

PHACE Syndrome Family Conference June 2018

Family Resource Sheet

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This is a list of agencies and organizations that you might find helpful. You may want to contact these agencies to ask about the specific services that they provide and how you can benefit from them.

AGENCY NAME & ADDRESS	AGENCY DESCRIPTION
Blaze Sports America www.blazesports.org	Agency that organizes sports programs for children and adults with physical disabilities. They also have summer camp programs available to youth.
Children's Heart Society Box 52088 Garneau Postal Outlet Alberta, T6G 2T5 Canada Phone: (780) 454-7665 Toll-free: (888) 247-9404 Email: contact@childrensheart.org Website: http://www.childrensheart.org	The Children's Heart Society is a non-profit, charitable organization committed to providing support, education, research and awareness for those children affected with congenital and acquired heart disease.
Children's Medical Services Division of Public Health Check your state services	This agency can assist in the cost of medical treatment and equipment once a family has met income criteria and the patient is medically eligible.
Family Voices P.O. Box 37188 Albuquerque, NM 87176 (505) 872-4774 or (888) 835-5669 Fax: (505) 872-4780	A national organization/network of families and friends of children and youth with special health care needs and disabilities that promotes partnership with families, in order to improve healthcare services and policies for children.
First Call for Help-United Way Call 2-1-1 www.unitedway.org	Free telephone help line available 24 hours a day, 7 days per week. Trained staff members help callers locate social services in their community. Spanish speaking staff available.
FOCUS-Families of Children Under Stress PO Box 941445 Atlanta, GA 31141 (770) 234-9111	This is a support group for parents of chronically ill or terminally ill children. They provide a newsletter, hotline number, monthly support meetings, annual conferences, and family get-togethers.
Friends of Disabled Adults and Children 4600 Lewis Road Stone Mountain, Georgia 30083 770-491-9014 www.foda.com	This agency provides services and referrals for families who have children with disabilities. Some services they offer include providing/assisting with mobility and medical equipment and other referrals.
The Georgia Advocacy Office 999 Peachtree Street, NW Suite 870 Atlanta, GA 30309 (404) 885-1234 1-800-537-2329 ul451.gsu.edu\gao	Protects and advocates for people in Georgia with developmental and other disabilities and persons with mental illness. Staff members provide information, training, referrals, direct representation, and legal advocacy. They help families having difficulty with the public school system.

AGENCY NAME & ADDRESS	AGENCY DESCRIPTION
Georgia Learning Resources System (GLRS) 1-800-282-7552 www.glrs.org www.boe.k12.ga.us	This is a parent and teacher support system for all persons who work with disabled children. They provide a library of resources, in-service training, and can work within the school system as needed. Great camp list.
Georgia Division of Rehabilitation Services Two Peachtree Street, NW Atlanta, GA 30303 (404) 657-3000 www.doas.state.ga.us/departments/dhr/rehab.html	Administrative offices for rehabilitation services for Georgia. Provides assessment, education, vocational training, and job placement for the disabled.
Georgia Division of Rehabilitation Services Tools for Life Two Peachtree Street, Suite 35.415 Atlanta, GA 30303 (404) 657-3084 www.gatfl.org	Provides information and referrals, assistive technology assistance, and location of resources to pay for devices.
Learning Disabilities Association of GA PO Box 1337 Roswell, GA 30077 (770) 514-8088	This agency provides information, referral, support groups, and advocacy to parents whose children have been diagnosed with learning disabilities.
Lekotek of Georgia 1955 Cliff Valley Way, Ste 102 Atlanta, GA 30329 404-633-3430 www.lekotekga.org	This agency offers support to families through family workshops, fun activities and play groups for children. They have a computer lending system and much more.
Little Hearts, Inc. P.O. Box 171 110 Court Street, Suite 3A Cromwell, CT 6416 USA Phone: (860) 635-0006 Toll-free: (866) 435-4673 Email: info@littlehearts.org Website: http://www.littlehearts.org	A national organization providing support, education, resources, networking, and hope to families affected by congenital heart defects. Membership consists of families nationwide who have or are expecting a child with a congenital heart defect.
NIH/National Institute of Child Health and Human Development 31 Center Dr Building 31, Room 2A32 Bethesda, MD 20892 Toll-free: (800) 370-2943 Email: NICHDInformationResourceCenter@mail.nih.gov Website: http://www.nichd.nih.gov/	Research conducted and funded by NICHD has helped save lives, improve wellbeing, and reduce societal costs associated with illness and disability. NICHD's mission is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes, and that all children have the chance to achieve their full potential for healthy and productive lives. The institute also aims to ensure the health, productivity, independence, and well-being of people through optimal rehabilitation.

AGENCY NAME & ADDRESS	AGENCY DESCRIPTION
National Organization of Vascular Anomalies PO Box 38216 Greensboro, NC 27438-8216 Email: khall@novanews.org http://www.novanews.org/information/phace-syndrome	Provides information and assistance in the management of hemangiomas and vascular malformations, including PHACE Syndrome.
Parent to Parent of America www.p2pusa.org	Provides emotional support and information for parents whose children experience disability or chronic illness. Parents are matched with other parents as closely as possible based on their child's diagnosis.
Parents Educating Parents 8318 Durelee Lane, Suite 101 Douglasville, GA 30134 (770) 577-7771 www.peppac.org	Provides parents of children with disabilities with information and training on laws that protect their children.
PHACE Syndrome Community 4514 Chamblee Dunwoody Rd., Suite 450 Atlanta, GA 30338 Telephone: 678-744-3971 E-mail: info@phacesyndromecommunity.org http://www.phacesyndromecommunity.org/	Organization providing support and resources for families who have children diagnosed with this syndrome. They also can connect families with specialists near them, raise awareness, conduct fundraisers and many other tasks benefitting the community of these families.
Ronald McDonald House Charities www.rmhc.org	Low-cost accommodations for family members during a patient's hospital stay. Subject to priority guidelines and availability. Call ahead for a reservation. You will want to have alternative plans for your accommodations in case the house is full.
Vascular Birthmarks Foundation P.O. Box 106 Latham, NY 12110 USA Toll-free: (877) 823-4646 Email: vbfpresident@gmail.com Website: http://www.birthmark.org	This foundation has networked hundreds of thousands of patients affected by a vascular birthmark into treatment. From Babies with Birthmarks to Global Ambassadors, the VBF has launched many successful programs for families and patients affected by a vascular birthmark or related syndrome.

Websites

Get in touch with the **Parent Training and Information (PTI) Center** that serves your area. Many States also have a **Community Parent Resource Center (CPRC)** that serves families of children with disabilities. To find the Parent Center nearest you, visit:

<http://www.parentcenterhub.org/find-your-center/>

www.anglephace.com – Personal journey site. This site is for friends, family and anyone else interested in how Arielle is facing PHACE Syndrome.

<http://www.cincinnatichildrens.org/health/p/phace> - Cincinnati Children's Hospital provides information and treatment to families who have children with PHACE Syndrome.

www.chw.org - Children's Hospital of Wisconsin houses the PHACE Syndrome registry research study and many of the lead investigators in PHACE research.

www.phacesfoundation.org - This Canadian charity organization is committed to advocating, educating and supporting PHACES Syndrome throughout Canada and internationally.

www.pedraresearch.org - The Pediatric Dermatology Research Alliance aims to form a solid foundation for pediatric dermatology research.

www.hemangiomaeducation.org - The Hemangioma Investigator Group is dedicated to advancing knowledge regarding infantile hemangiomas through collaboration, research and education.

www.choa.org – Children's Healthcare of Atlanta has a Vascular Malformations clinic offering medical treatment and support to families who have a child diagnosed with PHACE Syndrome.

Journal Articles via the internet (subscription may be required)

Siegel DH. PHACE syndrome. UpToDate, Inc. 2017 Jun 19 Available at: <https://www.uptodate.com/contents/phace-syndrome> Accessed February 28, 2018.

McKusick VA., ed. Online Mendelian Inheritance in Man (OMIM). Baltimore, MD: The Johns Hopkins University; Entry No:606519; Last Update:02/09/2015. Available at: <https://omim.org/entry/606519> Accessed February 28, 2018.

Alvarez H, Lasjaunias P. PHACE Syndrome. Orphanet Encyclopedia, March 2007. Available at: http://www.orpha.net/consor/cgi-bin/OC_Exp.php?lng=EN&Expert=42775 Accessed February 28, 2018. PDQ Pediatric Treatment Editorial Board. Childhood Vascular Tumors Treatment (PDQ®). PDQ Cancer Information Summaries [Internet]. <https://www.ncbi.nlm.nih.gov/books/NBK343452/> Updated January 26, 2018. Accessed February 28, 2018.