

## Resource List to Accompany the Video

### ***Rare Disease Challenges: Support for Patients & Families***

Watch the Video at [www.youtube.com/user/aHUSclinical](http://www.youtube.com/user/aHUSclinical)

*A chronic illness or rare disease diagnosis affects not only the patient but also impacts all individuals and groups associated with the patient as well. This list provides links to organizations and resources that offer assistance to those dealing with common issues and concerns that arise for rare disease patients and those who care for them.*

*Managing medical aspects may impact family dynamics, personal relationships, professional or work aspects, and other interactions across all areas of everyday life. Following categories of resource links that offer specific assistance, we have offered **Patient & Family Assistance Tips** suggesting how patients and their family can be supported by practical actions of friends, relatives, coworkers, or community members.*

***This video and its resource list are Rare Disease Advocacy Efforts of the***

***Atypical HUS Community at [www.atypicalhus.org](http://www.atypicalhus.org)***



## **CAREGIVERS – ADVOCACY AND SUPPORT**

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

<http://caregiveraction.org/resources/>

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

<http://www.caregiver.org/caregiver/jsp/home.jsp>

**Empowering Caregivers** This site provides a safe, nurturing site for all caregivers with emotional and spiritual support and a vast amount of both online and off-line resources

for caregivers.

<http://www.care-givers.com/>

**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 to information about various illnesses, help with costs of medications, disability benefits and more.

<http://www.invisibledisabilities.org/about/aboutida/>

**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.

<http://www.healingwell.com/aboutus.aspx>

**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 like workplace issues, benefits and considerations for families with special needs. Others include information regarding health care and insurance, Title V, and family-centered care. <http://www.familyvoices.org/work>

## COPING WITH SOCIAL AND EMOTIONAL ISSUES

[U.S. National Library of Medicine](#) a service of the [National Institutes of Health](#)

Excerpt from ***Coping with Chronic Illness***

<http://www.nlm.nih.gov/medlineplus/copingwithchronicillness.html>

Having a long-term, or chronic, illness can disrupt your life in many ways. You may often be tired and in pain. Your illness might affect your appearance or your physical abilities and independence. You may not be able to work, causing financial problems. For children, chronic illnesses can be frightening, because they may not understand why this is happening to them.

These changes can cause stress, anxiety and anger. If they do, it is important to seek help. A trained counselor can help you develop strategies to regain a feeling of control. Support groups might help, too. You will find that you are not alone, and you may learn some new tips on how to cope.

**Great Articles, Resources and Tools compiled by the NIH, addressing social & emotional issues:**

[How to Help a Friend or Loved One Suffering from a Chronic Illness](#)

(American Psychological Association) Also available in [Spanish](#)

[Living with a chronic illness - dealing with feelings](#)

Also available in [Spanish](#)

[Living with a chronic illness - reaching out to others](#)

Also available in [Spanish](#)

[Managing Care for Adults with Long-Term Medical Illness](#)

(Agency for Healthcare Research and Quality)

[Financial Management during Crisis \(For Parents\)](#)

(Nemours Foundation) Also available in [Spanish](#)

**Caring for a Seriously Ill Child** (Kids Health by Nemours Foundation)

[http://kidshealth.org/parent/system/ill/seriously\\_ill.html](http://kidshealth.org/parent/system/ill/seriously_ill.html)

Siblings of Children with Chronic Illnesses (American Academy of Pediatrics)

<http://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Siblings-of-Children-with-Chronic-Illnesses.aspx>

**Students With Chronic Illnesses:**

Guidance for Families, Schools, and Students (NIH article)

<http://www.nhlbi.nih.gov/files/docs/public/lung/guidfam.pdf>

[Balancing Academics and Serious Illness \(For Parents\)](#) (Nemours Foundation)

## 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

<http://www.PANFoundation.org>

**Patient Advocate Foundation (PAF)** A national non-profit 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.

[www.patientadvocate.org](http://www.patientadvocate.org)

**UnitedHealthcare Children's Foundation** <http://www.uhccf.org/apply.html> The 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 the available commercial health benefit plan. 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.

See also [http://uhccf.org/apply\\_applicant.html](http://uhccf.org/apply_applicant.html)

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. Visit <https://applications.cerner.com/firsthand/>

**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 - like paying their rent and utility bills - so they can focus on crucial medical care.  
[http://www.teamcontinuum.net/apply\\_for\\_a\\_grant](http://www.teamcontinuum.net/apply_for_a_grant)

**BrightHand** 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.  
[http://brighthand.org/?page\\_id=33](http://brighthand.org/?page_id=33)

**(NHGRI)** at the **National Institutes of Health (NIH)** has information about financial assistance resources for people who need help paying for medical care.  
<http://www.genome.gov/11008842>

## AGE SPECIFIC RESOURCES

### CHILDREN

**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.

<http://health.nih.gov/category/ChildTeenHealth>

**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. An excellent article about children coping with chronic medical conditions

<http://www.healthychildren.org/English/health-issues/conditions/chronic/pages/Coping-With-Chronic-Illness.aspx?nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token>

**The Department of Pediatrics at National Jewish Health** gives detailed information and suggested steps to help families cope with a child's chronic illness. "Understanding Children and Chronic Illness: Protecting your child's emotional health" pdf <http://www.nationaljewish.org/pdf/Understanding-ChildrenChronicIllness.pdf>

**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. [http://www.aacap.org/cs/root/facts\\_for\\_families/the\\_child\\_with\\_a\\_longterm\\_illness](http://www.aacap.org/cs/root/facts_for_families/the_child_with_a_longterm_illness)

**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) <http://www.sensory-processing-disorder.com/sensory-processing-disorder-checklist.html>

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 <http://www.ncld.org/checklists-a-more/checklists-worksheets-a-forms/ld-checklist-of-signs-and-symptoms>

**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. <http://www.familyvoices.org/>

**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.)

<http://www.ssa.gov/pubs/10026.html>

**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 <http://www.nasn.org/MemberCenter/DiscussionLists/SCHLRNL> .

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. For more about the role of an IHP, visit <http://nasnupgrade.winxweb.com/PolicyAdvocacy/PositionPapersandReports/NASNPositionStatementsFullView/tabid/462/ArticleId/32/Individualized-Healthcare-Plans-IHP-Revised-2008>

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,

*“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 with a detailed overview of Title V <http://www.amchp.org/AboutTitleV/Pages/default.aspx> FMI see an overview of Title V at Family Voices [http://www.familyvoices.org/admin/work\\_titlev/files/TitleVforCYSHCN.pdf](http://www.familyvoices.org/admin/work_titlev/files/TitleVforCYSHCN.pdf) 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).

**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.

<http://www.campsunshine.org>

## AGE SPECIFIC RESOURCES - TEENS

**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. Includes resources such as: [Dealing with a Health Condition](#)(Nemours Foundation) Also available in [Spanish](#)  
<http://health.nih.gov/category/ChildTeenHealth>

**Chronic Illness Resources for Teens.** These resources are the result of a collaboration between the Koop Institute (C. Everett Coop in partnership with Dartmouth Medical School) and the S.T.A.R. Program for teens with chronic illness.  
[http://geiselmed.dartmouth.edu/koop/resources/chronic\\_illness/](http://geiselmed.dartmouth.edu/koop/resources/chronic_illness/)

**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. FMI about teen and family issues, see <http://www.focusas.com/index.html>

**TeensHealth** is part of the **KidsHealth** family of websites, and is a place for teens that 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.  
[http://kidshealth.org/teen/your\\_mind/problems/deal\\_chronic\\_illness.html#](http://kidshealth.org/teen/your_mind/problems/deal_chronic_illness.html#)

## AGE SPECIFIC RESOURCES - 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 such as [Living with Multiple Health Problems: What Older Adults Should Know](#)(AGS Foundation for Health in Aging)  
<http://nihseniorhealth.gov/>

**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.  
<http://www.healthinaging.org/>

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](#)

## 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 Occupational Therapists Association, Inc. has resources viewable at <http://www.aota.org>

**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. Visit <http://www.moveforwardpt.com/Default.aspx>

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. <http://www.asha.org/public/>

**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. FMI see <http://www.musictherapy.org/>

**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. Resources available at <http://www.arttherapy.org/aata-newsandinfo.html>

## 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.

<http://www.rarediseases.org/about/vision-mission>

**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 Web site 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.

<http://rarediseases.info.nih.gov/>

**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 help people find useful information about genetic conditions and rare diseases.

<http://rarediseases.info.nih.gov/GARD/Default.aspx?PageID=4>

**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.

<http://www.nih.gov/about/>

**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. <http://www.eurordis.org/>

**Canadian Organization for Rare Disorders (CORD)**

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. Offering information and resources, visit CORD at <http://www.raredisorders.ca/index.html>

## 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.

<http://www.rareconnect.org/en>

**Genetic Alliance** Their programs and initiatives focus on a broad range of topics in genetics, health and advocacy with a website that offers resources such as Disease InfoSearch, Newborn Screening and Family Health History. Their initiatives improve health systems through partnerships with communities and individuals. Learn more at [www.geneticalliance.org](http://www.geneticalliance.org)

The **Global Genes 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.

<http://globalgenes.org>

The **Rare Disease United Foundation** is a non-disease specific, state-based organization that was formed to work on rare disease issues at a state level to provide support and advocacy for all challenged by rare disease issues

[www.rarediseaseunited.org](http://www.rarediseaseunited.org)

## ORGANIZATIONS FOR UNDIAGNOSED OR UNNAMED SYNDROMES

**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.

<http://www.undiagnosed-usa.org/> SWAN also has organizations in other countries, too.

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. They strive to provide answers to patients with mysterious conditions that have long eluded diagnosis, and they are committed to advance medical knowledge about rare and common diseases. See <http://rarediseases.info.nih.gov/Resources.aspx?PageID=31>

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

<http://www.inod.org/home0.aspx>

## OTHER RESOURCES FOR PATIENTS, FAMILIES, AND CAREGIVERS

### TOOLS – ORGANIZATIONAL MANAGEMENT

The Rare Disease **Grab N Go Tool Kit** <http://atypicalhus.ning.com/page/grab-n-go-tool-kit> consists of four helpful forms to assist patients, family members, caregivers, and all who face the challenges of a chronic illness or rare disease. Check out the 'Apps Page' for technology assists regarding aspects that include organizing medications, tracking appointments, and sharing caregiving tasks.

**LabTracker** <http://atypicalhus.ning.com/page/labtracker>

Track lab trends to monitor patient health. A handy trifold for patients or caregivers to keep with them, the *LabTracker* provides an organized format to record your lab results and other important health data.

**Patient Self-Advocacy Tool** <http://atypicalhus.ning.com/page/self-advocacy-tool>

Our *Patient Self-Advocacy Tool* provides an organized format to list concerns, issues, and questions that arise at home between visits to your health professionals. Great for adult patients or those caring for a patient with chronic illness, this trifold is ideal to fill in at home and bring to your next visit to the clinic, hospital, or doctor.

**Urgent Care Directives** <http://atypicalhus.ning.com/page/rd-tool-3>

A multi-purpose tool, this simple form can provide vital information about your chronic illness or rare disease in urgent care settings. Whether on file at the office or school or carried by patients as a safeguard, families can feel more secure knowing that an medical emergency team can begin their response with more robust medical information.

**Emergency Care Card** <http://atypicalhus.ning.com/page/rd-tool-4>

A specialized Emergency Card just for rare disease patients and their medical needs! When patients can't speak for themselves, and the caregiver is not immediately available, the *Emergency Care Card* steps in to fill the information void by providing vital information necessary for emergency treatment that is rapid and appropriate for aHUS patient needs.

**Apps Page** <http://atypicalhus.ning.com/page/apps-for-patients-carers>

Patients, caregivers, and family members face many challenges in the face of a rare disease diagnosis or an ongoing chronic illness. This page offers a short list of online resources for patients (with their caregivers and family) challenged with chronic illness or rare disease issues. These apps can help you organize and manage treatment schedules, medical appointments, drug lists, nutrition planning, caregiver coordination, and MORE.

## PATIENT & FAMILY ASSISTANCE TIPS

### ***How Relatives, Friends, Neighbors, Coworkers and Others Community Members Can Help***

***Whether newly diagnosed or coping with life challenges years later, some common issues and concerns arise for rare disease patients and those who care for them. Managing medical aspects may impact family dynamics, personal relationships, professional or work aspects, and other interactions across all areas of everyday life. A chronic illness or rare disease diagnosis affects not only the patient but also impacts all individuals and groups associated with the patient as well.***

***Stress about finances, relationships, and responsibilities can weigh heavily on all concerned. This resource section contains practical applications and ideas for patients, families, and caregivers. Also offered are suggestions for how patients and their family can be supported by actions of friends, neighbors, coworkers, a faith community, or anyone who wants to put their heartfelt good wishes into meaningful action.***

## TIPS REGARDING PEDIATRIC PATIENTS

Children can help make a list of their ‘comfort’ items to bring to treatment/hospital, such as a special blanket, music, or personal items. Older children may wish to pack their own bag of special items for treatment times or hospital stays.

Friends, relatives, or other caring individuals should consider checking in with parents or caregivers regarding visits, gifts, or needs. Remember that a chronic illness affects the entire family’s schedule and lifestyle. If you are able, offer to help with a specific task or chore that is within your skills and ability. (“Do you need help with x,y.z?”).

Each child is different. For some, discussing what the child might experience during medical care may alleviate their fear of the unknown. For other pediatric patients, this preview of events can induce stress. Consult professionals (medical staff, school counselor, therapist, social worker, etc.) about your child’s emotional needs and concerns so that you are prepared with helpful resources.

Keep teachers, school counselors, and the school nurse informed about [the rare disease patient in a school setting](#). Parents and caregivers of school age children should explore the need for an Individual Health Plan (IHP) with public school administrators, and learn what options exist for optimizing the learning experience for rare disease patient. Request a Pupil Evaluation Team (P.E.T.) meeting with school staff, and prepare a list of concerns and issues to discuss.

Get acquainted with Child Life personnel and explore available resources within the hospital or healthcare settings. Child Life staff are trained professionals who address the social, emotional, and developmental needs of pediatric patients. They can also help reduce patient stress to maximize the patient’s quality of life, both during treatment and during hospital stays.

Nursing staff may be able to utilize a ‘patient doll’ or other teaching aid to model procedures and answer questions, which may reduce concern and act to reassure the pediatric patient.

Children are not defined by, and should not unnecessarily be confined by, their chronic illness or rare disease diagnosis. Even very young children can sense stress in familiar faces, so be aware that your tone of voice, body language, and personal stress level can impart unspoken messages to pediatric patients. Be supportive of the child’s needs and situation, and know that you ‘set the tone’ by your actions and reactions.

Parents and caregivers can encourage pediatric patients to employ stress reduction or relaxation techniques appropriate to the patient’s age and health status, including:

*Yoga          Creative imagery          Breathing exercises          Reiki          Journal Writing*  
*Faith Community Involvement          Favorite Activities          Exercise          Counseling/Therapy*  
(Some hospitals/clinics offer at-site activities and/or practitioners to assist patients- ask!)

## TIPS REGARDING SIBLINGS OF PATIENTS

Ask about the siblings' feelings and needs (as well as those of the patient) - respect them.

For adult siblings of patients, consider whether it's more effective/efficient to designate a 'point person' for communications flow regarding family updates and/or for interactions with key medical personnel. Utilize a smartphone app that allows siblings to share information, schedules, and caregiving tasks. *(Ask medical staff about the adult patient's "Authorization to Share Medical Information With Designated Individuals". Know that HIPAA regulations can prevent providers and healthcare facilities from sharing personal medical information without such written authorization.)*

Utilize creative writing or journaling to express emotions and/or reduce stress: "When ..... happens, I feel -----". In some instances, young siblings may be jealous of the extra attention or gifts given to the patient.

For young siblings of patients, offer special time/events with extended family or friends when possible.

Discuss/offer options and accommodations for treatment days, hospital visits, and other realities that present scheduling issues which may affect family life.

For chronic illness or rare disease that may have a genetic component, realize that siblings may be concerned about their own potential for illness. In some instances, a young sibling may irrationally blame themselves for their brother or sister's diagnosis and health status. Address such concerns, or concerns about depression regarding any family member, with healthcare professionals, therapists, counselors, or social workers.

Siblings of a patient may benefit from stress reduction or relaxation techniques appropriate to their age and personal situation, including:

*Yoga | Creative imagery | Breathing exercises | Reiki | Journal Writing Faith Community Involvement | Favorite Activities | Exercise | Counseling/Therapy*

### **TIPS FOR RELATIVES, FRIENDS, NEIGHBORS, COWORKERS AND OTHER COMMUNITY MEMBERS**

Ask about the patient's feelings and needs (as well as those of their family) - respect them.

Friends, relatives, or other caring individuals should consider checking in with the patient or their family/caregivers regarding visits, gifts, or needs. Remember that a chronic illness affects the entire family's schedule and lifestyle. If you are able, offer to help with a specific task or chore that is within your power to execute fully ("Do you need help with x,y,z?").

Recognize that when a healthcare crisis arises or a chronic illness has been ongoing for an extended period of time, attitudes and needs can change dramatically.

Patients are not defined by, and should not unnecessarily be confined by, their chronic illness or rare disease diagnosis. Even very young patients can sense stress in familiar faces, so be aware that your tone of voice, body language, and personal stress level can impart unspoken messages to others. Be supportive of the patient's needs and situation, and know that you 'set the tone' by your actions and reactions.

Each patient and their situation is different, but there is one firm rule when individuals or families must deal with challenges faced by chronic illness or a rare disease. What is that one firm rule? Ask the patient and their family about their wishes regarding others sharing their situation and details, then honor those guidelines.

Be sensitive about what personal and medical information you share with others about the patient and their family, as well as how that is shared. Some patients and their families draw inward and request time to process matters privately. Others may welcome comfort in the form of a public outpouring of sentiment posted across multiple Facebook pages. Some families would appreciate having a benefit organized to help with their financial burdens resulting from medical treatment, while other families would prefer that friends rally around an awareness campaign specific to their medical diagnosis. Don't assume, ask what is comfortable for the patient and their family.

Consider creating a FAQ sheet of medical facts and resources, after checking to see if the patient or caregiver would appreciate this. If so, this information could be distributed to friends, extended family, a faith community, school, the workplace or other similar groups to raise awareness. Consider adding a designated contact point on this FAQ for sharing updates (like CaringBridge) as well as a point person for individuals or groups to contact with their offers of support or assistance.

Offer to work with adults involved (patient, caregivers, family, support circle members) to create options and accommodations for issues likely to occur: transportation, meals, workload on the job, family tasks that need to be reassigned to others, and similar everyday issues.

Utilize caregiver apps to organize, manage, and coordinate various aspects of care or support. While some smartphone apps specialize in medications and appointment management, many other apps assist with coordinating schedules among multiple caregivers. (See the Apps Page list, or visit the iTunes or GooglePlay sites for app options.)

Organize a 'circle of support' for meals, transportation, childcare, household tasks, or other aspects which the patient and their family have designated for welcomed assistance.

Not in the same geographic area as the patient and their family, but still want to help? Determine their wants, needs, and concerns before creating an assistance plan. Some rare

disease patients and their families simply desire your personal time to share their thoughts and feelings by phone or email, while others might welcome a hosted Facebook or crowdfunding page online. You might volunteer to connect the patient or their family with programs or resources offered by local service groups, resource centers, or their own faith community.

If you are not local to the area or have limited time or skills, you can still support the patient and their family. Think creatively, and consider their needs. If you are financially able, sending a favorite meal by a local restaurant delivery service may be well received, while others might appreciate having a laundry or housecleaning service prepaid to assist with household chores. If finances are tight, consider pooling funds or joining with others to provide support services.

Needs and concerns change and arise as time marches on, or as health status fluctuates. For chronic illness and rare disease patients, the road is often long and challenging. Show you care, and periodically touch base to offer renewed support and assistance. Support means different things, to different people, at different times. Ask. Consider. Offer. Assist. Connect.

### **TIPS FOR THE WORKPLACE – CONSIDERATIONS FOR EMPLOYERS/COWORKERS/PATIENTS/CAREGIVERS**

Employers and patients/caregivers should inform themselves about workplace laws and policies that relate to their situation. (See *Rare Disease Organizations* list for resource links.) Many larger companies have a Human Resource Department or designate a company officer to coordinate workplace policies, which aim to bring out the best in their employees and so better contribute to the success of the company.

Patients/Caregivers should provide to their employer any details regarding information about medical treatments that may impact the employee's work schedule, their work responsibilities, their coworkers' workload, or other work-related aspects. Early on, arrange a meeting between the patient/caregiver and their employer to consider any impact the chronic illness or rare disease might have on the workplace, its people, the company, and its business clients or its products. Explore possible accommodations needed.

Patients/Caregivers might consider creating an information packet for employers, or the company's Human Services Department or HR official. This might include information about the chronic illness or rare disease, educational materials from healthcare providers, a compiled list of links to online resources or other assets/documentation.

Employers and coworkers can be proactive, and plan ahead for various situations that may arise at work. In a supportive work environment or business, the patient/caregiver may be asked what flexibility would be appreciated at work to accommodate medical needs and their family impact. Think creatively, plan options in advance so that all parties understand accommodations, roles, and their responsibilities.

Be compassionate. Imagine what you would think, how you would operate in your workplace, and what creative solutions might help to make the work environment more effective for all concerned. Strong business models and successful companies can indeed have a productive workplace while demonstrating flexibility, showing empathy, and offering support to patients or caregivers challenged by chronic illness or a rare disease.

Recognize that when a healthcare crisis arises or a chronic illness has been ongoing for an extended period of time, attitudes and needs can change dramatically. Employers can be watchful for signs of stress or depression, such as decreased productivity or changes in behavior, and offer these employees support backed by the company's policy on therapy and counseling.

A rare disease diagnosis or chronic illness affects the entire family's schedule and lifestyle. Offer to work with patient/caregiver to create options and accommodations for issues likely to occur: transportation, meals, workload on the job, family tasks that need to be reassigned to others, and similar everyday issues.

Needs and concerns change and arise as time marches on, or as health status fluctuates. For chronic illness and rare disease patients, the road is often long and challenging. Show you care, and periodically touch base to offer renewed support and assistance. Support means different things, to different people, at different times. Ask. Consider. Offer. Assist. Connect.

### **TIPS FOR ADULT PATIENTS AND CAREGIVERS OF PATIENTS**

Talk with hospital staff, therapists, social workers at the hospital or clinic, school counselors, the Human Resources Departments or officer at work, and professionals in associated roles to outline your situation, needs, and concerns.

Consider whether it's more effective/efficient to designate a 'point person' for communications flow regarding updates and/or for interactions with key medical personnel. Utilize a smartphone app that allows your 'support circle' to share information, schedules, and caregiving tasks. *(Ask medical staff about the adult patient's "Authorization to Share Medical Information With Designated Individuals". Know that HIPAA regulations can prevent providers and healthcare facilities from sharing personal medical information without such written authorization.)*

Consider creating a FAQ sheet of medical facts and resources, after checking to see if the patient or caregiver would welcome this. If so, this information could be distributed to friends, extended family, a faith community, school, the workplace or other similar groups to raise awareness. Consider adding a designated contact point on this FAQ for sharing updates (like CaringBridge) as well as a point person for individuals or groups to contact with their offers of support or assistance.

Offer to work with adults involved (patient, caregivers, family, support circle members) to create options and accommodations for issues likely to occur: transportation, meals, workload on the job, family tasks that need to be reassigned to others, and similar everyday issues.

Utilize caregiver apps to organize, manage, and coordinate various aspects of care or support. While some smartphone apps specialize in medications and appointment management, many other apps assist with coordinating schedules among multiple caregivers. (See the Apps Page list, or visit the iTunes or GooglePlay sites for app options.)

Organize a 'circle of support' for meals, transportation, childcare, household tasks, or other aspects which the patient and their family have designated for welcomed assistance.

Encourage caregivers to connect with a specialized online caregiver support network to gain specific support and assistance (see caregiver resource listings). Caregivers should utilize the website's resources and tools, including participation in forums or conversation threads dedicated to certain interests and needs.

Pre-arrange options and accommodations for treatment days, hospital visits, household/family tasks and other scheduling issues that affect family life for a rare disease patient, their siblings, their parents, their caregivers and others involved. Be creative, use caregiver apps to coordinate tasks and schedules, and organize a wide 'circle of support' to enlist for assistance.

Make time to enjoy the patient in your care and/or yourself, no matter how small the gesture or how little opportunity presents itself. Take a few moments to renew and refresh yourself, even if it's only moments of time to breathe deeply, reflect in thought or prayer, or otherwise gather strength.

Patients, as well as their family members and caregivers, may benefit from stress reduction or relaxation techniques appropriate to their age and personal situation, including:

*Yoga | Creative imagery | Breathing exercises | Reiki | Journal Writing Faith Community Involvement | Favorite Activities | Exercise | Counseling/Therapy*

Make it easy to track health trends, manage medical information, and store/retrieve important information. Create an accordion file 'Care Folder' and 'Home Folder' to organize information, materials, and important documents. (See Below)

## **MANAGE AND ORGANIZE INFORMATION FOR HEALTHCARE AND YOUR PERSONAL LIFE**

Struggling to avoid being buried under a mound of medical paperwork? Unable to retrieve that one important piece of information that is critical to find? Organizing materials with an accordion file is a quick and low cost way to manage information and reduce stress as you're better prepared. Below are two types of accordion file systems, for medical aspects and for

personal life, but many families opt to utilize both systems. Tips are provided below for categories and use to start your own accordion file.

*What is an accordion file? An accordion file, also known as an expanding file, is an alternative to storing documents in a notebook or binder (cost ranges from \$8 dollars and up, at office supply stores or online). It is a portable file holder with indexed dividers to separate, organize, and store paperwork. It has pleated sides which allows the accordion file to expand, and often included paper tab inserts to mark contents of each divider. Most styles available have a flap and elastic cord or Velcro closure to ensure that filed paperwork remains securely in place.*

### **'Care Folder' or Medical Accordion File**

A Convenient Way to Bring Vital Info to your Appointments

The *Care Folder* or Medical Accordion File can become an especially critical asset if an adult patient becomes too ill to self-advocate, and a family member needs to step into a primary caregiver role. Easy to bring to treatment centers, hospitals, and doctors' offices, the accordion file acts as a handy organizing tool that lets you immediately store important medical papers for easy retrieval in the future. It also provides a clear overview of your medical status, contact info for your providers,

*Labeled file folders in an accordion file contain vital information critical for your care in the event that you are unable to speak for yourself*

- \* Emergency Contact info
- \* Names and Contact info for primary Care Physician/ Specialists
- \* Meds Schedule (keep updated)
- \* Medical History/Concerns (highlights)
- \* Special care needs (dialysis schedule, central line issues, special diets, etc)

**"Home" Accordion file**- This stays at home as a 'central repository'" that contains vital information/documents to keep your world running smoothly

*Labeled file folders in an accordion file contain vital information critical for your world (home, work, personal finances, work contact info) in the event that you are incapacitated.*

- \* Monthly Bill Schedule, with acct. numbers and passwords
- \* Emergency
- \* Contact info for workplace/school/close friends
- \* Bank Account info (sample statement, passwords)
- \* Power of Attorney, Living Will, other Legal Documents
- \* Military documents
- \* Copy of Birth Certificate/Marriage Certificate
- \* Copy of deeds, mortgages, tax return

## CAREGIVERS

Connect with an online Caregiver support site (see top of this resource list). Utilize their resources and tools, including participation in forums or conversation threads specific to your interests and needs.

Utilize caregiver apps to organize, manage, and coordinate various aspects of care. Some apps specialize in medications and appointment management while other apps assist with coordinating schedules among multiple caregivers. (See the Apps Page, or visit the iTunes or GooglePlay sites for app options.)

Pre-arrange sibling options and accommodations for treatment days, hospital visits, and other scheduling issues that affect family life of a pediatric patient.

Create a FAQ sheet of medical facts and resources – distribute to friends, extended family, faith community, school, workplace

Work with adults involved to create options and accommodations for issues likely to occur: transportation, meals, workload on the job, family tasks that need to be re-delegated to others

Make time to enjoy today with the patient in your care, no matter how small the gesture or how little opportunity presents itself.

Take a few moments to yourself, even if it's only time to breathe deeply or gather strength.

Create a **"Care Folder" Accordion file** for Children with Special Medical Needs

Create a **"Care Folder" Accordion file** for your spouse or Life Partner to bring to medical treatment and a **"Home" Accordion file** to give you BOTH piece of mind!

## FRIENDS/EXTENDED FAMILY

**Ask the patient/family what they feel comfortable sharing** (Respect that some people might not want to see commentatry related to their personal situation on your Facebook page.)

Offer specific assistance rather than use general wording like "What can I do to help". Offer to walk their dog. Host a young patient's siblings for a pizza and movie night at your home so the parents can visit their hospitalized child – or even so that parents can share a dinner alone to reconnect their relationship and take time to destress. Offer to do yard work or other chores that can often fall off-schedule.

Ask about the patient and family's options and accommodations for issues likely to occur: transportation, meals, family tasks that need to be re-delegated to others. Create options to assist them. Consider using a smartphone app to coordinate people and tasks.

Ask the patient or their family about the need for a fundraiser. If a fundraiser would be welcome, remember that some online options exist in terms of outreach or crowdfunding.

Offer to comb the internet to compile a resource list just for them. Check for current, reliable links containing organizations that offer information, sites with tool kits, or sites that offer educational or research assets. Don't forget to list helpful apps for iPhone or Android devices.

For chronic disease patients, the road is long and challenging. Show you care. Remember to check in with a phone call or email after the diagnosis or discharge – time marches on but the problems may remain constant for patients, caregivers, and family members.

### **IN THE WORKPLACE – CONSIDERATIONS FOR EMPLOYERS/WORKMATES/PATIENTS/CAREGIVERS**

Patient/Caregivers and Employers should Inform themselves about workplace rules and laws.

Patient/Caregivers can provide information about the medical diagnosis and consider possible accommodations that may be necessary. Meet with employers and workmates to discuss this impact on the patient/caregiver's workplace.

Employers and workmates can be proactive, and ask what accommodations would be appreciated at work. Think creatively, plan options in advance so that all parties understand accommodations and responsibilities.

Be compassionate. Imagine what you would think, how you would operate in your workplace, and what creative solutions might help to make the workplace more flexible for all concerned.

**Looking for MORE resources?** Check out many more categories and links to assist patients, caregivers, and families facing the challenges of a chronic illness or rare disease diagnosis.

## Rare Disease Resource List

<http://atypicalhus.ning.com/page/usa-rare-resource-list>

This resource list to accompany the video ***Rare Disease Challenges: Support for Patients & Families*** was created as an advocacy and awareness effort in support of rare disease patients and their families.

These assets were created specifically to be shared by rare disease patients, families, and caregivers as well as by the non-profit organizations who support and assist them. Patient communities, caregiver networks, non-profit organizations and rare disease advocacy groups are welcome to include this video and its list as part of their own resource kits. Other use of this material is prohibited, unless written consent is provided.

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*Rare Disease Advocacy and Awareness*

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The Atypical HUS Foundation



aHUS Information Rare Disease Advocacy

[www.atypicalhus.org](http://www.atypicalhus.org)