



Nancy Barnett copyright 2011



Boston Children's Hospital

Participate in the Lymphatic Anomalies Registry

What is the purpose of the study? Boston Children's Hospital Vascular Anomalies Center is collecting data from patients with vascular anomalies, focused on those with lymphatic anomalies including CLOVES syndrome. We are contacting families and their physicians to gather these data for the Lymphatic Anomalies Registry to further our understanding of the presentation characteristics, clinical progression, complications and outcomes of these rare disorders.

Who can participate? All families with CLOVES are eligible, whether or not the patient is known to have lymphatic involvement. Many other lymphatic disorders are also being studied.

What do I have to do if I'm in the study? We will be contacting you for a phone interview regarding your child's vascular anomaly. The questions focus on past and current symptoms you/your child has had related to the vascular anomaly. We will also ask about past and current medical and surgical treatments that you/your child has received. Additionally, we will request permission for medical records release and to contact your physician(s) for relevant supplemental history, laboratory data, imaging studies, and treatment information.

What are some of the factors you will be looking at? We will be looking at a number of symptoms including (but not limited to) overgrowth, hand and feet physical or functional differences, neurological symptoms, other organ involvement, blood clotting, etc. We will ask about treatments, including surgical resection, interventional procedures (e.g. sclerotherapy), medical therapies and satisfaction/complications with treatments. All data will be reviewed by our research team at Boston Children's for accuracy and stored in a HIPAA-compliant database.

What is the time commitment for the study? We will contact you by phone in order to obtain consent, answer any questions regarding participation, and carry out a structured phone interview. The length of the phone interview varies by the age and complexity of the patient. We will ask your permission to keep in touch on an annual basis. It is not necessary to travel to Boston to participate in the registry.

Study Principal Investigator: Dr. Cameron Trenor
For additional information regarding this study, please contact:

www.lymphaticregistry.org

Vascular Anomalies Center

Email: lymphaticregistry@childrens.harvard.edu

Phone: (617) 355-5226

Fax: (617) 730-0752