

# THE Beat



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## Meet **Vasculearn Network** (VLN)

We're thrilled to share a new chapter in our journey! After almost 20 years as the **North American Thrombosis Forum (NATF)**, we've grown, evolved, and transformed. Today, we're proud to introduce ourselves as **Vasculearn Network (VLN)**.

Our rebranding reflects a deep look into our identity and a forward-thinking vision for advancing research, education, and empowerment in thrombosis and related conditions, such as atrial fibrillation, stroke, heart attack, cancer, diabetes, and obesity. This shift emphasizes our commitment to expanding networks that unite clinicians, researchers, patients, and caregivers. While our mission to improve lives through education remains steadfast, we are now reaching further and thinking on an even larger scale.

This change is more than just a name; it's a renewed commitment to serving our community with knowledge, resources, and support. While this is a "soft launch," stay tuned for a new website in the coming months, offering an even more user-friendly experience for patients, caregivers, and clinicians alike.

Thank you for being part of this journey with us. Here's to circulating knowledge and saving lives!

**Mission:** Vasculearn Network is a nonprofit organization dedicated to improving the lives of those affected by blood clots and related diseases. Through our comprehensive resources and innovative programming, we strive to educate patients and clinicians about thrombosis and its complications.

**Vision:** To be the premier educational resource on blood clots and related diseases.





Mary and Chad at their first event post-recovery.

## A Story of Survival and Gratitude: Meet Chad and Mary

What began as a typical day — biking, playing pickleball, and dinner with friends — became an unexpected battle for health and advocacy. On August 5, 2023, Mary woke in the middle of the night to find her husband, Chad, missing from bed. "I thought he was up working on his laptop like he sometimes did," Mary recalls. When he wasn't at his computer, Mary called out his name but didn't receive a response. "When he didn't answer, I checked the bathroom, and there he was, unconscious." She quickly called 911, and Chad was taken to a local hospital.

The events that followed would change both their lives, leading them through a challenging journey of numerous hospital stays, months of waiting, and several life-threatening moments.

### A Sudden Crisis

Chad had always been healthy, so Mary had no idea how critical the situation was. "He was perfectly healthy, fit, and athletic at 69 years old," she recalls. She grabbed only her husband's essentials, expecting they'd be home soon and never anticipating the harrowing road ahead that would last for nearly 5 months.

While waiting to speak with the doctor, Mary called her children on the phone to explain what had happened. Still thinking the situation wasn't serious and that they'd be home soon, she told them not to worry.

But the reality hit hard when the doctor overheard her and urged, "Get your children here immediately." **The family was told Chad might not survive the night.**

Chad had a ruptured aneurysm, leading to a severe brain bleed followed by cardiac arrest. Doctors performed aggressive CPR, and after 5 minutes, Chad was revived but remained unstable. He was intubated quickly, without time for muscle relaxants to protect his lungs. The procedure, along with CPR, caused lung damage that eventually led to respiratory failure and sepsis.

Chad was flown by helicopter to a larger hospital for specialized care that night. Mary and her family drove to the city and waited in a conference room, wondering if they'd ever get to speak to him again.

### A Fight for Survival

When Chad arrived by MedFlight, he briefly regained consciousness and faintly squeezed a doctor's hand—a hopeful sign of responsiveness. "If it weren't for that weak squeeze, things might have been different," Mary recalls. Doctors then put Chad in a medically induced coma to stabilize him. "He was so fragile. Every time we controlled one issue, another arose," she says.

In the ICU, Chad faced multiple complications. "I kept saying unless someone tells me he's brain dead, I want every life-saving measure possible," Mary recalls.

It took several days before doctors could safely address Chad's brain bleed because he was too unstable. Eventually, his neurosurgeon treated the aneurysm using [endovascular coiling](#). This less invasive technique treats the aneurysm from inside the blood vessels. This procedure guides a tiny coil through the blood vessels to the damaged area to block blood flow and prevent further bleeding. Coils are especially helpful in emergency situations. Typically, a single aneurysm may require multiple coils to effectively block blood flow and prevent rupture. If more than one aneurysm is found, additional coils may be used to prevent further bleeding events.

### Complications from Immobility

Because of the brain bleed, it was too risky to give Chad blood thinners for blood clot prevention. However, as Chad lay immobile in a coma, his circulation slowed, increasing his risk for blood clots. He soon developed deep vein thromboses (DVTs), clots that form in the deep veins, often in the legs. These clots traveled to his lungs, causing multiple pulmonary emboli (PE). **"He didn't have any family history of clots or any other risk factors," recalls Mary.**

### Setbacks of Transfer

About a month later, Chad woke up. Doctors removed his ventilator, and he was moved to a floor for less critically ill patients. But the day after he was moved, Mary got a call that Chad was struggling and needed to be put back on the ventilator. He was transferred back to the ICU — the burn trauma ICU this time since the neuro ICU was short on beds. While the staff was skilled, they didn't have the specialized experience he needed, so Mary advocated to get him back to the neuro ICU. Eventually, he required a feeding tube to assist with nutrition and underwent a tracheostomy, a surgical procedure where a tube is placed in the windpipe for long-term breathing support.

## From Celebration to Crisis

Eventually, Chad made enough progress in his recovery to be discharged from the ICU to a long-term acute care facility. "It was a huge deal; everybody was clapping because they were so happy he had survived," said Mary.

Things were slightly different at this facility compared to the hospital. Mary was understandably concerned for her husband. There was less frequent monitoring, and with strict visiting hours in place, she couldn't see Chad until later in the afternoon. "It was terrifying to leave him there, knowing he couldn't speak up if he needed something," she remembers. Mary came in to see her husband the next day to find him unresponsive and seizing. **The aneurysm had re-ruptured, and Chad was rushed back to the hospital.**

Back at the hospital, Chad's blood pressure was dangerously low, his pupils were unresponsive, and he was experiencing seizures. The doctors needed to relieve the pressure in his brain, but there was one problem. Chad had been put on blood thinners after his PE and couldn't have any procedures or surgeries until an agent was administered to reverse his blood thinners. Without an antidote to his blood thinners prior to the procedure, he would have been at risk for severe or fatal bleeding.

All they could do now was wait.

**"We had to wait for the antidote, and it seemed like forever.** We're standing there watching the monitors, hearing the alarms, and asking the medical staff if they can do anything. But all they could do was give him fluids."

After the reversal agent was finally administered, the doctors performed the procedure to relieve the pressure in Chad's brain – but the bleeding continued. The neurosurgeon re-coiled the aneurysm, but brain scans the next day showed that blood was still leaking. To stop it, the surgeon needed to do a [craniotomy](#) (where part of the skull is removed to access the brain), but several multidrug-resistant infections, including pneumonia, made surgery risky. With no other choice, the neurosurgeon went ahead and successfully repaired the aneurysm.



Chad's first time outside the hospital with Mary and their sons.

## Advocating for Safety

After spending another month in the ICU, Chad was ready to be discharged again. He was scheduled to return to the facility where he'd first experienced complications after his previous discharge from the hospital. Mary was hesitant at first because of their prior experience. The problem was that Chad was back on blood thinners to prevent a clot, and if something were to happen again with his brain bleed, he would need to be close to a hospital that had the antidote to reverse his blood thinners. The only option was to go to the same facility close to the major hospital.

Mary knew she had to advocate for her husband and would only go back if given the right to visit him beginning in the morning rather than in the afternoon. The facility also had robotic video surveillance that she insisted be used continuously on Chad. "I just needed a little peace of mind. I needed to know he was safe there," she states.

## Things Began to Take a Turn

Chad's progress seemed promising as he prepared for transfer to inpatient rehab. After only being tube-fed for several months, he was fed chicken and began choking severely. He couldn't stop coughing for days, and mucus and blood poured from his tracheostomy tube. He then became disoriented. "We finally reached the point where he could talk with us and ask about work. But after that, he no longer knew who we were," Mary recalls.



Scan the QR code to access important website links

Chad would once again need to return to the hospital for treatment of additional complications and an evaluation for his confusion. The doctors discussed placing a [ventriculoperitoneal \(VP\) shunt](#) — a small tube to help drain excess fluid from the brain — to see if it would improve his confusion, but they were hesitant. Instead, they performed a lumbar puncture to remove some of the cerebrospinal fluid, hoping to relieve pressure and improve his confusion. He slightly improved, but not enough. His family didn't want him to go back to the long-term acute care facility, so instead he went to an inpatient rehab.

## Refusing to Give Up

"In an inpatient rehab facility, patients must show continual improvement. Part of me thought he was starting at such a low point that he was bound to improve at least somewhat. We had those few good days before the choking incident, but now he was weaker and couldn't answer basic questions like what city or season it was. What could we do to get Chad back?"

But Chad didn't make any improvement, and the rehab told Mary it was time to decide on a nursing home.

**She was given until Monday to pick a home for her husband.**

Mary fought against sending him to the nursing home. She noticed his growing physical weakness and mental confusion and felt there had to be something else causing his decline. Her instincts were right – Chad's condition worsened, and he was sent back to the hospital. Chad's brain scans revealed worsening [hydrocephalus](#), a condition where excess fluid builds up in the brain, increasing pressure.

After being treated for an infection in the hospital, his neurosurgeon decided it was time for a permanent VP shunt.

## A Time for Thanks

A week after his infection cleared, Chad underwent surgery, and by Thanksgiving, he was a completely different person. **"We walked in, and he knew he was in Boston and who we were. We were rejoicing,"** Mary recalls. After recovering, Chad returned to inpatient rehab, weaker

but improving. "He could participate and knew who he was and what he was doing," says Mary. Even after catching COVID, Chad kept up with his therapies.

After months in the hospital, Chad came home in a wheelchair and on a feeding tube. Mary, now managing his recovery herself, watched him grow stronger every day. "Nothing has been easy, but he relearned to swallow, eat, tie his shoes, and write. Now, he walks, drives, and even played golf yesterday. He still struggles with balance and strength, but other than that, he's back," she says proudly. Both his short-term and long-term memory are intact. In addition, four months after his return home, a retina surgeon performed surgery on his left eye to restore the vision he had lost after his brain bleed.

### Be the Advocate

Through nonstop challenges, Mary stood by Chad as a strong advocate, carefully tracking his medications, procedures, and vital signs. She regularly questioned doctors, seeking

clear explanations and pushing for answers when things seemed off. "You have to be their voice," she says. "I had to push for things. He couldn't speak for himself."

Mary didn't just take notes; she actively collaborated with the medical team and addressed communication gaps. "I knew I couldn't just sit back," she recalls. Her dedication and vigilance kept Chad's care on track, ensuring he received optimal treatment through every setback.

### Message of Hope

Reflecting on their experience, Mary and Chad have a message for others facing similar journeys: **"Don't give up too early. Some doctors were ready to give up on me, but I'm here. Keep fighting."** Chad's recovery was made more difficult by vascular complications, including PE and the challenge of having to urgently reverse his anticoagulation (blood thinners). Chad believes that Mary's role as his advocate made all the difference. "If you have a loved one in a critical situation, be their voice.



Chad playing golf with his daughter.

Write everything down, ask every question, and don't be afraid to speak up," Mary advises.

Through the darkest moments, Chad's resilience and Mary's unwavering dedication have led to a recovery once thought impossible. Today, Chad is back to enjoying life, and both he and Mary are sincerely grateful to the neurosurgeon, neurocritical care doctors and ICU nurses, retina surgeon, and the entire healthcare team that helped save him.

## A Heart-Healthy Holiday Recipe

The holidays are a busy and joyous time — but not a time to ignore your health! Overeating food with unhealthy fats, sugar, and processed ingredients can lead to atherosclerosis, the buildup of cholesterol and other substances in the arteries. [This process](#) causes plaque to form, which can eventually rupture and trigger blood clots. These clots can block blood flow, increasing the risk of heart attacks or strokes. Choosing heart-healthy foods like fruits, vegetables, and healthy fats can help lower this risk. Making mindful food choices during the holidays can help support your heart and reduce the risk of harmful clots.

**Here's a recipe that's both delicious and heart-friendly! Courtesy of the [American Heart Association](#).**

## Rosemary Balsamic Roasted Vegetables

### INGREDIENTS Servings 8

- **Cooking spray**
- **1/2 pound Brussels sprouts**, brown ends trimmed off and cut in half
- **1/2 medium cauliflower** cut into florets
- **4 medium carrots** sliced
- **1/2 pound turnips** peeled, cut into 1/2-inch cubes
- **1/2 pound beets** peeled, cut into 1/2-inch cubes
- **1/3 pound sweet potatoes** peeled, cut into 3/4-inch cubes, optional
- **3 tablespoons balsamic vinegar**
- **3 teaspoons extra-virgin olive oil**
- **2 teaspoons no-calorie sweetener** granulated
- **2-3 tablespoons fresh, chopped rosemary OR 2-3 teaspoons dried rosemary**
- **2 medium garlic cloves** minced
- **1 teaspoon onion powder**
- **1/2 teaspoon pepper**
- **1/4 teaspoon salt**



### DIRECTIONS

1. Preheat the oven to 375°F.
2. Lightly spray 13 x 9 x 2-inch baking dish with cooking spray.
3. Place all the vegetables in a large bowl.
4. In a small bowl, whisk together the vinegar, oil, no-calorie sweetener, rosemary, garlic, onion powder, pepper, and salt. Pour over the vegetable mixture, tossing to coat.
5. Pour the vegetable mixture into the baking dish. Bake for 30 to 35 minutes, stirring once, or until all the vegetables are tender when easily pierced with a fork.

# Upcoming Patient Events

All groups are virtual and start at 7:00 PM EST



## Blood Clot Support Group

Hosted by Joelle Hochman, RRT, Chair of Patient Engagement & Education

After experiencing a blood clot, it's normal to have a lot of questions. Many people are left feeling confused about why this happened to them and are anxious about it happening again.

We're pleased to offer a support group experience where patients can share their stories, connect with others who've had blood clots, and receive emotional support.

**December 19, 2024**

**January 16, 2025**

**February 20, 2025**

**March 20, 2025**

## Cancer-Associated Thrombosis Support Group (Quarterly)

Our cancer-associated thrombosis (CAT) support group is for individuals who are receiving cancer treatment and have been diagnosed with a blood clot. We recognize the physical, emotional, and psychological toll that managing both conditions can take.

Join us on World Cancer Day to share stories, connect with others who have a dual diagnosis of cancer and blood clots, and receive emotional support.

**February 4, 2025**

## Blood Clot Education Group

Join our Blood Clot Education Group to connect with others and learn about all things related to blood clots. Get accurate information, hear from experts on the latest research and treatments, and share your experiences. Each session includes participant introductions and a Q&A with a clinician, where you can submit questions in advance.

**January 8, 2025**

**February 13, 2025**

**March 11, 2025**

## Women's Blood Clot Support Group

Did you know that women have a higher risk for blood clots over their lifetime than men? Being pregnant, taking birth control pills or hormone therapy, or even receiving infertility treatment are risk factors unique to women. Women who take blood thinners may also have side effects that don't affect men, including heavy periods, spotting between cycles, or bleeding after sex.

February is Women's Heart Month, dedicated to raising awareness about women's unique heart health challenges, including the risk of blood clots. Join other women of all ages in a quarterly support group to connect, ask questions, and receive support.

**February 25, 2025**

## Long-PE and CTEPH Support Group (Quarterly)

Have you or someone you care for experienced a pulmonary embolism (PE)? VLN offers a dedicated support group for patients with post-PE syndrome and CTEPH (Chronic Thromboembolic Pulmonary Hypertension). This group provides a safe space to connect with others, receive support, and learn more about managing life after PE.

Each session includes introductions and a Q&A with a clinician, where you can submit questions in advance.

**January 23, 2025**

In all online groups, a clinician will be available to answer general questions about blood clots. Please note that they cannot provide personalized medical advice to any patients.

**To register for these programs, please visit Patient Events on our website at <https://thrombosis.org/events/patients/>**

**Do you like what you see in *The Beat* and find this information helpful?**

Please consider making a [donation](#) to VLN to further support blood clot education.



Please help us spread the word about these support groups! More information can be found on our [website](#).

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