for parents, caregivers, or representatives of children younger than age 18 who have disabilities that might make them eligible for Supplemental Security Income (SSI) payments. It is also for adults who became disabled in childhood and who might be entitled to Social Security Disability Insurance (SSDI) benefits. (This SSDI benefit might be considered a “child’s” benefit because it is paid on a parent’s Social Security earnings record.)

The Supplemental Security Income (SSI) program may pay benefits to disabled adults and children who have limited income and resources.

Publications:

The Red Book — An overview of USA Disability Programs

ClinicalTrials.gov, a site sponsored by the National Institutes of Health, is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world. Its searchable database provides patients, family members, and the public with information about current ongoing clinical research studies.

Part of the Social Security Act, Title V is the state program For Children and Youth with Special Health Care Needs (CYSHCN). Federal law mandates that Title V/CYSHCN programs serve these children.

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This definition can include physical conditions or children with disabilities. The Association of Maternal & Child Health Programs (AMCHP) works to improve the health of women, children, youth, and families, including those with special health care needs. AMCHP’s resource page with a detailed overview of Title V

FMI see an overview of Title V at Family Voices or visit HRSA, an agency of the U.S. Department of Health and Human Services.

**State Pharmaceutical Assistance Programs**
Many states and the U.S. Virgin Islands offer help paying drug plan premiums and/or other drug costs, as part of the Medicare program.

**MEDICAL INFORMATION (GENERAL)**

**Medline Plus**, a service of the U.S National Library of Medicine and the National Institutes of Health, provides a rich source of information, resource links, videos, and more. Search for information by disease, organ, or topic.

**MedlinePlus - Medical Dictionary** Part of Medline Plus, this sub-site can search for and definite medical terms.

**Lab Tests Online**
Lab Tests Online (AACC) has been designed to help the patient or family caregiver to understand the many clinical lab tests that are part of routine care as well as diagnosis and treatment of a broad range of conditions and diseases. The American Association for Clinical Chemistry (AACC) is an international society of medical professionals from various laboratory medicine fields.

**Healthfinder.gov** is a U.S. government website offering a variety of information, resources, and tools. Their wide range of health topics are selected from approximately 1,400 government and nonprofit organizations.

**Disability.gov** is an award-winning federal Web site that contains disability-related resources on programs, services, laws and regulations to help people with disabilities lead full, independent lives.
TRANSPLANTS
United Network for Organ Sharing UNOS is the private, non-profit organization that manages the U.S. organ transplant system. Information, materials, and resources are provided.

Children’s Organ Transplant Association: COTA exists to assist patients who require a life-saving organ, bone marrow, cord blood or stem cell transplant. COTA provides resources for Transplant Families.

Transplant Living | After The Transplant
Transplant Living provides a variety of post-transplant resources, with information and resources for organ transplant recipients.

National Marrow Donor Program - Patient Advocacy 1-888-999-6743
The National Marrow Donor Program Office of Patient Advocacy is here to help. On this Web site, you can find information to help you: Talk with your doctor, choose a transplant center, answer questions about caregiving, and prepare for life after transplant. Contact - patientinfo@nmdp.org

The Bone Marrow Foundation 1-800-365-1336
The Bone Marrow Foundation website will provide you with financial assistance resources, information, programs and services about bone marrow/stem cell transplantation you need whether you are a patient, family member, friend, bone marrow donor or doctor. Contact - TheBMF@BoneMarrow.org

BMT InfoNet 1-888-597-7674
The Blood & Marrow Transplant Information Network offers a variety of information and resources. Contact - help@bmtinfonet.org

TOPIC-SPECIFIC ORGANIZATIONS

American Cancer Society offering information and resources for Cancer: Breast, Colon, Lung, Prostate, and Skin.

The American Chronic Pain Association raises awareness about chronic pain issues and facilitates peer support and education for individuals with chronic pain and their families, allowing these individuals to live more fully in spite of their pain.

The American Heart Association building healthier lives, free of cardiovascular diseases and stroke. This AHA site includes risk assessment for heart attack and stroke, resources for advocates and scientists, and a “Heart and Stroke A-Z” guide.
The **American Liver Foundation** strives to facilitate, advocate, and promote education, support, and research for the prevention, treatment, and cure of liver disease. Resources include a toolkit for patients with liver (biliary) disease and tips for caregivers.

**American Lung Association** Providing a variety of information and resources, their site features a Lung Disease Data Base and a toll free Lung Helpline.

**American Pain Foundation** 1-888-615-7246
The American Pain Foundation is an organization serving people with pain through information, advocacy, and support.

**American Society of Hematology** 1-202-776-0544
Links to blood disease resources and related publications, including a search function for abstracts.

**American Thyroid Association (ATA)** is a professional society of experts focused on research and treatment of thyroid pathophysiology. A specific portion of the site is dedicated for “Public & Patients.”

**Arthritis, Musculoskeletal and Skin Diseases National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)** Sponsored by the National Institutes of Health, this page offers news, events and fact sheets, plus information on patient enrollment in clinical trials.

**BloodLine** 1-434-817-2010
Online resource exclusively dedicated to the fields of hematology and oncology.

**BMT InfoNet** 1-888-597-7674
Blood & Marrow transplant information network. Contact - help@bmtinfonet.org

**Give Kids the World** 1-800-995-5437
Nonprofit organization that provides cost-free visits to Central Florida attractions and Give Kids the World Village. Contact - dream@gktw.org

The **Heart, Lung and Blood Institute (HLBI)**, site sponsored by the NIH and the Department of Health and Human Services, offers information regarding clinical trials, news, and resources.

**Make-a-Wish Foundation**
This foundation grants the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength and joy.

**National Eye Institute (NEI)** Sponsored by the NIH, this site provides health info, research, and clinical studies about the eye and vision issues.
**National Institute on Deafness and Other Communication Disorders [NIDCD]** A site sponsored by the National Institutes of Health, it provides health info, news about research, and an index of conditions and disorders.

The **National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)** provides health and disease info for the public and the scientific community, as well as conducting and supporting basic and clinical research.

The **National Institute of Neurological Disorders and Stroke (NINDS)** is sponsored by the National Institutes of Health and features news and resources, plus links to neurological studies that are seeking patients. The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

The **National Kidney Foundation (NKF)** provides information on kidney disease for patients and doctors.

**Partners Against Pain** 1-800-877-5666
Partners Against Pain® is an alliance of patients, caregivers, and healthcare providers working together to alleviate unnecessary suffering by leading efforts to advance standards of pain care through education and advocacy.

**Project Sunshine** 1-212-354-8035
Project Sunshine is a nonprofit organization that provides free social, educational and recreational programs to children and families affected by medical challenges.

**Special Olympics** transforms lives through the joy of sport, every day, everywhere. The world’s largest sports organization for people with intellectual disabilities, it serves nearly 4 million athletes in more than 170 countries.

**Starlight Children’s Foundation** 1-310-479-1212
Starlight Children’s Foundation is dedicated to improving the quality of life for children with chronic and life-threatening illnesses and life-altering injuries by providing entertainment, education and family activities that help them cope. Contact - info@starlight.org
NUTRITION

The Academy of Nutrition and Dietetics (formerly the American Dietetic Association) provides accurate information and various resources about nutrition, wellness, and related areas.

American Nutrition Association The American Nutrition Association promotes optimal health through nutrition and wellness education. Educating both laypeople and professionals about the health benefits of nutrition and wellness, it focuses on science-based nutrition.

GENETICS

The Genetic Basics: Sponsored the Office of History within the National Institutes of Health, this resource gives an overview of genes, chromosomes, and their role in genetic diseases.

Genetics Home Reference (GHR) provides consumer-friendly information on medical genetics for patients and their families.

The U.S. Human Genome Project was a 13-year effort coordinated by the U.S. Department of Energy and the National Institutes of Health. The project goals included the identification of all the approximately 20,000-25,000 genes in human DNA, then to store, analyze, and discuss data and its utilization. This link leads to multiple resources for diseases, treatment, research, family history, and other references.

This link brings you to 'Genetics 101', an educational overview explaining cells, DNA, and genes before moving into more detailed topics. http://www.ornl.gov/sci/techresources/Human_Genome/project/info.shtml

Gene Gateway is a collection of guides and tutorials with various Internet tools that the public can use to investigate in detail genetic disorders, chromosomes, genome maps, genes, sequence data, genetic variants, and molecular structures.

Online Mendelian Inheritance in Man (OMIM) is a database of published scientific research relating to medically important human genes, traits, and genetic disorders. The site was developed by the National Center for Biotechnology Information (NCBI). The language is technical, as it a very comprehensive source of information.

The Family Health Portrait Tool is an easy-to-use online tool developed by the National Human Genome Research Institute and the Surgeon General's Office to help consumers gather their own family health history.

Genes in Life, a sponsored by the Genetic Alliance, is a user-friendly resource for anyone interested in genetics and health, with a primary focus on genetic services. It
includes information on genetic testing and working with healthcare professionals along with interactive features, such as an “ask the experts” section.

THERAPY INFORMATION AND ORGANIZATIONS

The American Occupational Therapists Association (AOTA) Occupational therapy services typically include customized treatment programs to improve one’s ability to perform daily activities and can offer comprehensive home and job site evaluations with adaptation recommendations. OT personnel can offer treatment, adaptive equipment recommendations, and usage training after performance skills assessments with their client. Programs include guidance to family members and caregivers, as well as information regarding work related topics, disability, and rehabilitation.

The American Physical Therapy Association (APTA) Search their resources at MoveForward PT, offering a wide variety of physical therapy topic-specific videos or podcasts, or browse by symptoms, conditions, or diagnoses. Don’t miss their innovative tool the Interactive Body.

The American Speech-Language-Hearing Association (ASHA) is the professional, scientific, and credentialing association for more than 150,000 members and affiliates who are audiologists; speech-language pathologists; and speech, language, and hearing scientists. Great resource lists on hearing, speech, balance, and additional topics.

American Music Therapy Association (AMTA) Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional. Music therapy interventions can be designed to improve communication, alleviate pain, promote physical rehabilitation, and more.

American Art Therapy Association (AATA) Art therapy is a mental health profession that uses the creative process of art making to improve and enhance the physical, mental, and emotional well-being of individuals of all ages. Research in the field confirms that the creative process involved in artistic self-expression helps people to become more physically, mentally, and emotionally healthy and functional, resolve conflicts and problems, develop interpersonal skills, manage behavior, reduce stress, handle life adjustments, and achieve insight.

Art Therapy in Health Care (please click on organization)

American Cancer Society, Beth Israel Center, Department of Integrative Medicine, Federal Emergency Management Agency, Johns Hopkins University, Mayo Clinic, National Institutes of Health, U.S. Department of Veterans Affairs, U.S. Substance Abuse & Mental Health Services Administration, Art Therapy in Health Care

Bibliography
TRAVEL AND ACCOMMODATIONS FOR PATIENTS

National Patient Travel Center  1-800-296-1217
Offering help and servicing to make referrals, NPTC provides "how to get there" assistance for any patient needing to travel to a distant specialized medical facility for evaluation, diagnosis or treatment. Contact - info@nationalpatienttravelcenter.org

Children’s Miracle Network
Financial assistance for transportation associated with medical treatment may be available at a local Children’s Miracle Network Hospital. Call the national office telephone number to be referred to the local program director at a local Children’s Miracle Network Hospital, and they will help locate financial assistance for transportation, if funds are available.

NIH Office of Rare Diseases Research (ORDR) — This link related to patient travel and lodging is a compilation of resources regarding many charitable or special-fare flights to research and treatment sites and low-cost hospitality accommodations for outpatients and family members. Additional information, as well as ambulance services, is also listed on the ORDR Web pages.

Ped-Onc Resource Center, a site dedicated to resources and information for parents of children with cancer, created by parents of children with cancer. Offers a vast array of travel options, including bus travel; most of these travel options serve all patient populations.

Angel Bus
Long distance, no cost motor coach or bus transportation for patients.

Air Charity Network
National charitable aviation network matching people in need with “free” flights and other travel resources that can provide healing and hope.

Aircare Alliance
Provides referrals to charitable, long-distance, or air medical transport options.

American Airlines: Miles For Kids In Need
Provides transportation for seriously ill children up to the age of 18 in need of conventional medical treatment. Patient must be recommended by a social worker.

Mercy Medical Airlift
Provides services to those in need of air medical transportation.
**The Children’s Inn at NIH**
A private, nonprofit, family-centered residence for pediatric outpatients and their families at the National Institutes of Health.

**Edmond J. Safra Family Lodge at NIH**
Offers a home-like place of respite for families and loved ones of adult patients who are receiving care at the NIH Clinical Center.

**Air Charity Network (ACN)**
Provides services to people in need of access to free air transportation to specialized health care facilities in case of family, community, or national crisis.

**Angel Flight at NIH**
Patient assistance, referral, and arrangements for all forms of ambulatory outpatient charitable or charitably assisted travel to and from distant specialized medical evaluation, diagnosis, and treatment; serves clinical trial patients.

### OTHER TRANSPORTATION PROVIDERS

**Corporate Angel Network (CAN)**
Arranges free travel on corporate jets for cancer patients, bone marrow donors, and bone marrow recipients.

**Angel Flight Veteran**
Arranges flights for veterans and active-duty military personnel and their families in need of compassionate medical air transportation.

**Air Ambulance Anywhere**
Provides fixed-wing air ambulance transport services for patients, family members, and providers of medical care; delivers bed-to-bed service, specialized medical care during transport, and other necessary incidentals for any of three levels of medical care — basic life support, advanced life support, and critical care — on domestic and international flights.

**Air Transport Services/Ambulances**
A listing of commercial national and international ambulance services.

**Air Compassion America**
A nonprofit patient advocacy/assistance organization that helps locate and coordinate bed-to-bed air ambulance services and/or airline medical escort services and assists patients’ families in saving an average of 40% off commercial air ambulance costs.

**Air Ambulance Specialists, Inc.**
Provides fixed-wing air ambulance transport services for patients, family members, and
providers of medical care; delivers bed-to-bed service, specialized medical care during transport, and other necessary incidentals for any of three levels of medical care — basic life support, advanced life support, and critical care — on domestic and international flights.

**American Jets, Inc: Air Ambulance**
Airborne intensive care ambulance unit that responds to emergencies around the globe, 24 hours a day, 7 days a week.

**National Patient Air Transport Helpline (NPATH)**
Provides information about all forms of charitable, long-distance medical air transportation. Will refer cancer patients to Mercy Medical Airlift for free tickets.

## OTHER LODGING PROVIDERS

**Joe’s House**
An accommodation expert to help patients with their travel needs with various types of lodging throughout the United States.

**National Association of Hospital Hospitality Houses**
Provides lodging and other supportive services to patients and their families when they are confronted with medical emergencies.

**The Ronald McDonald House** program provides a “home-away-from-home” for families so they can stay close by their hospitalized child at little or no cost, thus improving the lives of children and their families by providing programs that strengthen families during their most difficult or challenging times.

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*This National Rare Disease Resource List is presented by The Foundation for Children with Atypical HUS as a public service for families, medical staff, and professionals who deal with the diagnosis of a rare disease.*

For inquires regarding our Foundation or the Rare Disease Resource List, please contact [linda@atypicalhus.org](mailto:linda@atypicalhus.org) or Co-Founder of The Foundation for Children with Atypical HUS, Bill Biermann at:

**The Foundation for Children with Atypical HUS**
attn.: Bill Biermann
One Campbell Plaza,
Suite B St. Louis, MO 63012
This State Rare Disease Resource List was compiled by Linda Burke, founder of www.atypicalhus.org. A dynamic resource list, it serves only as a starting point for your information search. Entries will be added, modified, and updated on a regular basis. National Rare Disease Resource Links can be found preceding these state lists – volunteer to add to your state’s resource list if it is not complete or listed here. Resource information and links to be considered for inclusion should be submitted to linda@atypicalhus.org.

States with Resource Coordinator Volunteers have created Detailed Resource Lists for:

MAINE, MASSACHUSETTS, RHODE ISLAND

(Alphabetical Listing for other States following these three states)
RARE DISEASE RESOURCE LIST
FOR THE STATE OF MAINE

Resource List Provided By: Our aHUS Foundation

INFORMATION AND RESOURCE CENTERS

2-1-1 Maine is a comprehensive statewide directory of over 8,000 health and human services available in Maine. The toll free 2-1-1 hotline connects callers to trained call specialists who can help 24 hours a day, 7 days a week. Finding the answers to health and human services questions and locating resources is as quick and easy as dialing 2-1-1.

The Maine Parent Federation is a statewide organization that provides information, advocacy, education, and training to benefit families of children and adults with disabilities and special health care needs.

A service of the Maine Parent Federation, Starting POINTS for Parents is an online community for families of children with disabilities Providing Opportunities for Information Networking, Training and Support as they learn, share, and connect about the educational and developmental needs of their children.

The Maine Health Learning Resource Center has a health educator at each location and can provide personalized help to patients to learn about a disease or treatment, as well as connect people with outreach, awareness, and resources.

The University of Maine Center for Community Inclusion and Disability Studies (CCIDS) brings together the resources of the university and Maine communities to enhance the quality of life for individuals with developmental disabilities and their families. They are committed to enhancing and promoting the interdependence, productivity, integration, and inclusion of Maine citizens with disabilities and their families.
**FAMILY FOCUSED RESOURCES**

**Gaining Empowerment Allows Results (GEAR)** helps connect parents to prevent isolation and share knowledge gained by experiences with their children’s disabilities. Through parent-to-parent sharing of experiences and knowledge, G.E.A.R. Parent Network empowers parents of children with behavioral health needs to build on their family’s strengths and to advocate for their family’s needs.

The **Maine Alliance of Family Organizations (MAFO)** is a statewide alliance that formed to better serve families of children with disabilities and special health care needs, and to strengthen family voice.

The MAFO video: **Working Together, Growing Stronger** offers personal stories of the importance of family organization support.

A **Family Information Specialist or FIS (DHHS Dept. of OCFS)** Providing information and referral services about resources needed by parents of a child with special needs, the FIS can offer resource lists that include such varied information as specialized summer camps, support groups, medical professionals, case management, and home & community based services.

Each FIS is a parent of a child with special needs who works with families and the Office of Children and Family Services (OCFS) to meet the needs of the children, also working closely with many different professionals and organizations.

**Southern Maine Parent Awareness (SMPA)** is dedicated to providing information, referral support and education to families who have children and youth with special needs throughout Maine. They offer individualized family conferences, consultation via telephone and email, and assistance in preparing for IFSP/IEP meetings.

**CHILD FOCUSED RESOURCES**

**The Maine Children’s Alliance (MCA)** is committed to improving the lives of Maine’s children, youth, and families. Acting as nonpartisan, data-focused advocates for public policies that improve the lives of Maine’s children, youth, and family, the MCA seeks to link research to practice and public policy as they serve as a resource on children and family policy issues.

Children’s Behavioral Health (CBH) provides information and assistance with referrals for children and youth with developmental disabilities/delays, intellectual disability (mental retardation), Autism Spectrum Disorders, and mental health disorders. Behavioral health treatment and services are available for children from birth up to their 21st birthday.

Families and Children Together (FACT) Their family focused programs encourage and foster the development and healing of children with emotional and behavioral challenges.

Camp Sunshine provides respite, support, joy, and hope to children with life-threatening illnesses and their immediate families through various stages of a child’s illness. The year-round program is free of charge to all families and includes 24-hour onsite medical and psychosocial support.

PROGRAMS AND SERVICES

Camp Sunshine provides respite, support, joy, and hope to children with life-threatening illnesses and their immediate families through various stages of a child’s illness. The year-round program is free of charge to all families and includes 24-hour onsite medical and psychosocial support. Bereavement groups are also offered for families who have lost a child to an illness.

The Morrison Center is a private, not-for-profit agency that specializes in the support and development of children and adults with and without disabilities. Offering a broad range of day programs and services, they support individuals and their families and encourage maximum growth and independence. Programs include the Friends First Preschool & Child Care Program, a K-12 School Program, and the adult AHEAD I and II programs.

The Maine Division for the Blind and Visually Impaired (DBVI) offers comprehensive services for visually impaired and blind individuals of all ages. Offering vocational rehabilitation services to help individuals retain or return to employment, DBVI can provide individual counseling, guidance, and vocational assessment as well as orientation and mobility instruction to develop independent travel skills.

Maine Health Learning Resource Center offers a helpful website for anyone affected by cancer.

National Alliance on Mental Illness of Maine (NAMI Maine) is dedicated to improving the quality of life of everyone affected by mental illness. Services are provided both directly and through a statewide structure of local affiliates and support groups. NAMI Maine offers compassion and provides social/emotional support, as they educate, inform, provide resources, and advocate for quality services.
The Pine Tree Society provides Maine children and adults with disabilities the opportunities and the means to create better lives for themselves and their families. People with disabilities may feel left out or isolated, but with the help of Pine Tree Society, they lead richer, more socially connected lives. Sharing a spirit of innovation, we help discover ways to break down barriers that many find insurmountable. Our service areas are: Assistive Technology, Communication, Community Supports, and Accessible Recreation.

Special Olympics transforms lives through the joy of sport, every day, everywhere. The world’s largest sports organization for people with intellectual disabilities, it serves nearly 4 million athletes in more than 170 countries.

LOCATION-SPECIFIC PATIENT SERVICES

CarePartners 1-877-626-1684  www.mmc.org/mh_body.cfm?id=3441 coordinates the provision of donated health care services for low-income, uninsured residents in four Maine counties (Cumberland, Lincoln, Waldo, and Kennebec). The program, a partnership among MaineHealth, physicians, hospitals, and other health care providers, helps community members who don’t qualify for public or private healthcare coverage programs get comprehensive, medically necessary healthcare.

The Children’s Center, a nonprofit organization, advocates for children with differing abilities and their families by offering programs that encourage individual growth and development of children, providing support for their families and promoting community inclusion. Respite Care is a statewide program, funded by the Department of Health and Human Services (DHHS) and run by contract agencies in Portland, Augusta, and Bangor. Respite Care supports families raising children with special needs. The Children’s Center is located in Augusta and offers a fully accessible playground that includes a unique 30-foot-long water feature.

The Beth Wright Cancer Center in Ellsworth offers support groups, resource materials, informational lectures and films, wellness activities, Reiki, Yoga, and transportation assistance.

The Patrick Dempsey Center for Cancer Hope & Healing provides free support, education, and integrative medicine services to anyone impacted by cancer. Patients served are in Androscoggin, and Cumberland.

ADVOCACY

Client Assistant Program — C.A.R.E.S. is a privately held company that provides advocacy, case management, and assistive technology for Maine’s citizens with disabilities. C.A.R.E.S. offers advocacy, case management, program evaluation, and policy development and administers three federally funded programs including
Independent Living Services (ILS) for veterans with disabilities through the Veterans Administration (VA) at Togus.

Disability Rights Center (DRC) provides individual advocacy through several different programs it operates. Each program has eligibility requirements and case selection criteria. Descriptions of the programs, the eligibility requirements, and the case selection criteria are available through DRC. DRC is available to provide training to individuals with disabilities, providers of services, the general public, and family/friend support networks.

Consumers for Affordable Health Care (CAHC) has worked to protect the rights of health care consumers in Maine. This nonprofit, nonpartisan organization is committed to helping all Maine people obtain quality, affordable health care with activities that include research, advocacy, education, and consumer assistance.

PATIENT ASSISTANCE PROGRAMS

MedAccess works with individuals and health care providers to identify ways patients can save money on prescription medications. The free program, administered by MaineHealth, helps patients and health care providers evaluate options.

Many hospitals are committed to treat all patients who need care regardless of their health insurance or financial status. For medically necessary treatment, most offer services to help you arrange for payment of your bill, from insurance billing to payment plans and even financial assistance, which may qualify you for free care or reduced payment. Eastern Maine Medical Center (EMMC) has a representative program similar to other hospitals and clinics throughout Maine; call your local hospital to inquire.
GOVERNMENTAL PROGRAMS OR AGENCIES

The Department of Health and Human Services (DHHS) for the State of Maine provides integrated health and human services to the people of Maine to assist individuals in meeting their needs within available resources, while respecting the rights and preferences of the individual and family. They strive to deliver services that are individualized, family-centered, easily accessible, preventive, independence-oriented, interdisciplinary, collaborative, evidence-based, and consistent with best and promising practices. For a wide array of programs and resources, see


The Children with Special Health Needs Program’s mission is to improve the health and well-being of this population by developing and sustaining community-based systems of care. Part of the Population Health, the Children with Special Health Care Needs program is affiliated with the Maine Department of Health and Human Services and the Maine Center for Disease Control & Prevention.

The Office of MaineCare Services (OMS) coordinates a variety of programs and benefits, ensuring that they operate under consistent policy in keeping with the Department’s goals and Federal mandates, and are administered effectively and efficiently. Programs include MaineCare (also known as Medicaid), Maine Rx Plus, Drugs for the Elderly and Disabled, and free or low-cost health insurance for families with children and pregnant women.

Katie Beckett is one MaineCare option for children under 18 with serious health conditions. If a child meets the rules for this option, that child may be eligible for MaineCare’s full benefits. Contact your local DHHS office if you have questions about the Katie Beckett benefit and ask to speak with the Katie Beckett Eligibility Specialist.

Maine CITE Program, affiliated with the Maine Department of Education, is the statewide organization designed to help make assistive and universally designed technology more available to Maine children and adults who need them.

A Family Information Specialist or FIS (DHHS Dept. of OCFS) Providing information and referral services about resources needed by parents of a child with special needs, the FIS can offer resource lists that include such varied information as specialized summer camps, support groups, medical professionals, case management, and home & community based services.
Each FIS is a parent of a child with special needs who works with families and the Office of Children and Family Services (OCFS) to meet the needs of the children, also working closely with many different professionals and organizations.

The Division of Vocational Rehabilitation (VR) is a Department of Labor program that helps people who have disabilities to find and keep a job. VR helps people who have physical, mental, or emotional disabilities and also assists students with disabilities in coordinating information and resources as they transition from high school to adult life.

The Office of MaineCare Services (OMS) oversees MaineCare (also known as Medicaid), Maine Rx Plus, and Drugs for the Elderly and Disabled.

MaineHealth Learning Resource Center offers a helpful website for anyone affected by cancer:

Medicare provides health insurance for people age 65 or older and under age 65 with certain disabilities.

**MAINE HEALTH CARE**

Ensuring that they operate under consistent policy in keeping with the Department’s goals and Federal mandates, and are administered effectively and efficiently. Programs include MaineCare (also known as Medicaid), Maine Rx Plus, Drugs for the Elderly and Disabled, and free or low-cost health insurance for families with children and pregnant women. [http://www.maine.gov/dhhs/oms/](http://www.maine.gov/dhhs/oms/)

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Consumers for Affordable Health Care (CAHC) has worked to protect the rights of health care consumers in Maine. This nonprofit, nonpartisan organization is committed to helping all Maine people obtain quality, affordable health care with activities that include research, advocacy, education, and consumer assistance.
EDUCATION

The Maine Department of Education is committed to shaping an education system that meets the needs of all learners and providing additional support to those who require it. Ensuring that students with special needs succeed in their learning, the Office of Special Services oversees early intervention services to eligible children age birth to under age three and their families (provided under IDEA, Part C) and Free Appropriate Public Education to eligible children age three to 20.

The Office of Special Services, part of the Maine Department of Education/Special Education Services, is responsible for the state’s oversight and support for the delivery of all special education services provided in Maine under the federal Individuals with Disabilities Education Act (IDEA). This includes early intervention services to eligible children age birth to under age three and their families, provided under IDEA, Part C, and Free Appropriate Public Education to eligible children age three to 20.

A guide to Special Education in Maine (online book). Chapter 11 has information on a 504 plan for children with special medical needs.

The Child Development Services system provides both Early Intervention (birth through two years) and Free Appropriate Public Education (for ages three through five years) under the supervision of the Maine Department of Education.

Grahamtastics Connection A nonprofit program that provides laptops and Internet access to connect chronically ill children to their world, particularly vital for those missing school due to hospitalization or treatment schedules.

TRAVEL AND ACCOMODATIONS FOR PATIENTS

Angel Flight Northeast 1-800-549-9980 arranges free flights for those requiring access to medical care.

Arbor House Located near Central Maine Medical Center in Lewiston, Arbor House provides lodging for patients and their families. For more information about the Arbor House, call 207-795-2398.

Hope Lodge, Boston, MA offers a free place to stay for patients who travel to Boston for treatments (through American Cancer Society 1-800-227-2345).

For inquires regarding atypical HUS or Maine’s Rare Disease Resource List, please contact linda@atypicalhus.org or Co-Founder of The Foundation for Children with Atypical HUS, Bill Biermann at: The Foundation for Children with Atypical HUS, attn.: Bill Biermann One Campbell Plaza, Suite B St. Louis, MO 63012
RARE DISEASE RESOURCE LIST
FOR THE STATE OF MASSACHUSETTS

Resource List Provided By: Rare Disease United Foundation

The Rare Disease United Foundation is a non-disease specific, state-based organization currently with communities in Rhode Island and Massachusetts. Disease specific organizations provide a wonderful resource for families and are critical to the advancement of research and treatments; however, for a considerable number of diseases no organization exists. The RDUF was formed so that each state has its own community. By connecting on a state level and encompassing all rare diseases, the RDUF can build strong rare communities in each state.

The Massachusetts Rare Disease Community (MRDC) is a chapter of the Rare Disease United Foundation, a non-disease specific, state-based organization. By connecting on a state level and encompassing all rare diseases, the RDUF can build strong rare communities in each state.

The Manton Center for Orphan Disease Research at Boston Children's Hospital was created to develop new methods for understanding, diagnosing and treating unusual diseases and to apply this knowledge to make fundamental scientific advances with broad implications for human health. To reach these goals, Children's joined in a partnership with The Manton Foundation to create a center devoted to understanding "orphan diseases" - genetic syndromes, immune system problems, errors of metabolism, neuromuscular disorders and other little-noticed but scientifically important disease processes.

MassResources.org is a small nonprofit organization with a big mission: to help make it possible for all Massachusetts residents to get the help and resources they need. We
believe that information about where to go for help, who is eligible for benefits, and how to apply should be easy to find and easy to use.

Disability Resources, Inc. is a nonprofit 501(c)(3) organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently.

INDEX
INDEX addresses the information needs of people with disabilities. We collect and maintain information on a wide variety of programs, agencies, and individual providers in Massachusetts that have something to offer to people with disabilities. INDEX is a project of the Eunice Kennedy Shriver Center at the University of Massachusetts Medical School.

Easter Seals provides services to ensure that children and adults with disabilities have equal opportunities to live, learn, work and play. Easter Seals’ vision is that all people with disabilities are empowered to reach their full potential. Easter Seals services help people of all ages with all kinds of disabilities, at more than 100 sites in communities all over Massachusetts -- individuals disabled through illness, accident or aging, as well as people born with disabilities.

The 17 Chapters of The Arc of Massachusetts work throughout the Commonwealth to provide services and supports to individuals with intellectual and developmental disabilities - such as Mental Retardation, Down Syndrome, Autism, and cerebral palsy - and their families on a case-by-case basis. Use our Chapter by City/Town Directory to find your closest chapter to your town in Massachusetts.

The Bridge Center is a fully accessible 20+ acre campus located in Bridgewater, MA that offers Year-Round, Summer Camp, and Equine Assisted Programs designed for children, teens and adults with special needs.

Formerly known as Handi Kids, The Bridge Center was founded as a 501(c)(3) non-profit organization in 1963 by the Knights of Pythias and has provided quality programming for 50 years. We offer opportunities to make friends, share experiences, discover abilities and uncover talents – building social, emotional and physical skills to promote full participation in the community.

The Disability Law Center (DLC) is the Protection and Advocacy agency for Massachusetts. DLC is a private, non-profit organization responsible for providing protection and advocacy for the rights of Massachusetts residents with disabilities. DLC receives federal, state and private funding but is not part of the state or federal government.

EK Shriver Center: With inspiration from Eunice Kennedy Shriver and her family, we pursue research, education, and service programs aimed at improving the quality of life for persons with intellectual and developmental disabilities and their families.
The Federation for Children with Special Needs provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

The Genesis Fund was formed to provide funding for children with special needs. We strive to ensure these children, who often have multiple disabilities, receive not only expert medical care but also coordinated comprehensive care.

For over 40 years, the Institute for Community Inclusion (ICI) has worked to ensure that people with disabilities have the same opportunity to dream big, and make their dreams a fully included, integrated, and welcomed reality. As a leader not only in Massachusetts, but also nationally and internationally, ICI strives to create a world where all people with disabilities are welcome and fully included in valued roles wherever they go, whether a school, workplace, volunteer group, home, or any other part of the community

MAB’s Mission is to work with individuals with disabilities to eliminate barriers and create opportunities. Our experience allows us to forge strong community partnerships so that we can meet the pressing need for high quality services and programs and transform lives.

The Tourette Syndrome Association of Massachusetts is an all-volunteer, non-profit organization whose mission is to support the needs of families affected by Tourette Syndrome. Our goal is to advocate for individuals with TS, educate the public and professionals about TS, and promote awareness.

Massachusetts Deafblind Family Alliance: We are a grassroots group united to promote and protect the interests of our family members with deafblindness. We endeavor to be the voice of those who cannot speak for themselves.

Massachusetts Government Portal to sites listing various Massachusetts government agencies, organizations, and resources.

Massachusetts Department of Education

Special Olympics Massachusetts provides year-round sports training, athletic competition and other health-related programming for athletes with intellectual disabilities throughout the state.

New England Hemophilia Association is the leading organization in New England dedicated to empowering individuals and families with bleeding disorders and building local and region-wide communities for them by providing diverse information sources, dynamic programming, individual and legislative advocacy, and emergency financial aid.
The **Parent-to-Parent Program** brings together parents facing similar challenges in raising their children with special needs. We believe that sharing experiences provides strength and support to each other.

**Prader-Willi Syndrome Association of New England** PWS is a non-inherited genetic disorder which is most often associated with a random deletion of the 15th chromosome. It is estimated that PWS occurs in 1 in 10,000 births. It affects both sexes and is unrelated to race. The cause is, as yet, unknown.

The mission of **Seven Hills Foundation** is to promote and encourage the empowerment of people with significant challenges so that each may pursue their highest possible degree of personal well-being and independence.

Through support, challenge and opportunity, **Triangle** empowers people with disabilities and their families to enjoy rich, fulfilling lives. We are committed to helping the world recognize that we are all people with ability.

**VSA Massachusetts** is part of an international network of VSA organizations serving 35 states and over 50 other countries. VSA is affiliated with The John F. Kennedy Center for the Performing Arts in Washington, D.C. The letters VSA now reflect the Vision of an inclusive community, Strength in shared resources and Artistic expression that unite us all.
A Message from Patty Weltin,
Founder of the Rhode Island Rare Disease Foundation (RIRDF)

The Rhode Island Rare Disease Foundation benefits Rhode Islanders living with a rare disease, regardless of disease. Disease specific foundations provide an invaluable resource for families; however, for a considerable number of diseases no foundation exists. Often, members of disease specific foundations are spread all over the world. The RIRDF will encompass all rare diseases. The diseases may be different, but the challenges faced by the rare disease community remain the same: inaccurate diagnosis, no diagnosis, lack of awareness, insurance and other reimbursement issues, and a terrible sense of isolation. By connecting locally and encompassing all rare diseases, the RIRDF can build a strong rare disease community in Rhode Island and throughout the country.

Rhode Island Rare Disease Foundation [http://www.rirdf.org](http://www.rirdf.org)

P.O. Box 16294 Rumford, RI 02916
Tel: 401-434-0052 FAX: 401-434-0039
riraredisease@verizon.net

The Rhode Island Rare Disease Community is a chapter of the Rare Disease United Foundation, a non-disease specific, state-based organization. By connecting on a state level and encompassing all rare diseases, the RDUF can build strong rare communities in each state.
**KIDSNET** helps assure that all children in Rhode Island are as healthy as possible by getting the right health screenings and preventive care at the right time.

**Early Intervention** services are designed to serve children younger than three years of age who are experiencing developmental delays in one or more of the following areas: cognitive, physical, communicative, social/emotional, or adaptive development skills.

**Rhode Island Parent Information Network** Our mission is to assist individuals, parents, families, and children to achieve their goals for health, educational, and socioeconomic well being by providing information, education, training, support, and advocacy for person/family centered care and systems change. A Family Voices state affiliate.

**About Families** teams children with special health care needs and their families with experienced, licensed clinical staff and dedicated family service coordinators with the goal of creating and implementing comprehensive plans of care that address the needs of the child and the family as a whole.

**The ARC of Blackstone Valley** is committed to supporting people with intellectual and developmental disabilities secure the opportunity to choose and realize their goals of where and how they live, learn, work, and play.

**Special Olympics Rhode Island** program is one of the world’s most dynamic, providing over 1,400 year-round sports training and athletic competitions for more than 2,800 athletes and hosting over 40 local, regional, and statewide tournaments and competitions each year in 25 official and demonstration sports.

If your organization assists Rhode Island rare disease patients, please highlight your efforts by forwarding your information to linda@atypicalhus.org and to the Rhode Island Rare Disease Foundation riraredisease@verizon.net.
Join the effort to support Rare Disease patients by creating a state by state resource list.

Please submit YOUR State’s Resource List - Contact Linda@atypicalhus.org for Details.

ALABAMA

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links. Coordinate a resource list for your state, we'll post your non-profit's logo!

Alabama Department of Human Resources  
(334) 242-1310  
The following programs are offered through the Department of Human Resources: Temporary assistance for needy families; general assistance; food stamps; childcare.

Alabama Department of Public Health  
(800) 252-1818  
The following programs are offered through the Department of Public Health: Social services; family assessment needs; family care; and child treatment.

Alabama State Employee Insurance Board  
(866) 836-9737  
Administering Health Benefits with excellence.
Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!

**Chronic and Acute Medical Assistance (CAMA)**
(800) 780-9972 dpapolicy@alaska.gov
The CAMA program is a state funded program designed to help needy Alaskans who have specific illnesses get the medical care they need to manage those illnesses.

**Health Care Services - Case Management Services**
Medicaid, through their contractor Qualis Health, provides case management services designed for patients with serious illnesses, injuries, and some chronic conditions.

**Health Care Services Alaska - Denali KidCare**
(888) 318-8890 denali.kid.care@alaska.gov
Denali KidCare is a State of Alaska program designed to ensure that children and teens of both working and non-working families can have the health insurance they need.

**Heating Assistance Program (HAP) – Alaska**
(800) 470-3058 liheap@alaska.gov
Apply for financial assistance for heating and utilities.

**State of Alaska Health and Social Services**
(907) 465-3030
Their mission is to promote and protect the health and well being of Alaskans.
Looking for Resource Links for this state? We are, too!
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Coordinate a resource list for your state, we'll post your non-profit’s logo!

**Arizona Consortium of Children with Chronic Illness (ACCCI)**
(480) 557-8445 accci@qwestoffice.net
The Arizona Consortium for Children with Chronic Illness (ACCCI) is dedicated to improving the quality of life for chronically ill children and their families through advocacy and education.

**Arizona Life Lines**
(888) 543-5637 june@arizonalifelines.com
Their goal is to help find insurance for patients with pre-existing conditions.

**Office for Children with Special Health Care Needs - Arizona**
(602) 542-1860
Their mission is to continuously improve comprehensive systems of care that enhances the health, future and quality of life for children and youth with special health care needs and their families.

**Raising Special Kids** exists to improve the lives of children with the full range of disabilities, from birth to age 26, by providing support, training, information and individual assistance so families can become effective advocates for their children.
ARKANSAS

Looking for Resource Links for this state? We are, too!
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CALIFORNIA

Looking for Resource Links for this state? We are, too!
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Parents Helping Parents, Inc. - Sobrato Center for Nonprofits - San Jose
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.
COLORADO

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Parent to Parent of Colorado
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.

CONNCTICUT

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Connecticut State Office of Rural Health
(860) 738-6378
Working together to promote the health of persons living in rural Connecticut through education, communication and partnerships.

PATH Parent to Parent of Connecticut
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.

United Way 2-1-1
(860) 571-7500 infoline@ctunitedway.org
2-1-1’s Health Care Resource Guide is intended to provide information on state, federal and privately purchased health insurance programs for Connecticut residents.
**DELAWARE**

*Looking for Resource Links for this state? We are, too!*  
Please contact Linda@atypicalhus.org to submit rare disease resource links.  
*Coordinate a resource list for your state, we'll post your non-profit's logo!*

**Child Life, Education and Creative Arts Therapy – CHOP - Delaware**  
(215) 590-2001  
The goal of the Oncology Child Life, Education and Creative Arts Therapy program is to help children and families cope with the emotional stress and anxiety associated with cancer therapy and treatment.

**Delaware Family Voices, Inc.**  
An affiliate of Family Voices, who aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

**Kelly Anne Dolan Memorial Fund - Delaware**  
(215) 643-0763 www.dolanfund.org  
The Kelly Anne Dolan Memorial Fund provides advocacy, education, information and financial assistance for the uninsured needs of families caring for terminally, critically and chronically ill, seriously disabled or severely injured children.

**FLORIDA**

*Looking for Resource Links for this state? We are, too!*  
Please contact Linda@atypicalhus.org to submit rare disease resource links.  
*Coordinate a resource list for your state, we'll post your non-profit's logo!*

**Children's Medical Services**  
(850) 245-4200  
The Children's Medical Services (CMS) program provides children with special health care needs with a family centered, managed system of care
Florida KidCare
(888) 540-5437
KidCare is Florida’s children’s health insurance program for uninsured children under age 19. It is made up of four parts: MediKids, Healthy Kids, and Children’s Medical Services Network for children with special health care needs, and Medicaid for kids.

GEORGIA

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!

LifeNet Georgia
(877) 957-5500
The mission of LifeNet is to provide safe, quality air medical service and patient care to the critically ill and injured.

Parent to Parent of Georgia
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.

HAWAII

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!
IDAHO

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
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INDIANA

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
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About Special Kids   Families and professionals in Indiana to go to “ASK” questions about children with special needs and to access information and resources about a variety of topics such as health insurance, special education, community resources and medical homes.

Call 2-1-1 2-1-1
Indiana 211 Partnership, Inc. (IN211) is a nonprofit organization dedicated to building the 2-1-1 system for Indiana. The goal is to create a seamless network of information and referral services that enables anyone in Indiana in need of human services to have quick referrals to those who provide them by dialing 2-1-1.

Family to Family
(800) 825-4733
INF2F brings together parents of young children with disabilities, developmental delays or special health care needs so they can share their knowledge, concerns, and experiences with each other.

First Steps
(317) 233-6092
First Steps’ goal is to assure that all Indiana families with infants and toddlers
experiencing developmental delays or disabilities have access to early intervention services close to home when they need them; this is accomplished through the implementation of a comprehensive, coordinated statewide system of local interagency councils called first steps.

**Healthy Indiana Plan**
(877)-GET-HIP-9 (438-4479)
The HIP plan covers individuals who do not live with a dependent child, and parents who earn up to approximately $44,000 annually for a family of four, have been uninsured for six months and do not have access to insurance through their employer.

**Hoosier Healthwise** (800) 889-9949 is a health insurance program for Indiana children, pregnant women, and low-income families. Health care is provided at little or no cost to Indiana families enrolled in the program.

**Indiana Children’s Special Health Care Services (CSHCS)**
(800) 475-1355
They provide supplemental medical coverage to help families of children who have serious, chronic medical conditions. Age birth to 21 years of age, who meet the program’s financial and medical criteria, pay for treatment related to their child’s condition.

**RX for Indiana**, (877) 793-0765 a website designed to help low income, uninsured Indiana residents get access to patient assistance programs where they qualify for free, or nearly free, prescription medicines.

**TANF** is a program that provides cash assistance and supportive services to assist the family, helping them achieve economic self-sufficiency.
Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we'll post your non-profit's logo!

Families Together Inc.
"Encouraging, Educating & Empowering". Assisting Kansas parents and their sons and daughters who have disabilities.
Looking for Resource Links for this state? We are, too!

Please contact Linda@atypicalhus.org to submit rare disease resource links.

Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Families Helping Families of Acadiana
Our mission is to assist and strengthen individuals with disabilities and their families through a coordinated network of resources, services and supports.
Looking for Resource Links for this state? We are, too! Please contact Linda@atypicalhus.org to submit rare disease resource links. Coordinate a resource list for your state, we'll post your non-profit's logo!

Resource List Provided By: Our aHUS Foundation

INFORMATION AND RESOURCE CENTERS

2-1-1 Maine is a comprehensive statewide directory of over 8,000 health and human services available in Maine. The toll free 2-1-1 hotline connects callers to trained call specialists who can help 24 hours a day, 7 days a week. Finding the answers to health and human services questions and locating resources is as quick and easy as dialing 2-1-1.

The Maine Parent Federation is a statewide organization that provides information, advocacy, education, and training to benefit families of children and adults with disabilities and special health care needs.

A service of the Maine Parent Federation, Starting POINTS for Parents is an online community for families of children with disabilities Providing Opportunities for Information Networking, Training and Support as they learn, share, and connect about the educational and developmental needs of their children.

The Maine Health Learning Resource Center has a health educator at each location and can provide personalized help to patients to learn about a disease or treatment, as well as connect people with outreach, awareness, and resources.

The University of Maine Center for Community Inclusion and Disability Studies (CCIDS) brings together the resources of the university and Maine communities to enhance the quality of life for individuals with developmental disabilities and their families. They are committed to enhancing and promoting the interdependence,
productivity, integration, and inclusion of Maine citizens with disabilities and their families.

**FAMILY FOCUSED RESOURCES**

**Gaining Empowerment Allows Results (GEAR)** helps connect parents to prevent isolation and share knowledge gained by experiences with their children’s disabilities. Through parent-to-parent sharing of experiences and knowledge, G.E.A.R. Parent Network empowers parents of children with behavioral health needs to build on their family’s strengths and to advocate for their family’s needs.

The **Maine Alliance of Family Organizations (MAFO)** is a statewide alliance that formed to better serve families of children with disabilities and special health care needs, and to strengthen family voice.

The MAFO video: **Working Together, Growing Stronger** offers personal stories of the importance of family organization support.

A **Family Information Specialist or FIS (DHHS Dept. of OCFS)** providing information and referral services about resources needed by parents of a child with special needs, the FIS can offer resource lists that include such varied information as specialized summer camps, support groups, medical professionals, case management, and home & community-based services.

Each FIS is a parent of a child with special needs who works with families and the Office of Children and Family Services (OCFS) to meet the needs of the children, also working closely with many different professionals and organizations.

**Southern Maine Parent Awareness (SMPA)** is dedicated to providing information, referral support and education to families who have children and youth with special needs throughout Maine. They offer individualized family conferences, consultation via telephone and email, and assistance in preparing for IFSP/IEP meetings.

**CHILD FOCUSED RESOURCES**

**The Maine Children’s Alliance (MCA)** is committed to improving the lives of Maine’s children, youth, and families. Acting as nonpartisan, data-focused advocates for public policies that improve the lives of Maine’s children, youth, and family, the MCA seeks to link research to practice and public policy as they serve as a resource on children and family policy issues.

**Department of Health and Human Services, Office of Children and Family Services (OCFS)** provides information and referrals for children to their 21st birthday with developmental disabilities/delays, mental retardation, Pervasive Developmental Disorder (PDD)/autism, and mental health disorders. The Office of Child and Family Services (OCFS) serves Maine’s children and their families through the Divisions of

**Children’s Behavioral Health (CBH)** provides information and assistance with referrals for children and youth with developmental disabilities/delays, intellectual disability (mental retardation), Autism Spectrum Disorders, and mental health disorders. Behavioral health treatment and services are available for children from birth up to their 21st birthday.

**Families and Children Together (FACT)** Their family focused programs encourage and foster the development and healing of children with emotional and behavioral challenges.

**Camp Sunshine** provides respite, support, joy, and hope to children with life-threatening illnesses and their immediate families through various stages of a child’s illness. The year-round program is free of charge to all families and includes 24-hour onsite medical and psychosocial support. Bereavement groups are also offered for families who have lost a child to an illness.

The **Morrison Center** is a private, not-for-profit agency that specializes in the support and development of children and adults with and without disabilities. Offering a broad range of day programs and services, they support individuals and their families and encourage maximum growth and independence. Programs include the Friends First Preschool & Child Care Program, a K-12 School Program, and the adult AHEAD I and II programs.

The **Maine Division for the Blind and Visually Impaired (DBVI)** offers comprehensive services for visually impaired and blind individuals of all ages. Offering vocational rehabilitation services to help individuals retain or return to employment, DBVI can provide individual counseling, guidance, and vocational assessment as well as orientation and mobility instruction to develop independent travel skills.

**Maine Health Learning Resource Center** offers a helpful website for anyone affected by cancer.
National Alliance on Mental Illness of Maine (NAMI Maine) is dedicated to improving the quality of life of everyone affected by mental illness. Services are provided both directly and through a statewide structure of local affiliates and support groups. NAMI Maine offers compassion and provides social/emotional support, as they educate, inform, provide resources, and advocate for quality services.

The Pine Tree Society provides Maine children and adults with disabilities the opportunities and the means to create better lives for themselves and their families. People with disabilities may feel left out or isolated, but with the help of Pine Tree Society, they lead richer, more socially connected lives. Sharing a spirit of innovation, we help discover ways to break down barriers that many find insurmountable. Our service areas are: Assistive Technology, Communication, Community Supports, and Accessible Recreation.

Special Olympics transforms lives through the joy of sport, every day, everywhere. The world’s largest sports organization for people with intellectual disabilities, it serves nearly 4 million athletes in more than 170 countries.

LOCATION-SPECIFIC PATIENT SERVICES

CarePartners 1-877-626-1684 www.mmc.org/mh_body.cfm?id=3441 coordinates the provision of donated health care services for low-income, uninsured residents in four Maine counties (Cumberland, Lincoln, Waldo, and Kennebec). The program, a partnership among MaineHealth, physicians, hospitals, and other health care providers, helps community members who don’t qualify for public or private healthcare coverage programs get comprehensive, medically necessary healthcare.

The Children’s Center, a nonprofit organization, advocates for children with differing abilities and their families by offering programs that encourage individual growth and development of children, providing support for their families and promoting community inclusion. Respite Care is a statewide program, funded by the Department of Health and Human Services (DHHS) and run by contract agencies in Portland, Augusta, and Bangor. Respite Care supports families raising children with special needs. The Children’s Center is located in Augusta and offers a fully accessible playground that includes a unique 30-foot-long water feature.

The Beth Wright Cancer Center in Ellsworth offers support groups, resource materials, informational lectures and films, wellness activities, Reiki, Yoga, and transportation assistance.

The Patrick Dempsey Center for Cancer Hope & Healing provides free support, education, and integrative medicine services to anyone impacted by cancer. Patients served are in Androscoggin, and Cumberland.
ADVOCACY

Client Assistant Program — C.A.R.E.S. is a privately held company that provides advocacy, case management, and assistive technology for Maine’s citizens with disabilities. C.A.R.E.S. offers advocacy, case management, program evaluation, and policy development and administers three federally funded programs including Independent Living Services (ILS) for veterans with disabilities through the Veterans Administration (VA) at Togus.

Disability Rights Center (DRC) provides individual advocacy through several different programs it operates. Each program has eligibility requirements and case selection criteria. Descriptions of the programs, the eligibility requirements, and the case selection criteria are available through DRC. DRC is available to provide training to individuals with disabilities, providers of services, the general public, and family/friend support networks.

Consumers for Affordable Health Care (CAHC) has worked to protect the rights of health care consumers in Maine. This nonprofit, nonpartisan organization is committed to helping all Maine people obtain quality, affordable health care with activities that include research, advocacy, education, and consumer assistance.

PATIENT ASSISTANCE PROGRAMS

MedAccess works with individuals and health care providers to identify ways patients can save money on prescription medications. The free program, administered by MaineHealth, helps patients and health care providers evaluate options.

Many hospitals are committed to treat all patients who need care regardless of their health insurance or financial status. For medically necessary treatment, most offer services to help you arrange for payment of your bill, from insurance billing to payment plans and even financial assistance, which may qualify you for free care or reduced payment. Eastern Maine Medical Center (EMMC) has a representative program similar to other hospitals and clinics throughout Maine; call your local hospital to inquire.
GOVERNMENTAL PROGRAMS OR AGENCIES

The Department of Health and Human Services (DHHS) for the State of Maine provides integrated health and human services to the people of Maine to assist individuals in meeting their needs within available resources, while respecting the rights and preferences of the individual and family. They strive to deliver services that are individualized, family-centered, easily accessible, preventive, independence-oriented, interdisciplinary, collaborative, evidence-based, and consistent with best and promising practices. For a wide array of programs and resources, see


The Children with Special Health Needs Program’s mission is to improve the health and well-being of this population by developing and sustaining community-based systems of care. Part of the Population Health, the Children with Special Health Care Needs program is affiliated with the Maine Department of Health and Human Services and the Maine Center for Disease Control & Prevention.

The Office of MaineCare Services (OMS) coordinates a variety of programs and benefits, ensuring that they operate under consistent policy in keeping with the Department’s goals and Federal mandates, and are administered effectively and efficiently. Programs include MaineCare (also known as Medicaid), Maine Rx Plus, Drugs for the Elderly and Disabled, and free or low-cost health insurance for families with children and pregnant women.

Katie Beckett is one MaineCare option for children under 18 with serious health conditions. If a child meets the rules for this option, that child may be eligible for MaineCare’s full benefits. Contact your local DHHS office if you have questions about the Katie Beckett benefit and ask to speak with the Katie Beckett Eligibility Specialist.

Maine CITE Program, affiliated with the Maine Department of Education, is the statewide organization designed to help make assistive and universally designed technology more available to Maine children and adults who need them.

A Family Information Specialist or FIS (DHHS Dept. of OCFS) Providing information and referral services about resources needed by parents of a child with special needs, the FIS can offer resource lists that include such varied information as specialized summer camps, support groups, medical professionals, case management, and home & community based services.
Each FIS is a parent of a child with special needs who works with families and the Office of Children and Family Services (OCFS) to meet the needs of the children, also working closely with many different professionals and organizations.

The Division of Vocational Rehabilitation (VR) is a Department of Labor program that helps people who have disabilities to find and keep a job. VR helps people who have physical, mental, or emotional disabilities and also assists students with disabilities in coordinating information and resources as they transition from high school to adult life.

The Office of MaineCare Services (OMS) oversees MaineCare (also known as Medicaid), Maine Rx Plus, and Drugs for the Elderly and Disabled.

MaineHealth Learning Resource Center offers a helpful website for anyone affected by cancer:

Medicare provides health insurance for people age 65 or older and under age 65 with certain disabilities.

MAINE HEALTH CARE

Ensuring that they operate under consistent policy in keeping with the Department’s goals and Federal mandates, and are administered effectively and efficiently. Programs include MaineCare (also known as Medicaid), Maine Rx Plus, Drugs for the Elderly and Disabled, and free or low-cost health insurance for families with children and pregnant women. http://www.maine.gov/dhhs/oms/

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Consumers for Affordable Health Care (CAHC) has worked to protect the rights of health care consumers in Maine. This nonprofit, nonpartisan organization is committed to helping all Maine people obtain quality, affordable health care with activities that include research, advocacy, education, and consumer assistance.
EDUCATION

The Maine Department of Education is committed to shaping an education system that meets the needs of all learners and providing additional support to those who require it. Ensuring that students with special needs succeed in their learning, the Office of Special Services oversees early intervention services to eligible children age birth to under age three and their families (provided under IDEA, Part C) and Free Appropriate Public Education to eligible children age three to 20.

The Office of Special Services, part of the Maine Department of Education/Special Education Services, is responsible for the state’s oversight and support for the delivery of all special education services provided in Maine under the federal Individuals with Disabilities Education Act (IDEA). This includes early intervention services to eligible children age birth to under age three and their families, provided under IDEA, Part C, and Free Appropriate Public Education to eligible children age three to 20.

A guide to Special Education in Maine (online book). Chapter 11 has information on a 504 plan for children with special medical needs.

The Child Development Services system provides both Early Intervention (birth through two years) and Free Appropriate Public Education (for ages three through five years) under the supervision of the Maine Department of Education.

Grahamtastics Connection: A nonprofit program that provides laptops and Internet access to connect chronically ill children to their world, particularly vital for those missing school due to hospitalization or treatment schedules.

TRAVEL AND ACCOMMODATIONS FOR PATIENTS

Angel Flight Northeast
1-800-549-9980 arranges free flights for those requiring access to medical care.

Arbor House Located near Central Maine Medical Center in Lewiston, Arbor House provides lodging for patients and their families. For more information about the Arbor House, call (207)-795-2398.

Hope Lodge, Boston, MA offers a free place to stay for patients who travel to Boston for treatments (through American Cancer Society 1-800-227-2345).

For inquiries regarding atypical HUS or Maine’s Rare Disease Resource List, please contact linda@atypicalhus.org or Co-Founder of The Foundation for Children with Atypical HUS, Bill Biermann at:The Foundation for Children with Atypical HUS attn.: Bill Biermann One Campbell Plaza, Suite B St. Louis, MO 63012
Looking for Resource Links for this state?  We are, too!  
Please contact Linda@atypicalhus.org to submit rare disease resource links.  
Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Resource List Provided By: Rare Disease United Foundation

The Rare Disease United Foundation is a non-disease specific, state-based organization currently with communities in Rhode Island and Massachusetts. Disease specific organizations provide a wonderful resource for families and are critical to the advancement of research and treatments; however, for a considerable number of diseases no organization exists. The RDUF was formed so that each state has its own community. By connecting on a state level and encompassing all rare diseases, the RDUF can build strong rare communities in each state.

The Massachusetts Rare Disease Community (MRDC) is a chapter of the Rare Disease United Foundation, a non-disease specific, state-based organization. By connecting on a state level and encompassing all rare diseases, the RDUF can build strong rare communities in each state.
The Manton Center for Orphan Disease Research at Boston Children’s Hospital was created to develop new methods for understanding, diagnosing and treating unusual diseases and to apply this knowledge to make fundamental scientific advances with broad implications for human health. To reach these goals, Children’s joined in a partnership with The Manton Foundation to create a center devoted to understanding "orphan diseases" - genetic syndromes, immune system problems, errors of metabolism, neuromuscular disorders and other little-noticed but scientifically important disease processes.

MassResources.org is a small nonprofit organization with a big mission: to help make it possible for all Massachusetts residents to get the help and resources they need. We believe that information about where to go for help, who is eligible for benefits, and how to apply should be easy to find and easy to use.

Disability Resources, Inc. is a nonprofit 501(c)(3) organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently.

INDEX
INDEX addresses the information needs of people with disabilities. We collect and maintain information on a wide variety of programs, agencies, and individual providers in Massachusetts that have something to offer to people with disabilities. INDEX is a project of the Eunice Kennedy Shriver Center at the University of Massachusetts Medical School.

Easter Seals provides services to ensure that children and adults with disabilities have equal opportunities to live, learn, work and play. Easter Seals’ vision is that all people with disabilities are empowered to reach their full potential. Easter Seals services help people of all ages with all kinds of disabilities, at more than 100 sites in communities all over Massachusetts -- individuals disabled through illness, accident or aging, as well as people born with disabilities.

The 17 Chapters of The Arc of Massachusetts work throughout the Commonwealth to provide services and supports to individuals with intellectual and developmental disabilities - such as Mental Retardation, Down Syndrome, Autism, and cerebral palsy - and their families on a case-by-case basis. Use our Chapter by City/Town Directory to find your closest chapter to your town in Massachusetts.

The Bridge Center is a fully-accessible 20+ acre campus located in Bridgewater, MA that offers Year-Round, Summer Camp, and Equine Assisted Programs designed for children, teens and adults with special needs.

Formerly known as Handi Kids, The Bridge Center was founded as a 501(c)(3) non-profit organization in 1963 by the Knights of Pythias and has provided quality programming for 50 years. We offer opportunities to make friends, share experiences,
discover abilities and uncover talents – building social, emotional and physical skills to promote full participation in the community.

**The Disability Law Center (DLC)** is the Protection and Advocacy agency for Massachusetts. DLC is a private, non-profit organization responsible for providing protection and advocacy for the rights of Massachusetts’s residents with disabilities. DLC receives federal, state and private funding but is not part of the state or federal government.

**EK Shriver Center**: With inspiration from Eunice Kennedy Shriver and her family, we pursue research, education, and service programs aimed at improving the quality of life for persons with intellectual and developmental disabilities and their families.

**The Federation for Children with Special Needs** provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

**The Genesis Fund** was formed to provide funding for children with special needs. We strive to ensure these children, who often have multiple disabilities, receive not only expert medical care but also coordinated comprehensive care.

For over 40 years, the **Institute for Community Inclusion (ICI)** has worked to ensure that people with disabilities have the same opportunity to dream big, and make their dreams a fully included, integrated, and welcomed reality. As a leader not only in Massachusetts, but also nationally and internationally, ICI strives to create a world where all people with disabilities are welcome and fully included in valued roles wherever they go, whether a school, workplace, volunteer group, home, or any other part of the community.

**MAB**’s Mission is to work with individuals with disabilities to eliminate barriers and create opportunities. Our experience allows us to forge strong community partnerships so that we can meet the pressing need for high quality services and programs and transform lives.

The **Tourette Syndrome Association of Massachusetts** is an all volunteer, non-profit organization whose mission is to support the needs of families affected by Tourette Syndrome. Our goal is to advocate for individuals with TS, educate the public and professionals about TS, and promote awareness.

**Massachusetts Deafblind Family Alliance**: We are a grassroots group united to promote and protect the interests of our family members with deafblindness. We endeavor to be the voice of those who cannot speak for themselves.

**Massachusetts Government** Portal to sites listing various Massachusetts government agencies, organizations, and resources.
Special Olympics Massachusetts provides year-round sports training, athletic competition and other health-related programming for athletes with intellectual disabilities throughout the state.

New England Hemophilia Association is the leading organization in New England dedicated to empowering individuals and families with bleeding disorders and building local and region-wide communities for them by providing diverse information sources, dynamic programming, individual and legislative advocacy, and emergency financial aid.

The Parent-to-Parent Program brings together parents facing similar challenges in raising their children with special needs. We believe that sharing experiences provides strength and support to each other.

Prader-Willi Syndrome Association of New England PWS is a non-inherited genetic disorder which is most often associated with a random deletion of the 15th chromosome. It is estimated that PWS occurs in 1 in 10,000 births. It affects both sexes and is unrelated to race. The cause is, as yet, unknown.

The mission of Seven Hills Foundation is to promote and encourage the empowerment of people with significant challenges so that each may pursue their highest possible degree of personal well-being and independence.

Through support, challenge and opportunity, Triangle empowers people with disabilities and their families to enjoy rich, fulfilling lives. We are committed to helping the world recognize that we are all people with ability.

VSA Massachusetts is part of an international network of VSA organizations serving 35 states and over 50 other countries. VSA is affiliated with The John F. Kennedy Center for the Performing Arts in Washington, D.C. The letters VSA now reflect the Vision of an inclusive community, Strength in shared resources and Artistic expression that unite us all.
MICHIGAN

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we'll post your non-profit's logo!

Children’s Hospital of Michigan - Kids Health Library
(313) 745-5437
Michigan, United States
Educational and recreational activities for children and teens.

MINNESOTA

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we'll post your non-profit's logo!

Family Voices of Minnesota
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.
MISSISSIPPI

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
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MISSOURI

Looking for Resource Links for this state? We are, too!
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Sharing Our Strengths (SOS) Support Matching Network
Missouri's parent to parent/peer support network for parents of children with
developmental disabilities or special healthcare needs, individuals with disabilities, and
professionals.

MONTANA

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!
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**The Arc of Omaha at the Ollie Webb Center**
Their mission is to enrich the lives of individuals with developmental disabilities and their families through support, programs and advocacy.

Looking for Resource Links for this state? We are, too!
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**Family TIES of Nevada** is dedicated to providing culturally competent support, information, and assistance to achieve family-centered care for individuals with disabilities or special health care needs through family, community and professional partnerships.
NEW HAMPSHIRE

Looking for Resource Links for this state? We are, too! Please contact Linda@atypicalhus.org to submit rare disease resource links. Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Parent to Parent of New Hampshire
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.

NEW JERSEY

Looking for Resource Links for this state? We are, too! Please contact Linda@atypicalhus.org to submit rare disease resource links. Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Catastrophic Illness in Children Relief Fund
(800) 335-3863
New Jersey, United States
The Catastrophic Illness in Children Relief Fund is intended to assist in preserving a family’s ability to cope with the responsibilities which accompany a child’s significant health problems.

Child Life, Education and Creative Arts Therapy - CHOP - New Jersey
(215) 590-2001
New Jersey, United States
The goal of the Oncology Child Life, Education and Creative Arts Therapy program is to help children and families cope with the emotional stress and anxiety associated with cancer therapy and treatment.
Kelly Anne Dolan Memorial Fund - New Jersey
(215) 643-0763
New Jersey, United States
The Kelly Anne Dolan Memorial Fund provides advocacy, education, information and financial assistance for the uninsured needs of families caring for terminally, critically and chronically ill, seriously disabled or severely injured children.

NJ Dept. of Human Services - State Subsidies for Childcare
(800) 332-9227
New Jersey, United States
Low- and moderate-income working parents can receive state subsidies for child care, including preschool instruction, after-school programs for children up to age 13, and care for children and teens with special needs.

NJ Family Care
(800) 701-0710
Trenton, New Jersey, United States
NJ Family Care is not a welfare program, but rather the State of New Jersey's way of providing affordable health coverage for kids and certain low-income parents.

New Jersey Statewide Parent to Parent
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.

NEW MEXICO

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we'll post your non-profit's logo!

Parents Reaching Out
Parents Reaching Out is a non-profit organization that works with parents, caregivers, educators, and other professionals to promote healthy, positive and caring experiences for families and children.
NEW YORK

Looking for Resource Links for this state? We are, too! Please contact Linda@atypicalhus.org to submit rare disease resource links. Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Family Health Plus - New York Dept. of Health
(877) 934-7587 dohweb@health.state.ny.us
Family Health Plus provides comprehensive coverage, including prevention, primary care, hospitalization, prescriptions and other services.

Parent to Parent of New York State
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.

NORTH CAROLINA

Looking for Resource Links for this state? We are, too! Please contact Linda@atypicalhus.org to submit rare disease resource links. Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Family Support Network of North Carolina
Families benefit from the help and support that other families can provide. From information about their child’s special needs, families can learn about available resources and make informed decisions about services and support.

Family Support Program of North Carolina
(800) 852-0042 FSP.CDR@unc.edu
Chapel Hill, North Carolina, United States
Family Support Network of North Carolina promotes and provides support for families with children who have special needs.
Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we'll post your non-profit's logo!

**Family Voices of North Dakota**
Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

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**Ohio**

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we'll post your non-profit's logo!

**StarShine Hospice - Cincinnati Children's**
(513) 636-7152 starshine@cchmc.org
The StarShine Hospice staff at Cincinnati Children’s Hospital Medical Center provides various services to patients and families in cooperation with your child's family and under the direction of your child's physician.
Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we'll post your non-profit’s logo!

**The Oklahoma Family Network**
The (OFN) Family-to-Family Health Information Center informs and connects individuals with special health care needs and disabilities, their families and professionals to services and supports in their communities.

**FACT Oregon**
Empowering Oregon Families experiencing disability or chronic health concerns.
**Looking for Resource Links for this state?** We are, too!  
Please contact Linda@atypicalhus.org to submit rare disease resource links.  
*Coordinate a resource list for your state, we’ll post your non-profit’s logo!*

**Child Life, Education and Creative Arts Therapy - CHOP**  
(215) 590-2001  
The goal of the Oncology Child Life, Education and Creative Arts Therapy program is to help children and families cope with the emotional stress and anxiety associated with cancer therapy and treatment.

**Kelly Anne Dolan Memorial Fund - Pennsylvania**  
(215) 643-0763  
The Kelly Anne Dolan Memorial Fund provides advocacy, education, information and financial assistance for the uninsured needs of families caring for terminally, critically and chronically ill, seriously disabled or severely injured children.

**Parent to Parent of Pennsylvania**  
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.
RHODE ISLAND

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we'll post your non-profit's logo!

A Message from Patty Weltin,
Founder of the Rhode Island Rare Disease Foundation (RIRDF)

The Rhode Island Rare Disease Foundation benefits Rhode Islanders living with a rare disease, regardless of disease. Disease specific foundations provide an invaluable resource for families; however, for a considerable number of diseases no foundation exists. Often, members of disease specific foundations are spread all over the world. The RIRDF will encompass all rare diseases. The diseases may be different, but the challenges faced by the rare disease community remain the same: inaccurate diagnosis, no diagnosis, lack of awareness, insurance and other reimbursement issues, and a terrible sense of isolation. By connecting locally and encompassing all rare diseases, the RIRDF can build a strong rare disease community in Rhode Island and throughout the country.

Rhode Island Rare Disease Foundation http://www.rirdf.org

P.O. Box 16294 Rumford, RI 02916
Tel: 401-434-0052 FAX: 401-434-0039
riraredisease@verizon.net

The Rhode Island Rare Disease Community is a chapter of the Rare Disease United Foundation, a non-disease specific, state-based organization. By connecting on a state level and encompassing all rare diseases, the RDUF can build strong rare communities in each state.

KIDSNET helps assure that all children in Rhode Island are as healthy as possible by getting the right health screenings and preventive care at the right time.
**Early Intervention** services are designed to serve children younger than three years of age who are experiencing developmental delays in one or more of the following areas: cognitive, physical, communicative, social/emotional, or adaptive development skills.

**Rhode Island Parent Information Network** Our mission is to assist individuals, parents, families, and children to achieve their goals for health, educational, and socioeconomic well being by providing information, education, training, support, and advocacy for person/family centered care and systems change. A Family Voices state affiliate.

**About Families** teams children with special health care needs and their families with experienced, licensed clinical staff and dedicated family service coordinators with the goal of creating and implementing comprehensive plans of care that address the needs of the child and the family as a whole.

**The ARC of Blackstone Valley** is committed to supporting people with intellectual and developmental disabilities secure the opportunity to choose and realize their goals of where and how they live, learn, work, and play.

**Special Olympics Rhode Island** program is one of the world’s most dynamic, providing over 1,400 year-round sports training and athletic competitions for more than 2,800 athletes and hosting over 40 local, regional, and statewide tournaments and competitions each year in 25 official and demonstration sports.

If your organization assists Rhode Island rare disease patients, please highlight your efforts by forwarding your information to linda@atypicalhus.org and to the Rhode Island Rare Disease Foundation riraredisease@verizon.net.
SOUTH CAROLINA

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Family Connection of SC
This statewide nonprofit organization links families of children with special healthcare needs and disabilities with resources, support and education.

LifeNet South Carolina
(800) 327-2611
South Carolina, United States
The mission of LifeNet is to provide safe, quality air medical service and patient care to the critically ill and injured.

SOUTH DAKOTA

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!
TENNESSEE

Looking for Resource Links for this state? We are, too!
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TEXAS

Looking for Resource Links for this state? We are, too!
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Camp for All is a barrier free camp for children and adults with special needs and challenging illnesses. This non-profit offers is open year-round for summer camps and for retreats in the spring, fall and winter. Directories List Special Needs Summer Camps.
FMI contact houstonoffice@campforall.org

Haleycurls for Hope Foundation
(512) 844-9541
Texas, United States The Haleycurls for Hope Foundation provides assistance to children receiving services at Dell Children’s Medical Center Cancer and Blood Disorder program and anyone with a histiocytic disorder regardless of location.

Texas Parent to Parent
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.
Looking for Resource Links for this state? We are, too! Please contact Linda@atypicalhus.org to submit rare disease resource links. Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Vermont Family Network (VFN) promotes better health, education, and well-being for all children and families, with a focus on children and young adults with special needs.

Parent to Parent of VA
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.
Virginia Garcia Memorial Health Center
(503) 352-8610
Focuses on the needs of migrant farmworkers, both through the health center and outreach programs into the migrant camps.

WASHINGTON

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Washington State Resources for Parents of Children and Youth with Disabilities
by the University of Washington.

WEST VIRGINIA

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!
Looking for Resource Links for this state? We are, too!
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Coordinate a resource list for your state, we’ll post your non-profit’s logo!

Parent to Parent of Wisconsin
An affiliate of Parent to Parent USA, providing emotional & informational support for families of children who have special needs.

Looking for Resource Links for this state? We are, too!
Please contact Linda@atypicalhus.org to submit rare disease resource links.
Coordinate a resource list for your state, we’ll post your non-profit’s logo!

This Rare Disease Resource List is presented by The Foundation for Children with Atypical HUS as a public service for patients, families, and all who deal with the diagnosis of a rare disease.

For inquires regarding our Foundation or the Rare Disease Resource List, please contact linda@atypicalhus.org or Co-Founder of The Foundation for Children with Atypical HUS, Bill Biermann at:

The Foundation for Children with Atypical HUS  attn.: Bill Biermann  One Campbell Plaza, Suite B  St. Louis, MO 63012
We support the mission and outreach of these Rare Disease organizations, and proudly partner with their rare disease awareness programs and educational resources. The Foundation for Children with Atypical HUS appreciates their efforts to provide information, insight, and support to rare disease patients, their families, and the medical professionals committed to providing them a high standard of care.

USA – learn more about the National Organization for Rare Disorders

Europe – Learn more about the European Organization for Rare Diseases

JOIN the CONVERSATION - Connecting Rare Disease Patients Globally

Information, resources, and support are available at RareConnect, a joint partnership of EURORDIS and NORD.

Participate in their annual Rare Disease Awareness efforts, recognized globally each year, the last day of February.

Rare Disease Day – last day of every February

USA Resources

European Resources
Special THANKS to:

Resources for MA and RI provided by the Rare Disease United Foundation, building a strong rare disease community throughout the United States. FMI visit www.rarediseaseunited.org

Thank you to the Histiocytosis Association for providing various resource links throughout. Learn about their global nonprofit organization dedicated to addressing the needs of patients and families dealing with the effects of histiocytic disorders at www.histio.org

We greatly appreciate the assistance from multiple rare disease organizations, patient advocacy groups, and others whose efforts have been invaluable in providing information and resources to rare disease patients, their caregivers and their families. THANK YOU!

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Looking for Rare Disease Resources for your State?

State Specific Resources appear following the National Resource Links

Please contact Linda@atypicalhus.org if you can provide additional national or state resource links. (We appreciate the advocacy groups who created detailed lists for MA, ME, and RI.) Revised October 2013