

he Beat

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\$ 2 Meet our April 2020 Titan of Thrombosis





Our Titans of Thrombosis series honors advocates and experts in the thrombosis field and showcases their important contributions.

Ruth Morrison is a clinical research nurse and has worked at the Brigham and Women's Hospital (BWH) Thrombosis Research Group (TRG) for 33 years. She began her nursing career at BWH in 1976. Prior to forming TRG, cardiac nursing was her main interest. Ruth has been involved

Ruth Morrison, RN, BSN

in numerous clinical trials focusing on the prevention, diagnosis, and treatment of blood clots. She's also been active in NATF for over a decade and devotes much of her time to educating and advocating for patients.

Q: Tell us about yourself.

A: I've been married for 36 years and have three children and a stepdaughter. As of last month, I have four grandchildren. (One was just born in March!) I retired from clinical nursing in April 2019 but still work part-time as a research nurse. My husband and I love to travel and spend time with our family. I got my real estate license four years ago and hope to use it more when I have some spare time.

I've worked at BWH my entire career. I started in the medical-surgical unit and then became the charge nurse in the coronary care unit (CCU), which is where patients go when they have a serious heart condition and require 24/7 monitoring. I don't know what exactly drew me to the CCU. I was young, I loved taking care of seriously ill patients, and it just seemed like a natural fit. In 1996, I got my certification in vascular nursing.

Q: What is vascular nursing?

A: Vascular nurses work with patients who have (or are at risk for) conditions that affect the blood vessels, like blood clots, atherosclerosis, peripheral artery disease, etc. Many of us do clinical work, research, and patient education.

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6 **Melissa's Story**

In the winter of 2007, Melissa Hogan woke up with a swollen leg and ankle.

As a healthy 24-year-old, she had no idea what was causing the swelling. At her doctor's office a few days later, an ultrasound confirmed



Melissa Hogan

a superficial blood clot in her leg. She was told to take some aspirin and come back if things

Upcoming Support Groups and Events

In-Person Blood Clot Support Group

Brigham and Women's Hospital, Boston, MA

Due to COVID-19, please check <u>www.natfonline.org</u> for updates on upcoming support groups.

Online Blood Clot Support Group:

Ask the Expert with Dr. Greg Piazza April 21, 2020 7:00 PM-8:00 PM

NATF Summit on Women's Cardiovascular Health

October 7, 2020 5:15 PM-8:30 PM Fairmont Copley Plaza, Boston, MA

For more information about any of these events, please visit www.natfonline.org/events or email events@natfonline.org.



MELISSA'S STORY Continued from page 1

got worse. Eventually, things did get worse. Melissa has had four recurrent blood clots since that day 13 years ago.

Q: What do you remember about your first clot?

A: What I vividly remember is that I started taking birth control 5-6 months before the clot developed. My doctor casually mentioned that oral contraception can cause blood clots, but I thought nothing of it. I stopped taking birth control after that first clot.

Q: Did you have any other risk factors for blood clots?

A: I had a risk factor that I didn't know about at the time. I have a fraternal twin sister and after returning from a trip to Europe, she started having swelling and leg pain – symptoms similar to the ones I had two years before. She's a runner and thought she had injured herself on a run. She ignored her symptoms for the longest time but finally went to the doctor. Lo and behold, she had deep vein thrombosis (DVT). A week later, she had trouble breathing and was diagnosed with a pulmonary embolism (PE).

She had a full workup and discovered that she was positive for Factor V Leiden, a genetic condition

that increases the risk for blood clots. My PCP recommended that I get tested, and my test also came back positive for Factor V. So, by my late 20s, I knew I had a predisposition to clots.

Q: How did you feel after getting the results from your testing?

A: I wasn't overly concerned. My doctor told me to be aware of anything unusual going on in my body, but I was encouraged to stay active and live my life normally. The next few years were uneventful, until I broke my foot in 2014.

Q: Did you need surgery on your foot?

A: No, but I was in a boot and on crutches for several weeks. After three weeks of being in the boot, my leg blew up like a balloon. It was really painful, like crying-in-the-shower painful.

I had a friend drive me to the hospital and sure enough, there was a large DVT in my right leg. I was referred to a hematologist and took warfarin for 6 months. I made a full recovery, aside from some lagging pain and swelling in my leg.

But my story doesn't end there. In 2016, I got an IV in my arm for a procedure and my arm started swelling a week later.

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The Emotional Effects of a Blood Clot: Tips to Manage Anxiety & Stress



EDUCATE YOURSELF

Learning as much as you can about DVT and PE can help you process what you're going through – but be wary about the resources that you use. You can find links to credible articles and websites at <u>https://natfonline.org/patients/</u> educational-resources.





JOIN A SUPPORT GROUP

Research shows that support groups improve quality of life and functioning. If attending an in-person group isn't an option, there are online options, such as NATF's online support group and the National Blood Clot Alliance discussion community. Social media is a great way to find support as well.





TALK TO YOUR HEALTHCARE PROVIDER

Bring a list of questions to your appointments and make your medical team aware of how you're feeling. If you feel that you can't manage your anxiety alone, your provider can refer you to a mental health professional.





PRACTICE SELF-CARE

Make time for hobbies, eat well, stay active, and try to get enough sleep.





When I started my nursing career, I didn't consciously realize that I was choosing vascular medicine – but I fell in love with it.

Q: You've been working at TRG, the Thrombosis Research Group at BWH, for more than 30 years. What is TRG and what's your role there?

A: TRG addresses the medical and psychological care of patients who have cardiovascular (CV) diseases, like blood clots, atrial fibrillation, and coronary artery disease.

During my time at TRG, I've worked on many clinical trials. I've helped recruit, screen, and enroll patients in trials and I've implemented lots of study protocols. If patients were hospitalized, I'd handle the inpatient, discharge, and follow-up processes. We'd all work as a team to make sure

the study protocol was carried out appropriately, and depending on the study, we'd follow these patients for years!

Q: What have you enjoyed most in your research role?

A: It's gratifying to see how our work impacts medical practice. Some of the trials I've worked on have dramatically changed how we

manage blood clots and other CV diseases. One of the most memorable trials looked at the use of an anticoagulant injection called low-molecular-weight heparin (LMWH) for blood clot treatment. This was a groundbreaking study because we found that patients with blood clots could go home and selfadminister LMWH instead of being admitted to the hospital.

Q: What should patients know about a clinical trial if they haven't participated in one before?

A: The purpose of a clinical trial is to see if there's a treatment that's potentially better than the therapies we're already using. We can't figure that out without the help of our patients – and likewise, lots of patients want to be a part of medical advancement. But people should know that once they consent to being in a trial, they don't need to stay the course if they're uncomfortable. They can always withdraw consent. I don't think people always realize that about research protocols.



Ruth and three of her grandchildren

To comply with study protocols, we watch patients closely and are always available to them. A huge part of the research process is providing support to participants.

Q: And outside of the clinical trial realm, you've provided support to hundreds of patients. You and NATF's president, Dr. Goldhaber, launched a blood clot support group almost 30 years ago. Tell us about that.

A: After having a blood clot, patients would come into the clinic with such a high anxiety level because they had no idea what was going on in their lives. Many patients had never heard of deep vein thrombosis (DVT) or pulmonary embolism (PE) and thought they might die. We'd spend a while counseling them, but then our clinic schedule would

> fall behind. So, we thought it would be nice if patients had a way to get medical information and emotional support, and the Boston PE/DVT Support Group was born. It's a great way to raise awareness about clots and it helps blood clot survivors feel less alone.

We still meet monthly and typically split the meeting into two parts. First, we explain "blood clot basics"

in lay terms and provide patients with insight into current trials, research, and guidelines. Then, we ask patients to share their stories, and we offer strategies for managing their anxiety. (See page 3 for some tips.)

Q: What's been the most important thing you've learned in your career?

A: I've learned compassion beyond belief. As a nurse, your priority is to keep people alive (or care for them when they're dying), help them maintain autonomy, work with them to manage stress, and care for them like you'd care for a family member. I've had moments every day in my career that I'll remember for the rest of my life, and I'm so grateful for those experiences.



Q: Did you fear that you had a clot in your arm?

A: I knew I had a clot. I get a very distinct feeling when I have a clot. It's not really pain, but it's an achy feeling. It's hard to describe if you haven't experienced it, but it's a sensation I've had with every clot.

An ultrasound of my arm confirmed a superficial clot and my doctor prescribed heparin injections. A week went by and my arm got worse. A second ultrasound showed that the clot had grown, even though I was on the injections. I switched to fondaparinux injections for 45 days and the clot went away. My hematologist told me that I'd need lifelong anticoagulation if I were to have another clot.

Q: And are you on lifelong anticoagulation now?

A: Yes. In 2018, I had unexplained pain behind my

left ankle. I exercise a lot between running and spin classes, so I thought I just tweaked something. A couple days later, I started getting that achy feeling and went to the emergency room. They didn't find a clot on my ultrasound – I was so relieved!

The swelling subsided a few days later, so I figured whatever injury I had was healing. I went to a spin class and midway through, it felt like there was a wall in my chest and I just couldn't get any air past it. I went back to the hospital and a CT scan confirmed PEs in both lungs. I was admitted to the hospital overnight and discharged on apixaban for life.

Q: How have the clots affected your life?

A: Physically, I still have pain in my right leg and it's always swollen in a certain spot. Compression stockings help. I wear them for a few hours every day and when I travel on planes.



Melissa and her twin sister, Kelly

Mentally and emotionally, the anxiety is the worst part. I think about my clots every day. Whenever I feel something off or weird, I wonder if I have another clot. Before my PE, there was a DVT in my body that didn't show up on ultrasound or that was too small to see. The doctors couldn't tell it was there, and that freaks me out.

Since the PE, I've been to the ER twice for false alarms – my leg has been swollen and I've had pain that I can't explain. The anxious feeling is always going to be a part of my life.

Q: How do you manage the anxiety, and what advice would you give to other blood clot survivors?

A: The best way that I can deal with it is to really listen to my body. If I feel that something's wrong, I'm not afraid to get it checked out. I'd tell anyone else the same thing. You know yourself best. If you

> think something's off, call your doctor or go to the emergency room.

Educate yourself, too. The more educated you are about your condition, the more you can advocate for yourself. In my experience, healthcare providers don't always think of blood clots right away when a healthy person comes in with shortness of breath or other "generic" symptoms. My knowledge about blood clots has helped me in those situations.

I also don't think women are counseled enough on the risks

that come with birth control. Birth control can be dangerous, and women need to be educated about the risks.

Q: Are you back to exercising?

A: Yes! All of my doctors have told me that being healthy and active really works to my advantage. I was fully recovered from my PE in a month – I feel very lucky. ■



Fighting blood clots through education

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