



The Vascular Anomalies Clinic brings together as many as eight subspecialties to serve patients' needs. Photo by Allyn DiVito.

Collaborative Care for **Pediatric Vascular Anomalies**

At Johns Hopkins All Children's Hospital's Vascular Anomalies Clinic, teamwork is key to charting the right course of care for patients.

By Hannah Stuart

VASCULAR ANOMALIES, a rare group of disorders involving blood vessels and lymphatic channels, can occur in any child or young adult. Patients who live with these tumors and vascular malformations did not have a dedicated subspecialty home on Florida's west coast until five years ago, when Johns Hopkins All Children's Hospital started the Vascular Anomalies Clinic.

"By establishing the clinic, we enabled families to receive a multidisciplinary approach to their child's care," says Jennifer Mayer, M.D., FAAP, hematologist and oncologist at Johns Hopkins

All Children's Hospital. "We are the only clinic of its kind on Florida's west coast and one of only a handful in the southeastern United States. We have the ability to bring the specialist to the patient, rather than a family having to make multiple separate appointments and travel great distances repeatedly."

Families can come to the Vascular Anomalies Clinic and be seen by up to eight subspecialists during a single visit. One family has worked with nearly that many during their son's journey through vascular care.

HELPING HUNTER

Hunter, age 11, first came to Johns Hopkins All Children's in September 2015 with his parents, Dayna and Levi, after complaining of fever, shortness of breath, decreased appetite, abdominal pain and generally not feeling well. After a visit to the Emergency Center, he was referred to the Vascular Anomalies Clinic.

"When Hunter's case was presented at our weekly multidisciplinary clinic, I listened to his history and the proposed diagnosis and realized the story didn't match," says Alex Rottgers, M.D., chief of pediatric plastic surgery at the hospital. "Based on my experience working with vascular anomalies, I was able to suggest a diagnosis of a very rare condition called generalized lymphatic anomaly [GLA], which my colleagues were able to confirm and treat. It was an advantageous scenario that I happened to have a knowledge of this very rare condition and was able to help in putting what was truly a medical puzzle together."

In GLA, also known as lymphangiomatosis, lymph tissue no longer works correctly and instead becomes invasive and problematic. Hunter had an abscess between his spine and the back of his heart, as well as lesions in his bones and enlarged lymph nodes in his chest and abdomen.

"Discovering what was wrong was a long process, and when they did come out with the diagnosis, there was very little information on the disease itself," Dayna says. "One thing I love about Hunter's doctors, and all the doctors at Johns Hopkins All Children's, is that if they don't know something immediately, they'll pick up the phone to consult with other doctors."

That team effort became apparent when Hunter's doctors developed a treatment plan. An interventional radiologist assessed his disease status, an endocrinologist worked to re-calcify lytic lesions in his bones, and Mayer managed his chemotherapeutic medication. A plastic surgeon was also available in an advisory capacity and a physical therapist helped Hunter regain his energy levels.

Many subspecialists also consulted on Hunter's case, including those from the fields of pulmonology, cardiology, genetics, orthopedics, infectious diseases and otolaryngology. Hunter pointed out that he even got a flu shot as a "going-away present" upon his discharge.

"A lot of departments were involved, and so were a lot of words I'd never heard before," Levi says. "They did a good job explaining things to us and answering our questions."

COLLABORATION IS KEY

"We could not have successfully treated Hunter without the careful, thoughtful collaboration among a dozen or more clinicians at Johns Hopkins All Children's," Mayer says. "Hunter has a stable disease now, and I am hopeful that his current investigational medication trial will enable his bony lesions to heal."

Due to the complexity of these rare disorders and their evolution as a child ages, they require the ability of a single site to contain a full array of subspecialties to manage them in an optimal manner. That's where Johns Hopkins All Children's steps in.

"Primary care doctors don't have to decide where to send their patients—whether they should refer them to a surgeon or to an interventional radiologist," says Mark Bittles, M.D., interventional radiologist at the hospital. "They can send them to us, and we can take it from there. Our clinic excels at spending time educating patients and taking care of these problems in their entirety. We're very attuned to patient needs." ■

VASCULAR ANOMALIES CLINIC AT A GLANCE

Primary specialties involved: General surgery, plastic surgery, interventional radiology, hematology-oncology, pathology, genetics, wound care, psychiatry and rehabilitation medicine

Clinic availability and locations:

Tuesday afternoons on the third floor of the Outpatient Care Center, 601 Fifth St. S. in St. Petersburg

Primary treatments available: We provide surgical treatment; medical management including topical, chemotherapeutic, targeted and personalized agents; and interventional radiology treatments such as sclerotherapy and embolization.

Referral required? Yes, a child's primary care provider must refer him or her.

For more information: Patients or referring physicians should call 727-767-4722.

