



The Beat

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"I Thought I Might Not See My Kids Again": Steve's Story



Steve T.

It was a warm Saturday in mid-June when Steve noticed that something was "off." As an avid athlete, he'd spent years participating in triathlons – multisport races that incorporate biking, swimming, and running. After several years of racing, he qualified for the World Triathlon Championships and spent nearly a year training for the big event.

"I was using races to improve my fitness because you never work as hard in training as you do in a race. So, I did a lot of races. In the span of three weekends, I think I did six races of different kinds, all involving

running, biking, and swimming. I had a Sunday race, so I spent this particular Saturday going through my normal 'day-before-a-race' routine. I did a 20-mile bike ride and felt a little sluggish but didn't think much of it at first. I returned from my bike ride and immediately changed into my sneakers for a four-mile run," Steve recalls.

As soon as he jogged out of his driveway, he experienced a pain in his ribs so intense that he had to stop. "I walked a little bit and tried running again, but the pain was awful. Something was definitely off, but I rested and ended up doing the race the next day. I didn't perform well, to no one's surprise."

Steve continued training for the Championships but started experiencing some breathing issues. "It seemed like I'd inflate my lungs to a certain point when I was at peak exertion, but then there was a line I couldn't cross – if I crossed a line, I experienced meaningful pain."

Steve contacted both his primary care doctor and a cardiologist and had a chest x-ray and echocardiogram. (Also known as an echo, an echocardiogram uses ultrasound waves to look at the heart's chambers and valves and to assess how blood is moving through the heart.)

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Blood Clot Management: Exploring the EKOS Catheter

People who develop a blood clot in the leg veins (called deep vein thrombosis or DVT) or lung arteries (called pulmonary embolism or PE) need urgent treatment with blood-thinning drugs (called anticoagulants). These medications prevent new blood clots from forming and are usually effective in preventing existing blood clots from growing or moving to the lung arteries. But

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even with blood-thinning drugs, patients with large or extensive blood clots are still at risk for serious health problems. Patients with PE may experience a worsening of their condition that leads to long-term disability or death. Patients with DVT may continue to struggle with chronic leg pain, swelling, and skin breakdown, reducing their activity and quality of life.

For these reasons, several catheter-based treatments have been developed to help rapidly remove blood clots. These treatments are given with blood-thinning medications and administered by doctors with specialized training, such as **interventional cardiologists, interventional radiologists, or vascular surgeons**. One such catheter-based treatment known as “ultrasound-assisted thrombolysis” (UAT) involves the EKOS™ Catheter, a device that’s designed to: (1) deliver a clot-busting drug to dissolve existing clots; and (2) use energy from sound waves to spread the drug out within the clot.

TREATMENT OF PE

The EKOS Catheter has been evaluated for the treatment of severe PE—meaning patients at imminent risk of death or who are having heart strain. It was approved by the U.S. Food and Drug Administration (FDA) for this purpose in 2014. With this treatment, the doctor uses imaging with **ultrasound** and x-rays to see the blood clots and position the EKOS Catheter within the clots through a small skin incision. A low dose of clot-busting drug is then infused through the catheter along with sound wave energy for 6-24 hours. During this time, the patient is monitored carefully in an intensive care unit. After the treatment is completed, the catheter is removed, and compression is applied to the site for about 10-15 minutes to help the small vein incision close.



EKOS Catheter
BostonScientific.com

Among the different methods that can be used to remove blood clots in patients with PE, EKOS Catheter UAT is currently the best-studied method. Key findings from studies include the following:

Randomized Trial	Who Was Studied	Findings
SEATTLE II	150 patients with PE that was severe enough to cause right heart enlargement	Patients who received EKOS Catheter UAT along with blood-thinning drugs (anticoagulants) experienced substantial clot removal and recovery of more normal heart size compared to before treatment. About 10% of patients experienced bleeding with the clot-busting drugs.
OPTALYSE	100 patients with PE	Found that with EKOS Catheter UAT and blood-thinning drugs, reduction in abnormal right heart enlargement can be achieved using very small doses of clot-busting drug (which may improve safety).
ULTIMA	50 patients with PE who were receiving blood-thinning drugs	Improvement in right heart enlargement was significantly greater in patients who were also treated with EKOS Catheter UAT versus patients who were not. This study is the only completed randomized trial comparing catheter-based treatments for PE with standard blood-thinning therapy.

A larger trial (HI-PEITHO) is now underway. This trial is large (about 500 patients) and is designed to confidently determine if EKOS Catheter UAT will improve important PE patient outcomes with reasonable safety. If so, then it would be reasonable to offer the treatment to more patients.



"I THOUGHT I MIGHT NOT SEE MY KIDS AGAIN": STEVE'S STORY

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Steve's tests didn't identify anything out of the ordinary.

The following week, Steve went out for a trail run and vividly remembers feeling like he was at high altitude. A few days later, he found himself stopping three times while running on a familiar route. "I just wasn't feeling like myself, but I kept running because that's what I love to do."

My mind went from blood clots to stroke to 'I'm dying and won't see my kids again.' That was emotionally very difficult.

On the heels of these episodes, Steve saw a pulmonologist and had some more testing done, including a CT scan with contrast. (CT scans provide a detailed view of the organs and blood vessels, and contrast refers to a dye that's used to highlight the specific areas of the body that are being evaluated.)

"Shortly after the scan, I was told 'your pulmonary arteries are about 90% blocked and you have blood clots throughout your lungs. We're taking you to the emergency room.' My mind went from blood clots to stroke to 'I'm dying and won't see my kids again.' That was emotionally very difficult. It was also hard to wrap my head around the fact that I was feeling fine if I wasn't exercising or trying to breathe deeply. Day to day, I felt fine – but there was this silent thing in me that was potentially deadly. It was tough to process that."

Steve also didn't know why his PE happened. "I started educating myself about the risk factors for blood clots, but nothing really checked out for me. I wasn't dehydrated, I wasn't a smoker, I didn't take steroids, I hadn't returned from a long trip on an airplane...my best guess is that I pushed my body to extreme levels. I sort of turn myself inside out when I race; perhaps I created some sort of perfect storm that then caused my PE."

Steve spent two nights in the hospital and was discharged with a prescription for warfarin, a

blood thinner used to prevent new blood clots from forming. "Within a few days, I was able to go for a walk, but I had to drop out of the World Championships. There was just no way that being on a blood thinner, I could risk a bike crash."

"Be honest with your doctors...and with yourself. I'd suggest that people take a step back and evaluate why they're doing what they're doing. If it's costing you your health, is it worth it?"

But what Steve remembers even more than the disappointment of having to withdraw from the Championships is the anxiety around his diagnosis. "It was very real for a long time," he says. "June 25th was the day I saw the pulmonologist for the first time...and for years after my PE, I had chest pain on June 25th. I gradually built up my exercise and was able to return to my normal level of activity, but the anxiety took a while to get past. That said, the experience wasn't all bad – it led to a lot of self-reflection, and I made a few changes in life because of it."

And for fellow athletes who may experience a health setback, Steve offers these words of wisdom: "Be honest with your doctors...and with yourself. Think about why you're pushing yourself so hard in the first place. A lot of us in the racing world are totally obsessed with activity and competition, but is it that important? There's an exercise I've heard about where you write your own obituary or what's on your tombstone. Do I want 'triathlete' to be on my tombstone? No, I don't. So why turn myself inside out for a sport? I'm proud of what I've done but I'd suggest that people take a step back and evaluate why they're doing what they're doing. If it's costing you your health, is it worth it? I'm not so sure it is." ■

Every patient has a story and NATF invites you to share yours! If you'd like to submit a patient story, please contact Aviva at ASchwartz@thrombosis.org.

Help Us Help You!

Our colleagues at World Thrombosis Day and ISTH have recently launched a survey about blood clots and cancer. If you or a loved one currently have cancer (or have had cancer in the past), please take 5 minutes to fill out this important questionnaire.



Scan or click the QR code to access the survey.





GLOSSARY

Interventional cardiologist

A doctor that specializes in delivering minimally invasive treatments for diseases of the heart or other blood vessels.

Interventional radiologist

A doctor that specializes in delivering imaging-guided, minimally invasive, catheter-based treatments.

Post-thrombotic syndrome

Chronic leg pain after a blood clot.

Randomized controlled trial

A study in which participants are randomly assigned to separate groups that compare different treatments or interventions.

Right heart enlargement

The right side of the heart takes blood from the body and pumps it to the lungs. When a large blood clot moves into the lung arteries (pulmonary embolism or PE), it sometimes causes the right side of the heart to pump against more resistance, which can affect its ability to work properly. When this happens, the right heart often gets bigger. In a patient with PE, right heart enlargement can be a sign of a heart that is not working normally.

Ultrasound

Energy from sound waves, which can be used either to image the body or, in a different form, to spread clot-busting drug within blood clots.

Vascular surgeon

A doctor that specializes in doing surgery or minimally invasive treatments on blood vessels, including veins.

TREATMENT OF DVT

EKOS Catheter UAT has also been used to treat patients with extensive DVT. Some doctors have adopted this method as their go-to treatment in hopes of reducing leg pain, swelling, and late **post-thrombotic syndrome** to a greater degree than other treatments. However, more research is needed to determine if that is truly the case.

- To date, one small pilot randomized trial of 50 patients (the BERNUTIFUL trial) confirmed that use of the EKOS Catheter (with or without the sound wave energy) to deliver clot-busting drugs removed clots from the leg veins – but benefits weren't associated with the sound wave energy itself.
- Another randomized trial of 184 patients (the CAVA trial) found EKOS Catheter UAT to successfully remove blood clots; however, it didn't result in fewer leg symptoms or better quality of life than blood-thinning drugs alone.

The role of EKOS Catheter UAT for DVT continues to be discussed and studied. While catheter-based therapies appear to be helpful for some patients with the most extensive blood clots, the best method to use is not clear at this time.

THE BOTTOM LINE

In recent years, science and innovation have produced new blood-thinning drugs, new imaging methods, and new catheter-based treatments with the potential to help patients with PE and DVT. Early studies suggest that EKOS Catheter UAT can rapidly remove clots in both conditions. Additional studies will help patients and doctors understand how to best translate such tools into clinical benefits for patients, and which patients should be treated.

**This article is for informational purposes only. NATF does not endorse any specific type of catheter-directed treatment or any manufacturer of such treatments.*



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Upcoming Patient Events



Support Group for Newly Diagnosed Patients

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

We're pleased to offer a virtual support group experience specifically for patients who've recently had a blood clot.* By popular demand, we've added a summer date.

Please join us on August 18, 2022 at 7:00 PM EST.

*This group is primarily geared towards patients who've had a blood clot in the past 12 months – but participants at any stage of diagnosis are welcome! If you're a longtime reader of *The Beat*, please help us spread the word about this support group! More information can be found on our [website](#).

NATF Support Group

This virtual support group is designed for patients at all stages of their blood clot journey. If you had your blood clot 20 days ago or 20 years ago, we welcome you to join us!

September 13, 2022

October 18, 2022

November 15, 2022

December 6, 2022

All meetings begin at 7:00 PM EST.

To register for these programs, please visit [Patient Events](#) on our website or email events@thrombosis.org.



SAVE THE DATE!

Optimizing Health after a Cardiovascular Event: An Evening with the Experts

Have you or a loved one recently had a heart attack, stroke, blood clot, or other heart-related event? Wondering where to begin with managing cholesterol, controlling blood pressure, exercising, or shopping for healthy food on a budget?

NATF is pleased to host an interactive program this fall on navigating life after a cardiovascular event. Our expert panel will talk about realistic ways to establish healthy habits and outline what you can do to lower the risk of a second cardiovascular event. The evening will conclude with a session dedicated to answering your questions.

October 6, 2022

5:30-9:00 PM

Fairmont Copley Plaza Hotel, Boston, MA

Covered topics include:

- How to control cholesterol, blood pressure, and diabetes
- What a "heart-healthy diet" actually means and how to eat well on a budget
- How to safely return exercise after a cardiovascular event
- Myths and realities about coffee, alcohol, chocolate, and vaping

The evening will begin with a cocktail reception at 5:30 PM, followed by a dinner program.

[Register Now](#)

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