

Children with Disabilities



Children who live with a disability have their own unique set of needs and goals. Providing children and their caregivers with materials that are child focused is a great way to connect them with helpful information on their level and gives them the support they need going forward. The websites and forums listed within this factsheet are a source of support and encouragement to children and their families as they go through treatment and recovery from a spinal cord injury or a paralysis-related condition. There are many organizations and specialized services for children ranging from hospital care, rehabilitation, and support of their caregivers and family members. Please also see our Pediatric Spinal Cord Injury fact sheet if you are specifically interested in that topic.

A Kid Again

<https://akidagain.org/>

777-G Dearborn Park Lane

Colombus, OH 43085

Phone: 614-797-9500

Email: customerservice@akidagain.org

This program offers free local events and activities for families with a child facing a life-threatening condition. These adventures are held at places like theme parks, sporting events, and museums with everything provided to ensure a stress-free retreat.

Ability Online

<http://www.abilityonline.org/>

12 Purple Rd.

Mono ON L9W 4G3 Canada

Phone: 416-650-6207

Email: information@abilityonline.org

An online community connecting kids with special needs for friendship and support.

BandAides & BlackBoards

<http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>

A website for kids and teens growing up with medical problems, as well as the adults in their lives.

Bethany Children's Health Center

<https://www.bethanychildrens.org/>

Donal W. Reynolds Complex

6800 NW 39th Expy

Bethany, OK 73008

Phone: 405-789-6711

Specialty Services: 405-440-9866

Email: info@bethanychildrens.org

This hospital is a leader in pediatric rehabilitation and 24-hour complex care. The health center offers inpatient and outpatient services for children. Along with this they have an adapted recreation and a fine arts complex, that is used to prepare patients for community re-entry after an accident or change in independence.

Can Do!

<http://www.ucando.org/>

The Can Do! website offers stories, activities, and resources to help people of all abilities overcome their challenges through a "can-do" attitude.

Offers stories, activities, and resources to help create a better understanding and deeper appreciation of how people can overcome their challenges and reach their dreams by using their abilities and a "can-do" attitude

Child Neurology Foundation

<http://www.childneurologyfoundation.org/>

8721 Colerain Ave.

P.O. Box 531001

Cincinnati, OH 45253

Phone: 888-417-3435

Email: programs@childneurologyfoundation.org

While the Child Neurology Society is the professional organization for the nation's pediatric neurologists, the Child Neurology Foundation serves pediatric patients through advocacy, education, research, and support initiatives.

Children's Hemiplegia and Stroke Association (CHASA)

<http://www.chasa.org/>

4101 W. Green Oaks, Suite 305-149

Allington, TX, 76016

CHASA offers information and support to families of infants, children, and young adults who have hemiplegia or hemiplegic cerebral palsy. The site includes the Hemi-Kids discussion group for families of children who have hemiplegia due to pediatric stroke or other causes.

Children's Hospital Association

www.childrenshospitals.org

CHA offers a directory of children's hospitals that are members of this organization. CHA also offers information on issues of importance to children's health with a focus on public policy and public health.

Christopher & Dana Reeve Foundation booklet:

<https://www.ChristopherReeve.org/booklets>

See What We Can Do, See Where We Can Go!

A book for **preschool age children** living with spinal cord injury or who have a family member living with SCI. The book was created in conjunction with staff from Kennedy Krieger Institute, a pediatric spinal cord injury rehabilitation center. The book is free, please call the Reeve Information Specialists at 800-539-7309 for a print copy.

Christopher & Dana Reeve Foundation booklet:

<https://www.ChristopherReeve.org/booklets>

Living with Spinal Cord Injury: Some Walk, I Roll. Let's Learn Why

A book for **grade school age children** living with spinal cord injury or who have a family member living with SCI. The book was created in conjunction with staff from Kennedy Krieger Institute, a pediatric spinal cord injury rehabilitation center. The book is free, please call the Reeve Information Specialists at 800-539-7309 for a print copy.

Council of Parent Attorneys and Advocates (COPAA)

<https://www.copaa.org/>

PO Box 6767

Towson, Maryland 21285

COPAA advocates for educational services for children with disabilities.

Data Resource Center for Child & Adolescent Health

<http://www.childhealthdata.org/>

Email: info@cahmi.org

The mission of the Data Resource Center (DRC) is to take the voices of parents, gathered through the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN), and share the results through a free online resource.

Enabling Devices

<http://www.enablingdevices.com/>

Phone: 866-794-0650

Catalog of products for people with disabilities, including toys and other products for children.

Exceptional Parent (EP)

<https://www.epmagazine.com/>

Phone: 201-515-6130

EP provides information and advice to families of children with disabilities and special needs through their website and online magazine.

Family Voices

<http://www.familyvoices.org>

561 Virginia Rd., Bldg 4, Suite 300

Concord, MA 01742

Phone: 781-674-7224, 888-835-5669 (Toll-free)

Family Voices' national network advocates for family-centered health care and provides information for families with children and youth with special health care needs. They offer a youth as self-advocates program.

Keep S'myelin: A Fun Resource for Kids about MS

<http://www.nationalmssociety.org/Resources-Support/Library-Education-Programs/For-Kids-Keep-S-myelin>

The National Multiple Sclerosis Society's website and newsletter teach kids about MS.

Kids' Waivers

<http://www.kidswaivers.org/>

Kids' Waivers is your site for Medicaid waivers, Katie Beckett or TEFRA programs, and other programs for children with disabilities or medical needs.

Magic Wheelchair

<http://www.magicwheelchair.org/>

A non-profit organization that creates Halloween costumes for children who use wheelchairs. Applicants must create a short video to submit and 5 children are chosen. Volunteer artists create a custom-fit costume for the child's specific wheelchair. There is no cost to the family.

National Resource Center for Patient/Family Centered Medical Home

<https://www.aap.org/en/practice-management/medical-home>

c/o American Academy of Pediatrics

345 Park Blvd.
Itasca, IL 60413
Phone: 630-626-6605
Toll free: 800-433-9016

The National Resource Center for Patient/Family Medical Home is a cooperative agreement between the Maternal and Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP) with a mission to ensure that every child and youth has access to a medical home. Their web site is funded by the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA). The NRCPFMH works to ensure that all children, including those with special needs, have access to a medical home. The organization provides medical home resources and advocacy materials, technical assistance, and tools to physicians, families, and other medical and non-medical providers who care for children.

<http://faculty.washington.edu/chudler/neurok.html>

Neuroscience for Kids

<http://www.php.com>

Parents Helping Parents (PHP)

Sobrato Center for Nonprofits-San Jose
1400 Parkmoor Avenue, Suite 100
San Jose, CA 95126
Phone: 408-727-5775, 855-727-5775 (Toll Free in CA)
Email: info@php.com

Formed to make sure children of all ages and backgrounds receive the resources, healthcare, education, and other services they need to reach their full potential, PHP offers information, training, and support to families, professionals and the communities in which they live.

<http://www.shrinershospitalsforchildren.org/>

Shriners Hospitals for Children

Shriners Hospitals offer care to children with neuromusculoskeletal conditions, burn injuries and other special healthcare needs at 22 locations in the United States, Canada and Mexico. Three locations (Chicago, Philadelphia, and Sacramento) are dedicated to spinal cord injury. Care is provided regardless of ability to pay.

<https://www.ssa.gov/pubs/EN-05-10026.pdf>

Social Security Administration: Benefits for Children with Disabilities

A publication from the Social Security Administration on federal benefits for children with disabilities or adults disabled since childhood. The booklet can be read online or downloaded as a PDF.

www.WalkinRollin.org

Walkin' & Rollin' Costumes

Email: info@walkinrollin.org

A non-profit organization that makes unique costumes for special needs kids, often incorporating a wheelchair as part of the costume. The costume is made free of charge to the families.

<http://www.kipsboat.org/index.html>

WAVES (Wheelchairs and Veterans Enjoying Summer, Inc.)

754 Shore Walk

Lindenhurst, NY 11757

Phone: 631-957-1838

Reservations: 631-495-6105

Email: kipsboat@msn.com

WAVES offers free fishing and boating to physically and mentally challenged children and adults. They operate in Long Island, NY from May to November and in Stuart, FL from November to May.

Wheelchairs 4 Kids

www.wheelchairs4kids.org

1200 S. Pinellas Ave., Suite 3

Tarpon Springs, FL 34689

Phone: 727-946-0963

Email: info@wheelchairs4kids.org

Wheelchairs4Kids is a non-profit that assists children in getting wheelchairs, home modifications, assistive devices, and vehicle modifications at no charge to them.

Videos

Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities. Woodland Park, CO: BraveHeart Press, 2001. DVD or VHS (7 minutes)

How Come You Walk Funny? Boston, MA: Fanlight Productions, 2004. (47 minutes)

A Toronto school features a kindergarten class where half the children use wheelchairs, walkers or crutches. Parents of non-disabled children have chosen to enroll their kids in the class.

In Harm's Way: Traumatic Brain Injury in Young Children. Brain injury awareness for Head Start Providers. Albuquerque, NM: New Mexico Aging & Long-Term Services, 2009. DVD (39 minutes)

Recognizing Strokes in Children: A Keeping Kids Healthy Program. Sherborn, Mass.: Aquarius Health Care Media, 2006. DVD (15 minutes)

Please note these materials are intended for adults unless otherwise noted. If you want materials written for children, please ask for our document called "Children's and Teen's Books and Videos about Disability". Please also see our "Pediatric Spinal Cord Injuries" fact sheet.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.

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