

Vascular Anomalies Clinic Patient Resources

Listed below are organizations and support groups that may be helpful to families and patients of the Vascular Anomalies Clinic:

AboutFace USA

A support group for people with facial differences. Includes information, peer networking, workshops, and educational support.

Phone 800-665-3223 ext. 21

Website: www.aboutface.ca

AVM Survivors

Online support group for patients and families that have had an Arteriovenous Malformation (AVM).

Website: www.avmsurvivors.org

Birth Defects Research for Children, Inc.

A 501(c) (3) non-profit organization that sponsors the National Birth Defect Registry and provides parents with information and support services for their children.

Website: <http://birthdefects.org>

CLOVES Syndrome Community

Supports, educates, empowers and improves the lives of those affected by CLOVES Syndrome.

Phone: 207-281-2130

Website: www.clovessyndrome.org

Exceptional Parent Magazine

A magazine for parents of children with special needs.

Website: www.eparent.com

Faces - The National Craniofacial Association

A non-profit organization serving patients with severe craniofacial deformities resulting from birth defects, injuries, or disease.

Phone: 800-3-FACES-3 (332-2373)

Website: www.faces-cranio.org

Project FAVA

Empowering the fibro adipose vascular anomaly (FAVA) community through outreach, education, and connection to researchers, medical organizations and to one another

Global Genes

Allies in rare disease. Library and online resources.

globalgenes@globalgenes.org

Hereditary Hemorrhagic Telangiectasia (HHT) Foundation

Cure HHT provides advocacy and support. Includes factual information, research updates, helpful links, and a newsletter.

Phone: 410.357.9932

Website: www.curehht.org

Infantile Hemangioma

A disease awareness web site created by Pierre Fabre Pharmaceuticals Inc.

Website: www.infantilehemangioma.com

Kennedy's Cause

Founded to raise awareness of Lymphatic Malformation, raise funds and support research for a cure.

Phone: 856-437-0605

Website: <http://kennedyscause.com/>

K-T Support Group

Klippel-Trenaunay syndrome and similar complex vascular malformations advocacy and support. Includes factual information, member resources, community forum and patient networking.

Phone: 513-722-7724

Website: <https://k-t.org>

Liam's Land for Lymphatic Malformation Research

Liam's Land's focus is research, a registry, funding genetic testing and clinical trials.

Website: www.liamsland.org

Lipedema Foundation

LF focuses on research for cause & effective treatment of lipedema.

Website: www.lipedema.org

Lymphangiomatosis & Gorham Disease Alliance (LGDA)

Promotes research that will identify effective treatments and ultimately a cure for these diseases. Provides support to patients and their families; education and hope to those affected by these rare lymphatic malformations. ****Website also has information on the International LGDA Registry for Lymphatic Malformations****

Phone: 844-588-5771

Website: www.lgdalliance.org

Lymphatic Education & Research Network (LE&RN)

LE&RN fosters and supports research re: understanding of the lymphatic system. Information on clinical trials & research updates.

Website: www.lymphaticnetwork.org

Lymphatic Malformation Institute

A 501(c)(3) nonprofit organization whose mission is to improve the clinical care of patients with generalized lymphatic anomaly (GLA)/lymphangiomatosis and Gorham-Stout disease by funding research focused on identifying effective therapies for treating these rare disorders of the lymphatic system.

Website: www.lmiresearch.org

Phone: 844-588-5771

M-CM Network

M-CM Network provides comprehensive medical information to aid in diagnosis and treatment decisions. Our goal is to establish a disease registry to collect data about affected individuals so that we can greatly expand the scope of what is known about M-CM

Website: www.m-cm.net

Phone: 518-392-2150

Medicaid - Transportation Assistance

Assistance available to patients who are enrolled in Medicaid coverage, including non-emergency medical transportation or

mileage reimbursement for outpatient appointments (local and long distance) as well as lodging and meal assistance if travelling from out of town for hospitalizations and out-patient visits.

National Lymphedema Network, Inc.

Advocacy and support for primary and secondary lymphedema. Includes factual information, physician and therapy centers, resources, and a newsletter.

Phone: 1-800-541-3259 or 510-208-3200

Website: lymphnet.org

National Organization for Rare Disorders (NORD)

An educational link for organizations and individuals concerned with a rare disorder. They monitor legislation, research diseases, award grants and network individuals.

Phone: 203.744.0100

Website: www.rarediseases.org

National Organization for Vascular Anomalies (NOVA)

Hemangioma and vascular malformation advocacy and support. Includes physician list, related support services, patient networking, blogs, and transportation services.

Website: www.novanews.org

NeedyMeds

Information on medicine and healthcare assistance programs.

Website: www.needymeds.org

Operation Respect

Includes information on the anti-bullying initiative, "Don't Laugh at Me," as well as professional development workshops and school assembly programs.

Phone: 212.904.5243

Website: www.operationrespect.org

Operation Smile

This is the website for Operation Smile a not-for profit international organization that treats facial deformities.

Phone: (Domestic Medical Program) 1-888-677-6453

Website: www.operationsmile.org

Parents Helping Parents

PHP increases the quality of life for children with special needs. Provides services and support for children, families, and caregivers.

Phone: 408-727-5775

Website: www.php.com

Pfizer RSVP

Reimbursement Solutions, Verification, and Payment HELPline. Program to help both insured and uninsured patients access Pfizer medicines (including Rapamune/Sirolimus).

Phone: 1-844-989-7284 - English/Spanish operator available

Monday – Friday 8:00 AM – 7:00 PM

Website: www.PfizerHelpfulAnswers.com

PHACE Syndrome Community

Support research and advocacy, networking among families, provide factual information and resources.

Phone: 678-744-3971

Website: www.phacesyndromecommunity.org

Proteus Syndrome Foundation

A 501c3 not-for-profit organization dedicated to improving the lives of Proteus patients by funding AKT1 research. We focus on providing family support in the form of education and networking individuals living with Proteus syndrome with other families and medical professionals. Phone: 901-756-9375

Website: www.proteus-syndrome.org

PTEN Hamartoma Tumor Syndrome Foundation

Education, financial assistance, research, awareness.

Website: www.ptenfoundation.org

Section 504

Section 504 of the Rehabilitation Act of 1973 ensures that individuals with disabilities are given protection from discrimination. Often at school, this means that a child in need of accommodations based on a disability that affects a 'major life activity' is allowed reasonable accommodations as determined by a 504 Committee. If you or your child needs accommodations under Section 504, or if you have questions, contact your social worker or your child's school.

Sturge-Weber Syndrome Community

Provides informational resources and support for families affected by SWS, which is typically a port wine stain birthmark that also has brain involvement. **Website:** <http://swscommunity.org/>

The Sturge-Weber Foundation

Support and information specific to Sturge-Weber syndrome, including Centers of Excellence, factual information and resources, and research updates. Information is available in English and Spanish

Phone: 973-895-4445

Website: www.sturge-weber.org

Supplemental Security Income (SSI)

The SSI program makes payments to those age 65 or older, blind, or disabled persons (including children) who have limited income and resources. Social Security has a strict definition of disability for children (condition must seriously limit his or her activities; and must have lasted, or be expected to last, at least 1 year or result in death).

Phone: 1-800-772-1213

Website: www.ssa.gov/disability

The United Healthcare Children's Foundation (UHCCF)

A 501(c)(3) charitable organization that provides medical grants to help children gain access to health-related services not covered, or not fully covered, by their parents' commercial health insurance plan. Families can receive up to \$5,000 annually per child (\$10,000 lifetime maximum per child). ****See your Social Worker for assistance with application****

Website: www.uhccf.org

Vascular Birthmarks Foundation

An international charitable organization that connects families affected by a vascular birthmark, tumor, or syndrome with the appropriate medical professionals. Provides information to families, sponsors physician education programs, mobilizes medical missions trips, and supports research and initiatives that promote acceptance for individuals with birthmarks.

Phone: 877-VBF-4646

Website: www.birthmark.org