## **Medical beds**

What this article is about: This article provides a brief overview of medical beds and provides links to resources where you can find more information and support.

There are a number of reasons that you might want a special bed for your child. If your child has a seizure disorder, he can be injured in a regular bed during a seizure. If she is an elopement risk, a special bed can prevent her from wandering off.

You may be feeling overwhelmed about the prospect of selecting and financing a special bed. This article from Complex Child magazine called, "Funding for Specialty Medical Beds" has all of the bases covered!

# **Patient Assistance Programs**

Sometimes, no matter how good your insurance is, the cost of your child's care is more than your insurance will cover. Patient assistance programs help to offset these expenses.

National Organization for Rare Disease (NORD) Patient Assistance brochure:

Alex's Lemonade Stand: travel grants for families battling childhood cancer

Alyssa V. Phillips Foundation, helps kids with CP pay for therapies and other treatments not covered by insurance

Angel Flight, free medical flights

Aubrey Rose Foundation, helps families with medical expenses

Aubrey's Warriors Foundation, financial assistance to families with financial hardship due to a child's illness

Autism Escapes, arranges air travel on private jets for families seeking medical care

Be Perfect Foundation, financial assistance for people living with paralysis

Believe in Tomorrow Children's Foundation, medical and respite housing to critically ill children and their families

Believe in Tomorrow, hospital and respite housing

Ben's Blankets, weighted blankets for children with sensory needs; you only pay the cost of materials

Bryan's Dream Foundation, helps families of children with brain tumors

Building Blocks for Kids, grants for health care related needs

Cancer Care, financial assistance to families of kids who have a cancer diagnoses

Challenged Athletes Foundation, grants for paralympic athletes

Chelsea Hutchison Foundation, seizure assistance dogs and seizure monitoring Different Needz Foundation, grants for medical services and/or services.

Eden's Hope, helps families of children with neuroblastoma

Family Reach, financial aid for families with a child who has cancer

First Hand Foundation, provides financial assistance for medical care, vehicle modification and travel

FODAC, provides refurbished equipment and services for disabled adults and children to improve their overall quality of life.

Fred's Footsteps, provides financial assistance to families during a child's illness

Friend's of Man, assists with medical and mobility equipment and prothesis

Generation Rescue, provides assistance for autism medical treatment for families in financial need

Gia Nicole Angel Foundation, assist with purchase of medical equipment

Grotto Humanitarian Foundation, provides dental services for children with special needs

Gwendolyn Strong Foundation, provides iPads for children with spinal muscular atrophy

Hands to Angels, helps families of children with rare genetic disorders

Hannah and Friends, provides quality of life grants for individuals with

developmental disabilities in Indiana, the Michiana area, New York, Rhode Island,

and Florida Holton's Heroes, assists families affected by post birth traumatic brain injury iPads for Apraxia, awards iPads and protective cases to aid in communication

J Kiffin Penry Patient Travel Assistance Fund, travel grants for epilepsy care

Jah Heart Foundation, assists children with cerebral palsy

Josh Provides, grants to medical services, medication, travel and devices related to epilepsy

June Brandy Foundation, assists families with children who have pediatric illness/disability

June Jessee Memorial Foundation, assists families in the St. Louis area with medical copayments, medications, medical equipment, overnight nursing care, formula and other items not covered by insurance.

Kya's Krusade, grants for therapies

Maggie Welby Foundation, provides grants to families in need Mark's Money, grants for individuals with Down Syndrome residing in Tennessee or Indiana

Matthew Larson Foundation, assists families of children with brain tumors

McLindon Family Foundation, provides adaptive bicycles for children with special needs.

MIRA Foundation, provides guide dogs for blind children ages 11-17

Miracle Ear Foundation, provides free hearing aids to individuals in need

Modest Needs, short term financial help for families in crisis situation

Molly Bear Foundation, grants for families of children with Trisomy 18

My GOAL Inc, grants for families of children with autism for treatments not covered by insurance or other sources

MY GYM Challenged America, provides grants for medical equipment and therapy equipment for families with special needs

Needy Meds, discounted and free medication programs and other services for low income families

Parker Lee Project, provides medical supplies and equipment to children at no cost to the families.

Project Mend, refurbishes mobility devices and assists families with medical equipment needs

Ray Tye Medical Foundation, funds life saving medical care and surgeries for those without insurance

Ride to Give, turns athletic ability into fundraising power for families with children who are disabled, injured, or ill.

Silent Stars, provides iPads for children with Childhood Apraxia of Speech

Small Steps in Speech, grant funds for speech and language disorder therapies

Snap4Kids, provides modest grants to families in need

Stepping Stones for Stella, provides buggies for children with special needs to enjoy outdoors to its fullest

The Arya Foundation, provides medical equipment such as ramps, special beds and walking aides.

The Danny Did Foundation, provides seizure/epilepsy devices to children in need

The HIKE Fund, provides hearing devices for children in need The Lindsay Foundation, treatment, medical, and rehab equipment grants

The M.O.R.G.A.N. Project, tools for fun and therapeutic experience for children with developmental and physical needs

The National Children's Cancer Society, financial assistance with travel, meals and lodging for families of children with cancer

The Prayer Child Foundation, assistance to children with disabilities

TJ Joy Memorial Fund, helps families to obtain seizure monitoring devices

Travis Roy Foundation, grants for people with spinal cord injuries

Two Angels Foundation, adaptive recreational equipment

UnitedHealthcare Children's Foundation, grants for children 16 years old or younger for health care expenses insurance does not cover

Variety of United States, services and equipment

Wheel to Walk Foundation, equipment not provided by insurance

Wheelchairs 4 Kids, medical equipment and assistive devices to families in need

# Law and Advocacy resources

What this article is about: This article provides an overview of special education law and advocacy resources.

#### **ADA National Network**

The ADA National Network provides information, guidance and training on the Americans with Disabilities Act (ADA), tailored to meet the needs of business, government and individuals at local, regional and national levels. The ADA National Network consists of ten Regional ADA National Network Centers located throughout the United States that provides personalized, local assistance to ensure that the ADA is implemented wherever possible.

#### **Protection and Advocacy for People with Disabilities Network**

Each state has a federally mandated protection and advocacy agency that safeguards and advances the civil and human rights of people with disabilities. Agencies provide information and referral, investigate complaints of rights violations, and work to resolve complaints through mediation, dispute resolution, and litigation.

**American Bar Association Commission on Disability** 

The Commission carries out an array of projects and activities addressing disability-related public policy, disability law, and the professional needs of lawyers and law students with disabilities.

#### **Wrights Law**

Parents, educators, advocates, and attorneys come to Wrightslaw for information about special education law, education law, and advocacy for children with disabilities.

# **Augmentative and Alternative Communication (AAC)**

What this article is about: This article provides an overview of Augmentative and Alternative Communication (AAC) devices and resources where you can find help and support.

What this article is about: This article provides an overview of Augmentative and Alternative Communication (AAC) devices and resources where you can find help and support.

The terms assistive device or assistive technology can refer to any device that helps a person with hearing loss or a voice, speech, or language disorder to communicate. These terms often refer to devices that help a person to hear and understand what is being said more clearly or to express thoughts more easily. With the development of digital and wireless technologies, more and more devices are becoming available to help people with hearing, voice, speech, and language disorders communicate more meaningfully and participate more fully in their daily lives.

#### Resources

National Institute on Deafness and Other Communication Disorders: Assistive Devices for People with Hearing, Voice, Speech, or Language Disorders

#### AAC Institute

Autism Speaks: Assistive Technology

## Assistive Devices, MEDLINEplus

MEDLINEplus is an online service of the National Library of Medicine and the National Institutes of Health. Updated daily, the site offers information on a range of health topics, in English and Spanish (En Español).

Institute of Medicine (US) Committee on Disability in America; Field MJ, Jette AM, editors. The Future of Disability in America. Washington (DC): National Academies Press (US); 2007. 7, Assistive and Mainstream Technologies for People with Disabilities. Available from: https://www.ncbi.nlm.nih.gov/books/NBK11418/

University of Washington DO-IT (Disabilities, Opportunities, Internetworking and Technology: How can parents promote the use of accessible technology in schools?

AAC Blogs

## **Assistive Technology**

## **Teaching All Students**

Free Resources from the Net for Every Learner

## **Travel and Lodging for Hospital Stays**

What this article is about: This article provides a brief overview of travel resources and links to resources where you can find more information and support.

#### We're looking for contributions to make this page better! Contact us if you have resources to add!

The following resources can help with travel and lodging costs. These organizations provide information about free or discounted land or air travel, specialized medical care during transport, and supportive lodging options. Some organizations have specific medical or financial eligibility criteria, so check their websites or contact them to learn about their requirements.

### What organizations can help with the cost of travel?

Below is a list of some organizations that can help patients arrange free or discounted transportation within the United States. Some organizations provide help to all patients in need. Others focus on specific groups of patients such as veterans, children, or cancer patients.

### **Organizations for all patients:**

<u>National Patient Travel Center</u> – Provides information about all forms of charitable, longdistance, medically-related transportation. Visit their webpage to request assistance.

<u>Air Charity Network</u> – Provides access to member organizations that offer free air transportation to specialized health care facilities or distant destinations needed during family, community, or national crisis. Call 877-621-7177 to be automatically routed to a member organization in your region.

<u>Angel Flight East</u> – Provides free air transportation to qualified patients and their families by arranging flights to distant medical facilities, delivering supplies to disaster areas, and reuniting families during desperate times. Call 215-358-1900 to learn more.

<u>LifeLine Pilots</u> – Facilitates free air transportation provided by volunteer pilots for passengers with medical and humanitarian needs. View the *Request a Flight* page on their website or call 800-822-7972 for assistance.

<u>Mercy Medical Angels</u> – Provides help with travel for specialized medical evaluation, diagnosis, or treatment. Call 888-675-1405 for help arranging transportation.

<u>Miracle Flights</u> – Provides free domestic or international travel to U.S. facilities for medical treatment, second opinions, and follow-up for patients in need. Call 800-359-1711 to find out if you qualify for assistance.

### Organizations for specific groups:

<u>Children's Flight of Hope</u> – Provides free air transportation to and from medical facilities in the eastern United States for seriously ill and injured children. To request a flight, <u>submit an online flight request</u> or call 919-466-8593 for assistance.

<u>Corporate Angel Network</u> – Arranges free travel on corporate jets for cancer patients, bone marrow donors, and bone marrow recipients. Call 914-328-1313 within three weeks of your appointment at a cancer treatment center.

## What organizations can help with the cost of lodging?

The following organizations can help you find a free or discounted place to stay when you travel for medical care in the United States. We also suggest that you contact your medical center to ask about local options for lodging assistance.

#### Nationwide:

<u>Healthcare Hospitality Network</u> – A nationwide professional association of nearly 200 nonprofit organizations that provide lodging and support services to patients, families, and their loved ones who are receiving medical treatment far from home. To find lodging in a specific area, use their online search form or call 800-542-9730.

<u>Joe's House</u> – A nonprofit organization providing cancer patients and their families an online list of nationwide discounted lodging near hospitals and treatment centers. To find lodging, call 877-563-7468 or <u>use their online directory</u>

Ronald McDonald House Charities – Provides families with housing and home-cooked meals, at little or no cost, close to their hospitalized child. To request a stay, contact the social services department at the hospital where your child will receive treatment.

## Museums

This article provides links to museum and arts programs that accommodate children with special needs.

#### Resources

National Endowment for the Arts: Visiting Museums with Children with Special Needs

Access Smithsonian

## Sibling support

What this article is about: This article provides links to resources on sibling support where you can find more information and support.

#### Resources

### <u>Sibshops</u>

Lucy Bennett. Sibshops: Workshops for Siblings of Children with Special Needs

Charlie's Teacher by Danielle Boyce

Complex Child Magazine: When the Special Needs Siblings Don't Play Nice

# **Disability Publications**

What this article is about: This article provides links to publications about children with special needs and disability.

### **Ability Magazine**

Focuses on health, disability and human potential and provides new insights on individuals levels of ability.

## **Exceptional Parent**

An online magazine for parents of children and young adults with disabilities, includes news forum, links, and online bookstore.

## **New Mobility**

An online magazine for users of wheelchairs. Includes calendar of events and news forums.

## **Journal of Developmental Medicine and Child Neurology**

The official journal of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) and the British Paediatric Neurology Association (BPNA). DMCN aims to enhance the care of children by worldwide dissemination of clinical research into the wide range of neurological conditions and disabilities that affect children to researchers, health professionals concerned with developmental disability and child neurology, and others involved in the care of children and young people.

### **Complex Child Magazine**

Complex Child is a monthly online magazine written by parents of children with special healthcare needs and disabilities. It is intended to provide medical information, along with personal experiences, in simple language that other parents can understand.

## Home modifications

What this article is about: This article provides a brief overview of home modifications and links to resources where you can find more information and support.

Home modifications are changes made to living spaces to adapt them for the needs of people with physical limitations. Home modifications may include making structural changes or adding assistive technology. Examples of modifications include something as small as replacing the knobs on cabinets with pull handles to large projects to widen doorways or installing ramps for wheelchairs.

Here is a list of our favorite resources for home modifications.

United Disabilities Services Foundation helps with all aspects of home modifications and other services for people with disabilities, http://www.udservices.org/services/home-modifications/

The PA Assistive Technology Foundation has a helpful page on home modifications:

https://patf.us/resource-category/home-modification/

Access Maine Home Modification Toolkit

http://www.accessmaine.org/Toolkits/HomeMod/homemod.htm

www.HomeMods.org

This web site is dedicated to promoting aging in place and independent living for persons of all ages and abilities. It offers training and education opportunities for professionals who wish to respond to the increasing demand for home modification services. It also serves as an information clearinghouse on home modification to equip professionals and consumers with a comprehensive inventory of resources such as a National Directory of Home Modification and Repair Resources.

Consumer Affairs Stair Lift Resources

This page from Consumer Affairs contains information regarding stairlifts including brand comparisons, stair lift features, and expert stair lift reviews. Additionally, it features an option which allows users to answer seven questions and get matched with a stair lift that meets their needs. Please be advised that you are required to enter your phone number and email address to get your results from the matching questionnaire.

https://www.consumeraffairs.com/homeowners/stairlifts/#

Information on building your own home wheelchair ramp including safety information and ramp specifications, manuals, and videos. http://www.klownwerkz.com/ramp/