

# **FACES:** The National Craniofacial Association 800-332-2373

## What is a Vascular Birthmark?

Very often, different doctors will use different terms to describe the same lesion. Advances are rapidly taking place in this field of study, so be sure you and your healthcare provider study the most recent materials. The correct treatment requires the correct diagnosis. Generally, **Vascular Birthmarks** are divided into two categories: **Hemangiomas** and **Vascular Malformations**.

## What are Hemangiomas?

**Hemangiomas** are benign (non-cancerous) tumors that may or may not be apparent at birth, but always become visible within one to four weeks after birth. They usually occur on the head or neck, but they can occur anywhere, including the internal organs. The **hemangioma** will grow and change for the first 12 months of life and then “involute” or regress. The involution can last from three to 10 years.

## What are Vascular Malformations?

**Vascular Malformations** are benign (non-cancerous) lesions that are present at birth, but which may not be visible for weeks or months after birth. Unlike Hemangiomas, Vascular Malformations do not have a growth cycle and then regress -- they continue to slowly grow throughout life. There are five types:

- **Port Wine Stains:** Always present at birth and thought to be associated with a deficiency in the nerve supply to the blood vessels.
- **Venous:** Often confused with a Hemangioma, these malformations will always grow, are soft to the touch, and the color disappears when compressed. Most commonly found on the jaw, cheek, tongue, and lips.
- **Lymphatic:** Formed when excess fluid accumulates within the lymphatic vessels.
- **Arteriovenous:** Caused when an abnormal amount of blood goes into the capillary beds and engorges the vessels.
- **Mixed:** A combination of any of the other four types.

## Why did this happen?

Vascular Birthmarks are not the result of anything the mother did or did not do during pregnancy. The causes are currently being studied and there appears to be an inherited cause, but a proven genetic link has not been found.

## Will my child need surgery?

Depending on the type of Vascular Birthmark, surgery may be recommended; however, the importance of obtaining a correct diagnosis is extremely important and often difficult. Before any surgery or treatment begins, be sure that your surgeon is extremely experienced in treating Vascular Birthmarks, that you have been given treatment options that you ask how many such treatments the doctor has performed, that you ask to see before and after pictures of similar cases, and that you ask to contact one or two of these families. Treatment options can include:

- Steroid Treatment: Ask about medication that can be given for stomach upset which often accompanies this treatment.
- Laser surgery
- Surgical removal of the lesion
- Combinations of the above

**New advances and procedures concerning Vascular Birthmarks are constantly being developed. Be an advocate for your child!**

## How do I get help for my child?

Your child should be treated by a qualified craniofacial medical team at a craniofacial center. Currently, FACES has information on many of these teams. This is by no means a comprehensive list of all the craniofacial teams. Please contact FACES for details.

## Am I alone?

No! There are many families and organizations that will be glad to talk with you and help you with information and support. Don't forget books, videos, and web sites. The following listings will get you started.

FACES: The National Craniofacial Association  
P. O. Box 11082  
Chattanooga, TN 37401  
(800) 332-2373

Email: [faces@faces-cranio.org](mailto:faces@faces-cranio.org)

Website: [www.faces-cranio.org](http://www.faces-cranio.org)

*We provide financial support for non-medical expenses to patients traveling to a craniofacial center for treatment. Eligibility is based on financial and medical need. Resources include newsletters, information about craniofacial conditions, and networking opportunities.*

The Vascular Birthmarks Foundation

P. O. Box 106

Latham, NY 12110

(877) VBF-LOOK; (877) 823-5665

Email: [hvbf@aol.com](mailto:hvbf@aol.com)

Website: [www.birthmark.org](http://www.birthmark.org)

*This network is dedicated to providing information to families, physicians, health care providers, and the insurance industry regarding the diagnosis and treatment of Vascular Birthmarks. They refer patients for treatment and diagnosis.*

NOVA (National Organization of Vascular Anomalies)

P.O. Box 38216

Greensboro, NC 27438

Email: [khall@mail.novanews.org](mailto:khall@mail.novanews.org)

Website: [www.novanews.org](http://www.novanews.org)

*Excellent website, includes newsletter, message board, physicians list and other resources*

National Health Law Program

1444 I Street, NE - Suite 1105

Washington, DC 20005

(202) 289-7661

Website: [www.healthlaw.org](http://www.healthlaw.org)

*Provides extensive information on health care laws affecting families of children with special needs.*

*Children with Facial Difference: A Parent's Guide.*

Written by Hope Charkins, MSW

*Excellent resource for parents to help them cope with medical, emotional, social, educational, legal, and financial challenges presented by facial differences of their children. Look for this book at your larger bookstore chains.*

Available at: [www.Amazon.com](http://www.Amazon.com)

*Birthmarks: A Guide to Hemangiomas and Vascular Malformation.* Written by Linda Shannon, MS, and

Connie Marshall, RN, MSN, with Milton Waner, MD.

*This 171-page paperback includes the latest treatments, support information and before and after photos for anyone dealing with facial birthmarks. Excellent resource!*

Available at: [www.amazon.com](http://www.amazon.com)

The following hospitals have dedicated programs:

Vascular and Birthmarks Institute of New York

210 East 64<sup>th</sup> Street, 7<sup>th</sup> Floor

New York, NY 10065

(212) 434-4050

Milton Waner, MD

Website: [www.vbiny.org](http://www.vbiny.org)

*Internationally recognized expert and pioneer in the treatment of hemangiomas and vascular malformations.*

Arkansas Children's Hospital Vascular Anomalies Center

1 Children's Way, Mail Slot 707

Little Rock, Arkansas 72202-3591

Gresham Richter, MD Coordinator: Amber Smith

Email: [mccalliemyraj@uams.edu](mailto:mccalliemyraj@uams.edu)

Website: [www.archildren.org](http://www.archildren.org)

Vascular Anomalies Center

Children's Hospital Boston

300 Longwood Avenue

Boston, MA 02115

(800) 355-7944

(617) 355-5226

Website: [www.childrenshospital.org](http://www.childrenshospital.org)

Vascular Anomalies Program

The Cleveland Clinic Foundation

9500 Euclid Avenue

Cleveland, OH 44195

Orhan Konez, MD, Vascular Specialist

216-445-0753 (216)

Website: [www.birthmarks.us](http://www.birthmarks.us)

Gregory Levitin, MD, FACS

The Hemangioma and Vascular Birthmark Center

425 N. Bedford Dr, Suite 203

Beverly Hills, CA 90210

(917) 699-3339

Website: <http://www.vascularbirthmarkcenter.com>