

Resources for Children With Cerebral Palsy and Their Families



Brought to you by:



**Cerebral
Palsy Guide**

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Resources for Children With Cerebral Palsy and Their Families

Everyone needs a little help from time to time, and this is especially true for parents or caregivers of children with cerebral palsy.

At Cerebral Palsy Guide, we primarily help families navigate the legal process. Our team will determine if you may be eligible to receive financial compensation to help cover the extra costs that come with raising a child with cerebral palsy.

Call today to find out how we can help (855) 257-2385.

In addition to legal guidance, our team cares about supporting your family. There are many organizations available to help in a variety of ways. To connect you easily with these resources, we have compiled this guide to help you get started.

Community Support Organizations

Parents often have a hard time coping with such a life-changing diagnosis like cerebral palsy.

Many families find that joining a support group can be incredibly beneficial. Organizations that offer emotional, medical, and financial support are great ways to help parents feel like they are not alone in this fight.

Support communities are a great place for new parents to get tips and advice from those who have already been through many of the early struggles of raising a child with cerebral palsy. By talking with people who have been in their shoes, parents and caregivers will come out feeling more prepared for their family's future.

Cerebral palsy support groups help to:

- Relieve stress and frustration
- Offer hope and an optimistic perspective
- Let families know that their struggles are not uncommon
- Find reassurance and understanding
- Provide a platform to share obstacles and achievements

Support Groups and Organizations

There are a number of support options available across the country. National organizations ensure that children and parents in any city have access to the resources they need. Local support groups have been established so that families can access the emotional and medical resources they need close to home.

The organizations listed below offer affiliate programs in most major cities in the United States. Simply visit their websites to find a list of nearby affiliate groups that provide an array of services for both children and adults with cerebral palsy.

CP Daily Living

cpdailyliving.com

Managed by a mother of a child with cerebral palsy and epilepsy, this site is designed to give families and caregivers dealing with cerebral palsy a central place for practical information and resources within the context of an emotionally supportive community.

CP Kids Coalition

reachingforthestars.org/cp-kids-coalition

This organization was founded by Reaching for the Stars (see below). The coalition is a group of young people who produce articles and engage in discussions about the issues surrounding transitioning into adulthood with cerebral palsy. This is a great place for young adults with cerebral palsy to meet other people they can relate to.

Cure CP

curecp.org

This organization was founded by two families that were directly affected by cerebral palsy. These parents created Cure CP to help fund and support research for cerebral palsy. Cure CP specifically supports research geared toward developing a cure and providing hope for the future.

Cerebral Palsy Foundation

yourcpf.org

This organization contributes millions of dollars each year to cerebral palsy research. This research involves studies and clinical trials and focuses on finding new treatments that increase mobility and improve the overall quality of life for people with cerebral palsy. The Cerebral Palsy Foundation also campaigns to increase the level of federal support for people with cerebral palsy. They are leaders in advocating for better educational programs for doctors, nurses, and therapists.

Cerebral Palsy Research Registry

cpr.northwestern.edu

Register your child into a secure database that is used to connect families with researchers studying cerebral palsy. A notification will be sent with studies that you qualify for, or you can opt to have researchers contact you directly. The choice to enroll in a particular study is entirely up to you and your family.

Easter Seals

easterseals.com

Easter Seals is a nonprofit organization that provides services for more than one million children and adults with autism and other disabilities, such as cerebral palsy. They provide support services for medical rehabilitation, residential services, job training, childcare, adult day programs, and camping/recreation.

Family Voices

familyvoices.org

Family Voices promotes quality health care for children and youth with disabilities. They work closely with government leaders and medical professionals to ensure that individuals with disabilities have their voices heard.

March of Dimes

marchofdimes.org

Their expansive support community provides a place to share stories through various online discussion boards and forums. They also have a large social network of parents who have experience raising a child with special needs. March of Dimes also connects their members with other parents located in the same part of the country. This is a great way to create a local support system that all parents can benefit from.

Parent to Parent USA

p2pusa.org

This non-profit organization provides emotional and informational support for families of children who have special needs. They match experienced, trained “Support Parents” with families in need. Their affiliate groups are typically started by parents of children with disabilities.

Reaching for The Stars

reachingforthestars.org

This advocacy group primarily strives to increase federal funding for cerebral palsy research. They focus on improving treatment methods used in children with cerebral palsy, and they work endlessly towards finding a cure.

The Arc

thearc.org

Founded in the 1950s by parents of children with an array of developmental disabilities, the Arc provides support for families and children with cerebral palsy across the nation. They offer more than 730 state and local chapters.

United Cerebral Palsy (UCP)

ucp.org

The mission of UCP is to educate, advocate, and provide support resources for individuals with disabilities. They aim to provide tools to be independent and lead a happy, healthy life. UCP also pushes for the social, legal, and technological changes that would make it easier for individuals with disabilities to achieve their dreams.

Local UCP affiliates include:

Alabama

UCP of East Central Alabama
ecaucp.org
415 Castle Avenue
Anniston, AL 36205
(256) 237-8203

UCP of Huntsville & Tennessee Valley
ucphuntsville.org
2075 Max Luther Dr. NW
Huntsville, AL 35810
(256) 852-5600

UCP of Mobile
ucpmobile.org
3058 Dauphin Sq. Connector
Mobile, AL 36607
(251) 479-4900

UCP of Northwest Alabama
ucpshoals.org
507 N Hook St.
Tuscumbia, AL 35674
(256) 381-4310

UCP of West Alabama
ucpwa.org
1100 UCP Pkwy.
Northport, AL 35476
(205) 345-3031

Arkansas

UCP of Arkansas
ucpark.org
9720 N Rodney Parham Rd.
Little Rock, AR 72227
(501) 224-6067

Arizona

UCP of Central Arizona
ucpofcentralaz.org
1802 W Parkside Lane
Phoenix, AZ 85027
(602) 943-5472

UCP of Southern Arizona
ucpsa.org
635 N Craycroft
Tucson, AZ 85711-1450
(520) 795-3108

California

UCP of Central California
ccucp.org
4224 N Cedar Ave.
Fresno, CA 93726
(559) 221-8272

UCP of the Golden Gate

ucpgg.org

1521 Webster St.
Oakland, CA 94612
(510) 832-7430

UCP of the Inland Empire

ucpie.org

70-017 Highway 111 Suite 5
Rancho Mirage, CA 92270
(760) 321-8184

UCP of Los Angeles, Ventura &
Santa Barbara Counties

ucpla.org

6430 Independence Ave.
Woodland Hills, CA 91367
(818) 782-2211

UCP of the North Bay

ucpnb.org

3835 Cypress Dr.
Petaluma, CA 94954
(707) 766-9990

UCP of Orange County

ucp-oc.org

980 Roosevelt Suite 100
Irvine, CA 92620
(949) 333-6400

UCP of Sacramento
and Northern California

ucpsacto.org

4350 Auburn Blvd.
Sacramento, CA 95841
(916) 565-7700

UCP of San Diego County

ucpsd.org

8525 Gibbs Dr. Suite 209
San Diego, CA 92123
(858) 571-7803

UCP of San Joaquin, Calaveras
& Amador Counties

ucpsj.org

333 W Benjamin Holt Dr. Suite 1
Stockton, CA 95207
(209) 956-0290

UCP of San Luis Obispo

ucp-slo.org

3620 Sacramento Dr. Suite 201
San Luis Obispo, CA 93401
(805) 543-2039

UCP of Stanislaus and
Tuolumne Counties

ucpstan.org

4265 Spyres Way Suite 2
Modesto, CA 95356
(209) 577-2122

UCP WORK, Inc.

ucpworkinc.org

5464 Carpinteria Ave. Suite B
Carpinteria, CA 93013
(805) 566-9000

Connecticut

UCP of Eastern Connecticut

ucpect.org

42 Norwich Rd.
Quaker Hill, CT 06375
(860) 443-3800

UCP of Greater Hartford

ucphartford.org

80 Whitney St.
Hartford, CT 06105
(860) 236-6201

District of Columbia

UCP National Office

ucp.org

1825 K. St. NW Ste. 600
Washington, DC 20006-1202
(202) 973-7000

UCP of Washington DC &
Northern Virginia

ucpdc.org

1110 U Street SE
Washington, DC 20020
(202) 269-1500

Delaware

UCP of Delaware

ucpde.org

700A River Rd.
Wilmington, DE 19809
(302) 764-2400

Florida

UCP of Central Florida

ucpcf.org

4780 Data Court
Orlando, FL 32817
(407) 852-3300

United Community Options
of South Florida

unitedcommunityoptionssfl.org

2700 W 81 St.
Hialeah, FL 33016
(305) 325-1080 x1277

UCP of Southwest Florida

ucpswfl.org

2203 30th Ave. W
Bradenton, FL 34205
(941) 251-4956

Georgia

UCP of Georgia

ucpga.org

3300 NE Expressway Building 9
Atlanta, GA 30341
(770) 676-2000

Hawaii

UCP of Hawaii

ucpahi.org

414 Kuwili St. Suite 104
Honolulu, HI 96817
(808) 532-6744

Illinois

UCP Land of Lincoln

ucpll.org

101 N 16th St.
Springfield, IL 62703
(217) 525-6522

UCP Seguin of Greater Chicago

ucpseguin.org

3100 South Central Avenue
Chicago, IL 60804
(312) 765-0419

Indiana

UCP of Greater Indiana

ucpaindy.org

6270 Corporate Dr.
Indianapolis, IN 46278
(317) 871-4032

Kansas

UCP of Kansas
ucpks.org
5111 E 21 St. N
Wichita, KS 67208
(316) 688-1888

Louisiana

UCP of Baton Rouge
mcmainscdc.org
1805 College Drive
Baton Rouge, LA 70808
(225) 923-3420

UCP of Greater New Orleans
ucpgno.org
2200 Veterans Memorial Blvd.
Suite 103
Kenner, LA 70062
(504) 461-4266

Maine

UCP of Maine
ucpofmaine.org
700 Mt. Hope Ave. Suite 320
Bangor, ME 04401
(207) 941-2952

Massachusetts

UCP of MetroBoston
ucpboston.org
71 Arsenal St.
Watertown, MA 02472
(617) 926-5480

UCP of Western Massachusetts
ucpberkshire.org
208 W St.
Pittsfield, MA 01201
(413) 442-1562

Michigan

UCP of Metropolitan Detroit
ucpdetroit.org
23077 Greenfield Rd. Suite 205
Southfield, MI 48075
(248) 557-5070

UCP of Michigan
ucpmichigan.org
1325 S. Washington Ave.
Lansing, MI 48910
(517) 203-1200

Minnesota

UCP of Central Minnesota
ucpcentralmn.org
24707 County Rd. 75
Saint Augusta, MN 56301
(320) 253-0765

UCP of Minnesota
ucpmn.org
200 University Ave. E
St Paul, MN 55101
(651) 265-7361

Missouri

UCP Heartland
ucpheartland.org
13975 Manchester Rd.
Manchester, MO 63011
(636) 227-6030

UCP of Northwest Missouri
ucpnwmo.org
3303 Frederick Ave.
St. Joseph, MO 64506
(816) 364-3836

Nebraska

UCP of Nebraska
ucpnebraska.org
920 S 107th Ave Suite 302
Omaha, NE 68114
(402) 502-3572

Nevada

UCP of Nevada
ucpnv.org
740 Freeport Blvd. Ste. 101
Sparks, NV 89431
(775) 322-6555

New Jersey

UCP of Hudson County
ucpofhudsoncounty.org
721 Broadway
Bayonne, NJ 07002
(201) 436-2200

New York

ADAPT Community Network
adaptcommunitynetwork.org
80 Maiden Lane, 8th Floor
New York, NY 10038
(212) 683-6700

UCPA of Long Island
ucp-li.org
250 Marcus Blvd.
Hauppauge, NY 11718
(631) 232-0011

North Carolina

Easter Seals UCP North
Carolina & Virginia
nc.eastersealsucp.com
5171 Glenwood Ave. Suite 211
Raleigh, NC 27612
(919) 783-8898

Ohio

Stepping Stones/UCP of Greater
Cincinnati
steppingstonesohio.org
2300 Drex Ave
Norwood, OH 45212
(513) 831-4660

UCP of Greater Cleveland
ucpcleveland.org
10011 Euclid Avenue
Cleveland, OH 44106
(216) 791-8363

Oklahoma

Ability Connection Oklahoma
acok.org
10400 Greenbriar Place Suite 101
Oklahoma City, OK 73159
(405) 759-3562

Oregon

UCP Oregon
ucpaorwa.org
305 NE 102nd Ave. Suite 100
Portland, OR 97220
(503) 777-4166

Pennsylvania

Alleghenies United Cerebral Palsy
alucp.org
119 Jari Drive
Johnstown, PA 15904
(814) 619-3398

UCP of Central Pennsylvania
ucpcentralpa.org
55 Utley Drive
Camp Hill, PA 17011
(717) 737-3477

UCP of Northeastern Pennsylvania
ucpnepa.org
425 Wyoming Avenue
Scranton, PA 18503
(570) 347-3357

UCP of South Central Pennsylvania
ucpsouthcentral.org
788 Cherry Tree Ct.
Hanover, PA 17731
(717) 632-5552

Rhode Island
UCP of Rhode Island
ucpri.org
200 Main St. Suite 210
Pawtucket, RI 02860
(401) 728-1800

South Carolina
UCP of South Carolina
ucpsc.org
1101 Harbor Dr.
West Columbia, SC 29169
(803) 926-8878

Tennessee
UCP of Middle Tennessee
ucpmidtn.org
1200 9th Ave. N Suite 110
Nashville, TN 37208
(615) 242-4091

Wisconsin
UCP of Greater Dane County
ucpdane.org
2801 Coho St. Suite 100
Madison, WI 53713
(608) 273-4434

UCP of West Central Wisconsin
ucpwcw.org
2153 EastRidge Center
Eau Claire, WI 54701
(715) 832-1782

Online Support Groups

Special Needs Moms for Moms

specialneedsmomsformoms.com

This online community provides a vast social network for parents and families of children with special needs. Members are able to share information through an online forum. Parents in this group can offer support, organize local meetups, and provide inspiration for other families.

Mommies of Miracles

mommiesofmiracles.com

This is the world's largest online support organization for mothers of children with disabilities. Mommies of Miracles provides a network of resources, products, and services that help inspire and educate mothers. They match families to create a local support system.

Special Education

By law, schools must provide special help to eligible children with disabilities. If your child is eligible to receive special education services, a team of school professionals will meet with you to write an individualized education program (IEP) for your child.

Individuals with Disabilities Education Act (IDEA) Services

sites.ed.gov/idea

Early intervention and school-aged services are available through the Individuals with Disabilities Education Act (IDEA).

Part C of IDEA covers early intervention services (birth through 36 months). Part B applies to services for school-aged children (3 through 21 years old).

Part C of IDEA: Early Intervention for Babies and Toddlers

Early intervention services can help children from birth through 36 months of age learn new skills, whether they have been identified recently with motor and movement delays or already have a cerebral palsy diagnosis. Early intervention services can start even before a diagnosis is made.

The first step is to have an Individual Family Service Plan (IFSP) developed by a team. This includes both parent and provider input. The IFSP describes the child's current level of development, family needs, specific services to be provided to the child and the family, and a plan to transition to public school.

Early intervention services may include:

- Family training
- Counseling
- Home visits
- Occupational, physical, or speech therapy
- Hearing loss services
- Health and nutrition
- Social work
- Assistance with service coordination
- Assistive technology devices and services
- Transportation

Part B of IDEA: Services for School-Aged Children

Free services for school-aged children with developmental disabilities are provided through the public school system.

Before Part B services start, an Individualized Education Plan (IEP) is developed for children 3 through 21 years of age who qualify for special education services from school districts. An IEP is similar to an IFSP, but it is more focused on the child's goals rather than the family's goals.

Services covered under IDEA are:

- Special education
- Physical, occupational, and speech therapy
- Supplementary aids and services
- Adaptive equipment
- Special communication systems

Center for Parent Information & Resources

parentcenterhub.org

This organization supports national Parents Centers who serve families of children with disabilities. You can locate a center near you on their site. The site also explains the IEP process in detail and offers information and materials for families about special education services.

Adaptive Clothing

There are lines of adaptive clothing specially-designed to fit wheelchairs, G/J tubes, diapers, and more. This can make a caregiver's life much easier and allow your child to be more comfortable. Some companies carry bodysuits in larger kid sizes, to keep hands away from medical equipment.

Koolway Sports

koolwaysports.com

Koolway Sports makes custom-made outerwear to fit a child's body frame and wheelchair configurations. Options include half-backs, full zippered sleeves, zippered hoods, hidden G/J tubes, and shoulder harness openings.

Ross Daniel Adaptive Apparel

rdadaptiveapparel.com

This company carries fashionable and comfortable adaptive socks and shirts to accommodate children who wear leg braces or ankle-foot orthotics.

Cat & Jack

target.com/c/kids-adaptive-clothing/-/N-11aue

Available through Target, this adaptive clothing comes with design features such as no-tag sensory-friendly, hidden opening for abdominal access, high-rise bottoms for diaper coverage, and more.

Shoes for AFOS

shoesforafos.com

Shoes for AFOS offers custom made shoes and boots to accommodate orthotics such as AFO, KAFO, DAFO, and SMO braces.

Playgroups

Playgroups for children with physical and cognitive disabilities are a great option for children with cerebral palsy. Playgroups meet during various times throughout the year and are available in most major U.S. cities. Under specialized care, children with cerebral palsy can grow emotionally, mentally, and physically from friendships and independence.

Summer Camps

Summer camps help to ensure that children with cerebral palsy are learning valuable social skills and independence.

Camps for children with cerebral palsy are equipped with accessible facilities and experienced staff. Children in camps participate in a number of activities, including swimming, hiking, fishing, crafts, sports, and campfires. By taking the focus off of their disability, children with cerebral palsy can form meaningful friendships and memories.

Some summer camps offer inclusive programs and activities to bring all kids together. This way, everyone can enjoy activities equally, and nobody is left out of all the fun. Other camps are dedicated exclusively for individuals with one or more of a wide range of special needs.

Very Special Camps

veryspecialcamps.com/summer/cerebral-palsy-camps

Locate a summer camp or program based upon your child's requirements and criteria in this directory of camps.

Medical Treatment

Treatment for cerebral palsy is multifaceted, often requiring multiple doctors and therapies. Early treatment usually has the greatest chance of improving a child's condition. The purpose of treatment for cerebral palsy is to promote the most normal, manageable, and healthy life possible.

American Academy for Cerebral Palsy and Developmental Medicine (AAPDM)

aacpdm.org/providers

The Academy is comprised of over 1,100 health professionals dedicated to education, research, and services for the benefit of people with cerebral palsy. Locate an AAPDM member by location, specialty, and/or patient type.

Financial Resources

The cost of caring for a child with cerebral palsy over a lifetime is around \$1 Million, in addition to normal living expenses. This can be an overwhelming figure for families.

By finding a financial support organization that works with their child's individual needs, parents can feel more secure about their family's future.

There are also government benefits available that can offset the costs of cerebral palsy treatment. By finding ways to manage the expenses associated with cerebral palsy, parents can ensure their child receives the therapy, medications, surgeries, and treatment they need to live a full life.

Children's Hemiplegia and Stroke Association (CHASA)

chasa.org

CHASA provides financial assistance and scholarships to families in need. It is dedicated to helping parents of children with cerebral palsy by creating a network to share information about treatment clinics and educational programs.

UnitedHealthcare Children's Foundation (UHCCF)

uhccf.org

UHCCF provides families affected by cerebral palsy with the opportunity to receive access to health-related services that are not covered by their family's commercial health insurance plan. This group provides grants of up to \$5,000 annually per child, even to families without a UnitedHealthcare insurance plan.

MORGAN Project

themorganproject.org

The MORGAN Project is a non-profit organization established by Robert and Kristen Malfara in honor of their son Morgan, who suffers from a rare form of leukodystrophy. Their mission is to raise awareness, offer support for parents of children with special health care needs, and provide guidance, resources, and gently-used disability equipment.

Government Benefits

There are five federally funded programs that offer additional income and insurance for those with cerebral palsy.

These programs include:

1. Supplemental Security Income (SSI)
2. Social Security Disability Insurance (SSDI)
3. Medicaid
4. Individuals with Disabilities Education Act (IDEA)
5. Children's Health Insurance Program (CHIP)

While this funding originates within the national government, benefits are accessible through your state or city government. This makes it easier for parents to apply for and receive the help they need without having to endure a lengthy process of evaluation.

Local government agencies are responsible for dispersing the funds allotted to their citizens with disabilities. To apply for these government benefits or insurance plans, parents should seek out any necessary applications and forms through their local council.

Supplemental Security Income (SSI) Benefits

ssa.gov/benefits/ssi

SSI is a monthly income for children and adults with serious disabilities, such as cerebral palsy. SSI is reserved for low-income families.

Social Security Disability Insurance (SSDI) Benefits

ssa.gov/disability

SSDI provides monthly income for adults that are unable to work due to their disability. SSDI does not require the applicant to have a certain income amount to receive benefits.

Medicaid Benefits

medicaid.gov

Medicaid is a federal health insurance program set up for families with limited income. Many families affected by cerebral palsy use Medicaid to help pay for medical expenses, housing, and assistive devices.

Individuals with Disabilities Education Act (IDEA) Benefits

sites.ed.gov/idea

IDEA is a federal law that requires schools to serve the educational needs of students with special needs. Children with cerebral palsy are generally eligible for special education and treatment services provided by IDEA.

This program offers services for individuals up to 21 years old. Also, children who are showing signs of cerebral palsy but haven't been officially diagnosed may still qualify for special education services. IDEA is meant to foster an environment that is more conducive to learning by providing access to an array of accommodation services.

Children's Health Insurance Program (CHIP) Benefits

healthcare.gov/medicaid-chip/childrens-health-insurance-program

CHIP provides low-cost health care coverage to families that exceed the income requirement for Medicaid through both Medicaid and separate CHIP programs. CHIP coverage is offered in every U.S. state, and the costs associated with CHIP coverage differ for each family. However, this health insurance option ensures that you won't have to pay more than 5% of your family's income for the year.

Legal Resources

Cerebral palsy can impact a child throughout their entire life. Oftentimes, children require therapies, surgeries, assistive devices, home modification, and more. Adults with cerebral palsy are likely to face many obstacles as they continue to manage their symptoms in adulthood.

If you have any reason to believe that your child's condition is the result of medical malpractice, begin the lawsuit process as soon as possible, as legal deadlines vary by state.

Your family may be entitled to receive valuable financial compensation that can be put towards alleviating the overwhelming cost of cerebral palsy treatment.

Contact the team at Cerebral Palsy Guide at (855) 257-2385 for a [free legal case review](#). They will be able to help determine if you are eligible for financial compensation and guide you through the legal process.

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