Deep Venous Disease Patient Advocacy

Moderator Suresh Vedantham, MD, asks Leslie Lake, Volunteer President of the National Blood Clot Alliance and bilateral PE survivor, about patient and physician engagement in the organization, educational and outreach initiatives in deep vein thrombosis/pulmonary embolism, how physicians can get involved in patient advocacy, and more.

MODERATOR
Suresh Vedantham, MD
Professor of Radiology and Surgery
Mallinckrodt Institute of Radiology
Assistant Dean for Clinical Research
Washington University School of Medicine
St. Louis, Missouri
vedanthams@wustl.edu

Leslie Lake
Volunteer President and Board Chair
National Blood Clot Alliance/Stop the Clot
New York, New York
llake@stoptheclot.org; stoptheclot.org

Dr. Vedantham: Relatively few physicians engage patient/layperson advocacy groups in earnest. What can advocacy groups achieve that is distinct from what physicians can address in other ways? How do perspectives and opportunities differ from physician professional organizations?

Ms. Lake: We have a saying at National Blood Clot Alliance (NBCA) that "we know the patient because we are the patient," and it is very true. The majority of our Board of Directors and staff have been personally impacted by blood clots. Being a patient gives you a very different perspective versus that of a clinician. We engage our patient community to truly understand their experience and where gaps in care may have occurred, and we answer their questions in a nonclinical way so they can be more easily understood. We certainly know and understand the time constraints of physicians, but this often results in patients not getting all of their questions answered. We step in and try to help them with these questions and create patient education materials such as our New Patient Guide, which was written for patients by patients and reviewed by venous thromboembolism (VTE) clinicians. It answers pretty much everything a patient would want to know about their clotting event in an easy-to-understand format. Not only do the patients love it, but a lot of clinics and clinicians use it as a resource.

Patients can experience posttraumatic stress disorder (PTSD) after a blood clot, which probably most clinicians don't think about. By engaging and listening to our community, we learned that this was a major issue for patients but something that was never really addressed by their clinicians. To learn more, we had 3,300 patients take a survey, and we learned that almost everyone had PTSD and anxiety related to their blood clot, sometimes for years afterward. This was groundbreaking, and we make sure to share that with clinicians. The results of this CLUES (Critical Look at Understanding the Emotional Suffering of Blood Clot Survivors) survey are being incorporated in treatment plans around the world—and that came from the patient's voice. Yes, the acute event is treated, but the treatment protocol needs to include the mental aspect as well as the physical.

Almost 3 million people from around the world come to us for information about blood clots. We have a patient group of almost 20,000 active patients, and last year, we received > 90,000 comments from patients. We learn from them, we identify issues, and we want to share that information with clinicians. Our goals are the same—to improve patient outcomes—but we may take different paths to get there.

Dr. Vedantham: The NBCA has been a force in deep vein thrombosis/pulmonary embolism (DVT/PE) patient advocacy for many years. What types of education and outreach activities does NBCA participate in, and how does it engage physician volunteers in these activities and in its leadership?

Ms. Lake: NBCA's outreach has really grown over the last few years. We developed a Thrombassador Program, a truly grassroots initiative that consists of NBCA-trained patients, caregivers, and clinicians who go into their local communities to speak about blood clots and raise awareness. After only 2 short years, we now have Thrombassadors in almost every state in the country. Our Thrombassadors go through a rigorous training program, which includes a clinical teach-in by a VTE expert. We have had a great response from clinicians offering to help with training.

We also recently launched B.L.A.C.K. Thrombassadors, which stands for Black Lives Advocating for Clot Knowledge. Knowing that the incidence and mortality of VTE, as well as access to life-saving medicine, is much worse for Black individuals than White individuals, these Thrombassadors address these health disparities in their communities.

We also launched PEP, which stands for Patients Educating Patients. Again, by being engaged with our patient community, we see the gaps in care and knowledge. We aim to close those gaps by hosting a live webinar every month, led by two patients and discussing a topic important to the patient community. We invite a clinician into the "patient house" to discuss these topics. It has been a huge success; we have had > 40,000 views of these PEP Talks, which are recorded and hosted on our YouTube channel. Patients can send in questions prior to and during the event. Topics have been as diverse, from compression to chronic thromboembolic pulmonary hypertension, and we have had as many as 600 patient questions during a PEP Talk. What this tells us is that patients are not getting all the information they need in a clinical setting.

We also launched our podcast last year, *Taking A Breath*, which is hosted by two patients. We invite everyday heroes on the show to discuss their blood clot story, and we also invite a physician to join us to share the clinical side with our listeners. It has been so well received; we have had > 140,000 downloads in little more than a year.

Three years ago, we launched Capitol Hill Day. The first was remote, and for the last 2 years, we have been on-site in Washington, DC. We meet with Congressional members and their staff, educating them about blood clots and seeking appropriation funding for a national blood clot education and awareness program to be developed within the Centers for Disease Control and Prevention (CDC) Division of Blood Disorders. This has been a huge undertaking and requires the input not just from patients but also from caregivers and clinicians. All stakeholders—our staff, our Board, our Medical and Scientific Advisory Board, and our Council of Emerging Researchers in Thrombosis—partake in these activities, but we still need more clinicians to be involved. Capitol Hill Day would be even more impactful if we had the support of more clinicians and the medical societies to which they belong.

Dr. Vedantham: What types of physicians does NBCA partner with? Is there a role for physicians who are experts in DVT/PE endovascular procedures, such as interventional radiologists (IRs), vascular surgeons, and interventional cardiologists? How can they get involved and be most useful?

Ms. Lake: NBCA partners with all disciplines, not just physicians. We work with nurses and physician assistants, pharmacists, and even physical therapists. We want to work with anyone involved with the PE/DVT patient in any capacity and share the patient experience and our material. With cross-education, we believe we will produce enhanced patient outcomes and a better understanding of patient needs.

We have seen an uptick in the involvement of IRs, vascular surgeons, and interventional cardiologists over the last few years given the increase in mechanical thrombectomy procedures performed on patients. Previously, we were highly focused on hematology, but management of DVT/PE is now multidisciplinary, and we want to include those who might not be VTE specialists such as primary care physicians or obstetrician/gynecologists.

We also launched our first Center of Excellence in April 2024, managed by an IR clinician and with a focus on VTE, and we intend to develop this program nationally. Demonstrating benchmarked clinical excellence is part of the requirement, as is robust patient education both in the hospital and posthospital setting, but we also require the Center of Excellence to demonstrate a commitment to the community they serve. Ensuring access to quality care for all is critically important to us. We need clinicians, particularly IRs, vascular medicine specialists, and interventional cardiologists, to champion this initiative with us, and we welcome their participation.

Dr. Vedantham: What are the most exciting ongoing initiatives at the Federal and State levels in the DVT/PE arena right now? What policy objectives does NBCA have, and are they feasible to achieve?

Ms. Lake: In 2022, we launched our first Capitol Hill Day with the goal of raising awareness of VTE to Congress and advocating for funding for the CDC Division of Blood Disorders to develop a national VTE education and awareness program and a national surveillance system. Capitol Hill Day has grown tremendously over the last 3 years and now incorporates patients, caregivers, and clinicians, and we need more clinicians to join us. This year, we had 50 Congressional meetings; next year, we want to double that.

In addition to getting March officially declared as Blood Clot Awareness Month, we have most recently been successful at getting language into the Federal budget regarding the need for a national VTE education and awareness program. The Senate Appropriations Committee has gone so far as to ask CDC for a detailed budget as to how the money would be spent.

On the Federal level, we have been working with Rep. Lisa Blunt Rochester from Delaware, who lost her husband, Charles, to PE, as she put forth her blood clot bill with a funding request of $100 million. At the State level, we worked on securing the passage of the Emily Adkins Bill in Florida, which was signed into law by Governor DeSantis in June 2023. Emily Adkins was a 23-year-old woman who died of PE. The Bill called for the establishment of a Blood Clot and PE Policy (BCPEP) workgroup, of which NBCA is a member. The five members of the BCPEP workgroup are charged with developing a risk surveillance system and policy recommendations to improve standard of care, surveillance, detection, treatment, and patient and public education related to blood clots.

Not only was this model used as the template for the Federal bill, but we have also been rolling it out to multiple states across the country. Although we continue to advocate in Washington, DC, we want to make sure we are following a parallel path at the State level. We are extremely proud of the progress we have made in just a few years. Although our goals are feasible, we are navigating a tricky political environment, and we need more clinicians and medical societies involved. ■

Disclosures

Dr. Vedantham: Member of medical and scientific advisory board for NBCA; Medi USA donates compression stockings to participants in a clinical trial he leads.

Ms. Lake: None.