



OCTOBER 2017

# The Beat

A publication of the North American Thrombosis Forum

## Patient Perspective – Melissa Shea

*Melissa is a mother to two beautiful children, a loving wife, and a dedicated professional. After experiencing a stroke, SCAD (heart attack), and pulmonary embolism (PE), Melissa became a regular attendee of NATF's Blood Clot Support Group.*

**HERE IS MELISSA'S INCREDIBLE STORY OF SURVIVAL AND RECOVERY.**

### Can you tell me about your health complications?

I've had several major health challenges in the past 8 or 9 years, all of which have been extremely challenging to get through both physically and emotionally.

I was pretty healthy until 2008. I gave birth to a healthy baby girl and 9 days after that I had a very bad headache, which was pretty much my only symptom. I went to the hospital, and I was diagnosed with a vertebral artery dissection, which is a tear in the vertebral artery in my neck that causes strokes. They were able to stop it. I was put on medication for it and, luckily, I didn't have to have surgery.

Fast forward to 2015. I had another successful pregnancy, with no complications. When my daughter was 3 weeks old, we were at the mall Christmas shopping and I had this feeling come over me. I knew something was wrong.

They took me to the nearest emergency room and diagnosed me with a spontaneous coronary artery dissection (SCAD), which is when the coronary artery

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## INR In-Home Testing

Patients on warfarin need to get their INR levels measured regularly. This often involves visiting a local anticoagulation clinic or healthcare provider. However, in-home testing, also known as self-testing and point-of-care testing, is a great option that many patients are not aware of.

"I think a lot of patients don't think of it as an option because they don't really know about it," explained Dr. Peter Collins, an advanced clinical practice pharmacist at Brigham and Women's Hospital. Dr. Collins works at Brigham and Women's anticoagulation clinic, where he helps patients on warfarin get set up with in-home INR testing.

"Doctor's offices, and even sometimes the anticoagulation clinics, don't necessarily present it as an option," he

continued, acknowledging that there is no specific reason behind why in-home testing isn't advertised to patients.

"I think education would definitely get more patients involved with it."

### HOW DOES INR IN-HOME TESTING WORK?

1. First, patients interested in in-home testing must speak to the doctor who prescribes their warfarin and manages their anticoagulation. The doctor will help them decide if they are a good fit for in-home testing. If so, the doctor submits a form to a medical service company with the patient's information.

There are a variety of companies that provide these machines. According to Dr. Collins, Brigham and Women's

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## 2017 Celebration of Gratitude

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Hospital works primarily with Alere to provide their patients with in-home testing services.

2. The medical service company will get patients set up with their machine and show them how to use it properly.

"Once the patient is determined to be a good candidate for self-testing, we go through a company that handles the testing of the INR results and the training," explained Dr. Collins "They send a trainer out to the patient's home to go over how to report the results and use the machine correctly. They also work with the patient's health insurance to cover the machine."

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## Letter from the Executive Director

After months of hard work, we are delighted to officially announce the launch of the new NATF website. The web address remains the same, [www.NATFonline.org](http://www.NATFonline.org), but the experience is all new.

Our goal with the new website is to provide our visitors an easier way to learn about new advances in thrombosis, provide emotional support to patients, and keep people up-to-date about NATF's educational and outreach programs. The new website is also easier to navigate and gives better access to the information you are looking for. We will be constantly updating our content with helpful information, articles, blogs, newsletters, announcements, and patient profiles, so be sure to check-in frequently.

In the true spirit of NATF, we have information for both patients and healthcare providers, which we hope will help facilitate more meaningful conversations between the two groups.

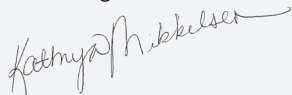
Speaking of conversations, the new site also features integrated social media buttons for Facebook and Twitter to foster improved communication with the NATF community.

We hope you find the new website fresh and modern. We worked hard to make sure the new website contains the important health information you need, but we are always looking for suggestions on ways to improve.

I look forward to hearing your feedback on the new website. I hope you find it useful, easy to use, and fun to engage with.

As always, thank you for your support of NATF, which makes things like our new website possible.

Warm regards,



Kathryn Mikkelsen  
Executive Director

### PATIENT PERSPECTIVE – MELISSA SHEA

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Melissa and her kids

tears and slows or blocks blood flow to the heart, causing a heart attack. After my SCAD, I did cardiac rehab and was put on several medications.

I was emotionally affected by the SCAD. Physically, I knew I was in good hands and I was being treated by some of the best cardiologists in the world, at some of the best hospitals in the world. But, emotionally, I definitely had a hard time.

In January of 2017, I was at work and noticed I was just a little bit short of breath. Nothing worth worrying about, I thought. So, I called my primary care doctor, just to ask, and she said, "You know what, with your history, you should probably go to the emergency room and check it out."

So, I went to the emergency room and they did all sorts of tests, which revealed I had several unprovoked pulmonary embolisms.

#### Did you have any risk factors for PE?

No. I hadn't been on a long plane ride. I hadn't been traveling. I didn't sit long hours at a desk. So, there were really no risk factors to explain why it would happen. That was another emotional toll that definitely affected me.

#### Tell me more about the emotional toll that your health problems caused.

The biggest emotional toll that the PE diagnosis had on me was just the unknown. I was already on a low dose aspirin. This wasn't supposed to happen to me. Obviously,

my medication was not correct. Obviously, something else was going on.

So, that was definitely hard. I have two small children that I need to worry about. I work. I have a family. I had a lot of questions: Should I be worried? Is this going to happen to me again? What caused it?

I hate to think of it as the sky is falling, but I had already had several major medical events and now this.

#### How did you get connected with the NATF Blood Clot Support Group, and how did it help?

I was seeing a hematologist after my PE. As I was leaving an appointment, I just happened to talk about needing a support group. My doctor's eyes immediately lit up. She knew exactly what would be good for me. She recommended NATF's Blood Clot Support Group.

I immediately went home and signed up, and I've been coming every month since. It's helped me immensely. I don't want to sound corny, but it's been a life-changing thing for me.

When do you ever get doctors or nurses that are immediately there for you? At support group, they're here to answer all of your question. You don't have to wait six months for an appointment. You don't have to wait until somebody gets back to you by email. You have that one-on-one experience in support group, and it's been life-changing for me.

There's only so many times that you can talk to your family and your friends, but talking to people who have been through it is huge for me. There's a lot less anxiety about it.

Melissa's experience with the Blood Clot Support Group inspired her to start her own support group for patients with SCAD.

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## INR IN-HOME TESTING

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3. Once patients are set up with their device and properly trained in taking and reporting their INR levels, they are ready to take over their own INR testing. When patients report their INR results, the anticoagulation clinics make their dosage adjustments and reports them to the patients in the comfort of their own home.

### WHO IS A GOOD CANDIDATE FOR IN-HOME TESTING?

INR in-home testing is a great resource that is beneficial for many patients. Dr. Collins estimates that 15 to 20 percent of his patients at Brigham and Women's Hospital self-test.

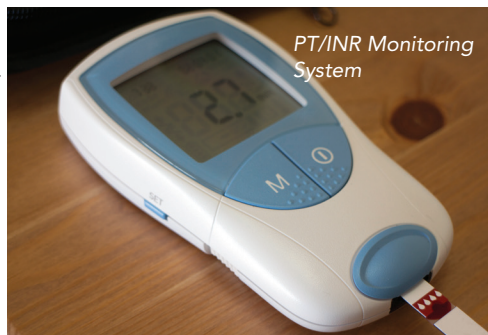
In-home testing is a great option for patients who can't make it to the lab frequently, who travel often, or who want to be self-sufficient. It's also good for patients who have difficulty leaving their homes. Patients must be on warfarin for 3 months before in-home testing can be approved by insurance. By doing this, patients will likely already have an established, stable warfarin dose that works for them.

"Most patients think of this as a no brainer. It's something that is more convenient. You don't have to give a full blood sample (just a finger stick). It's much less invasive," said Dr. Collins. However, he noted that in-home testing is not for everyone.

"When a patient shows interest in in-home testing, we look at the indication for their anticoagulation. There are some thrombophilias that interfere with how the machine measures the INR ratings," he explained, citing antiphospholipid syndrome. "For those patients we would want to avoid the point-of-care testing."

### IN-HOME TESTING MAY LEAD TO LESS BLOOD CLOTS

Studies show that patients who self-test have a higher rate of being in the correct INR range. They spend closer to 71 percent of their time in range, compared to patients who visit anticoagulation clinics and spend 60-65 percent of their time in range.



PT/INR Monitoring System

### What benefits come with in-home testing?

- In-home testing is convenient.
- It allows patients to test their INR levels without the need for frequent visits to a lab.
- In-home testing only requires a finger stick, instead of a full blood sample.

"The time in range is much better in these patients," Dr. Collins noted. "The occurrence of adverse thrombotic events is decreased in this population."

Part of this could be related to how often these patients have their INR levels tested. Insurance mandates that they are tested at least twice a month. This leads them to receiving more frequent dosage adjustments to balance their INR levels.

Dr. Collins also noted that this difference in INR range may stem from the types of patients who seek out in-home testing and shepherd it through the approval process. These patients are often highly motivated and invested in their healthcare. They take their treatments seriously, strictly adhering to their treatment plans.

### ARE THERE ANY CHALLENGES TO IN-HOME TESTING?

In-home testing is not for everyone, and it does come with challenges.

One major issue is that the in-home testing machines can be less accurate than testing at a clinic.

"It's not as accurate as venipuncture, but we have additional tools to ensure we're getting the most accurate result and dosing it appropriately," said Dr. Collins. "We have policies in place to help with that."

Although self-testing machines are approved by the FDA, Brigham and Women's Hospital tests the accuracy of the machines themselves. Dr. Collins has found that some of his patient's machines can be up to 20-30 percent off in measuring INR levels. To counteract this, Brigham and Women's

Hospital compares the results of the patient's first few in-home tests with tests taken at the clinic.

Patients who self-test must also understand that they may have to return to the clinic for testing, if their INR levels are found to be high.

*As with all forms of treatment and testing, INR in-home testing has its challenges and benefits. It's not the appropriate testing method for every patient. If you are interested in pursuing in-home testing, talk to your doctor to learn about what options are best for you.*

## Finding Support in Chicago

Support groups for deep vein thrombosis (DVT) and pulmonary embolism (PE) are an important part of post-diagnosis care for patients and their caregivers. They give patients an insight into how others have coped with the disease, serve as a safe place for them to discuss their anxieties after being diagnosed with a blood clot, and give them access to accurate and reliable information.

Here in Boston, NATF holds monthly online and in-person support group meetings, which take place at Brigham and Women's Hospital. There are also other support groups across the country. One such support group is the NorthShore University HealthSystem's Clot Aware support group, located in Chicago, IL.

### CELEBRATING SIX YEARS OF SUCCESS

In June, the NorthShore University HealthSystem's Clot Aware support group, hosted by Drs. Joseph Caprini and Alfonso Tafur, celebrated their six-year anniversary. NATF was proud to attend their Thank You Meeting on June 10, 2017. This exciting event was held to honor and recognize support group members.

The NorthShore University HealthSystem's Clot Aware support group serves the Chicago, IL community. Similar to NATF's Boston-based support group, it provides a supportive environment for patients to discuss their medical

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## FINDING SUPPORT IN CHICAGO

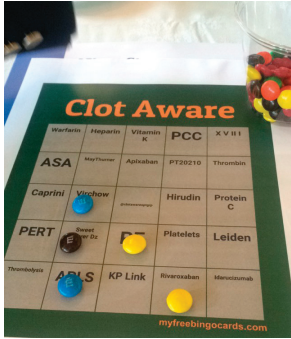
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treatments, share their common concerns, and learn up-to-date information about their condition.

"The most helpful thing for me has been listening to the experiences that other patients have had," said Loisann Koestler, who has been participating in the support group for one year. Patients often discuss topics such as anticoagulation, compression stockings, physical challenges, or changes in lifestyle caused by their disease.

"It's been enlightening," remarked one participant.

"The group has been amazing," said another.



The Thank You Meeting featured a healthy lunch for patients to enjoy, a poster session featuring new research, and music performed by several talented doctors. Dr. Tafur led attendees in an exciting and informative round of "Clot Awareness Bingo."

"It's all about education and educating the public," said Dr. Caprini, who founded the group.

He described the support group members as "disciples," who go out and spread thrombosis awareness among their friends and families. By educating his patients, the support group helps create a network in the community. Participants leave the support group and want to share what they've learned, so that their loved-ones can avoid PE or DVT.

## BUILDING SUPPORT IN YOUR COMMUNITY

When Dr. Caprini began his support group in Chicago, he was inspired by the work of Dr. Samuel Goldhaber, his colleague and the president of NATF, Ruth Morrison, RN, and Kathryn Mikkelsen, executive director of NATF. Dr. Goldhaber and Ruth started their Boston-based support group over twenty-five years ago.

Today, NATF is striving to provide support across the United States and is looking for passionate doctors and patients to begin new support groups. Like the groups in Chicago and Boston, these new support groups will help not only provide support to patients and caregivers, but also spread awareness in their communities.



*Dr. Caprini and two support group members*

*Are you interested in starting a blood clot support group in your community? Contact Kelly Meredith at [kmeredith@natfonline.org](mailto:kmeredith@natfonline.org)*

*Interested in attending the Chicago support group meetings? Reach out to Nancy Lala at [nlala@north-shore.org](mailto:nlala@north-shore.org). Patients, family members, and friends are welcome to attend.*

## Heart Healthy Recipe

Fall is in full swing. As the leaves continue to change color and temperatures begin to drop, warm yourself up with a bowl of hearty chicken noodle soup.



### HEARTY CHICKEN NOODLE SOUP

*From: American Heart Association's Simple Cooking with Heart Program*

This is a great recipe for people on the go. Just add the ingredients

together in a crock-pot and leave them to cook. By the time you're home from work, dinner is ready!

This recipe is designed to be cooked in a 6-quart (or larger) crock-pot.

#### Ingredients:

- 1 pound of boneless, skinless chicken breast
- 3 cups of peeled, sliced carrots
- 3 cups of chopped celery
- 1 can of low-sodium chicken broth
- 6 cups of water

- 3 bay leaves
- 2 teaspoons of Italian spice blend
- 1 teaspoon of garlic powder
- ½ teaspoon ground black pepper
- 1 cup of fresh dill
- 1 (12 ounce) bag of egg noodles, cooked

#### Recipe:

1. Place your chicken breasts at the bottom of the crock-pot. Then, add your carrots, celery, chicken broth, water, bay leaves, Italian spice blend, garlic powder, black pepper, and salt.
2. Cover your crock-pot. Cook your soup until the chicken is fully cooked. This can take 8 hours on low heat or 4 hours on high heat.
3. Take your bay leaves out of the soup.
4. Remove the chicken from the soup and place it into a medium bowl. While the chicken is out, stir in your dill. At this time, your crock-pot should be off, but you can leave the soup covered to keep it warm.
5. Once your chicken has cooled, cut it into bite-sized pieces. While doing this, cook your egg noodles.
6. Add your chicken back into the soup.
7. Place cooked egg noodles in serving bowls, and ladle soup over them.

*Have a recipe you'd like to share? Email [info@natfonline.org](mailto:info@natfonline.org). We look forward to hearing from you!*

## NATF Welcomes High School Interns

Avanti Upad and Aryana Gavankar, high school seniors from Atlanta, GA, spent part of their summer vacation interning at the NATF office. In June, they joined us through a partnership with the Georgia Thrombosis Forum, an affiliate organization that works with young volunteers in Georgia to spread awareness of thrombosis. The students spent the month researching thrombosis awareness and helping NATF plan for World Thrombosis Day.

Here's what Avanti and Aryana had to say:

*"The past four weeks working at the NATF Office have been insightful, knowledgeable, and navigable in many ways pertaining to exploring my interests, as a student. I learned a lot in my time at the office, specifically in the fields of research, marketing, and publications. I did this through several projects from creating brochures and researching about blood clots, to running booths to spread awareness for thrombosis.*

*I thoroughly enjoyed researching more behind thrombosis and hearing what others have to say about it both online and offline. If I had another opportunity to come back, I would definitely take it in a heartbeat!"*

– Avanti

*"The time I spent as a summer intern in NATF was both insightful, as well as a wonderful learning experience. As a high school student, there are few times where we are able to interact with adults in a work environment. This internship taught me many skills and gave me an unforgettable experience.*

*The experience as an intern at NATF was very congenial. It was a comfortable working environment. I gained a proper understanding of a work environment, consisting of deadlines, steady yet focused individuals, and a receptive staff. This internship helped me develop my work ethic, patience, passion as well as dedication towards my work."*

– Aryana

**NATF would like to thank Avanti and Aryana for all of their hard work!**



Avanti and Aryana conducting a survey at Brigham and Women's Hospital



Avanti at the NATF display at the PERT Consortium

## PATIENT PERSPECTIVE – MELISSA SHEA

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Melissa and her family

**Melissa, can you tell us about the SCAD support group you started?**

Because of the NATF Blood Clot Support Group, I had the idea that if it had helped me, it would certainly help other people. I reached out to my cardiologist to start another support group to help survivors of SCAD. We had our first meeting last week and over 50 people showed up. It was hugely successful. I explained to my cardiologist what we do at the

NATF Blood Clot Support Group, and she just kind of followed those guidelines. It was a huge success, and I'm super proud of that.

**Are there any last thoughts you'd like to share?**

I would definitely like to say thank you to Dr. Goldhaber, Ruth, and the NATF staff for putting on support groups. I know that they must hear that a lot, but it's been life-changing to go from having a lot of anxiety and questions and just having a real hard time dealing with it, to being able to come here, even once a month. The people of NATF have been great. So, I can't thank them enough for all that they do.

And I hope that, with the new support group that I've begun with my cardiologist, maybe someday people will think that I've brought something similarly great to them.

I appreciate everything that NATF does. Dr. Goldhaber has been doing support groups for 25 years, and hopefully he does it for another 25 years, because I'll be there.

## 2017 Celebration of Gratitude



CELEBRATION  
OF  
GRATITUDE

**"Going the Distance" for the North American Thrombosis Forum**

October 18, 2017  
Joseph B. Martin Conference Center

NATF would like to invite you to join us for the 2017 Celebration of Gratitude, our new premier fundraising event. It will be an exciting night of inspiration, thanksgiving, and fun. First, join us for an evening cocktail hour and then hear from our guest speaker, Olympic medalist and blood clot survivor, Lynn Jennings.

For more information and registration, visit [www.NATFOnline.org](http://www.NATFOnline.org).





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## Upcoming Events

### **2017 Celebration of Gratitude "Going the Distance" For the North American Thrombosis Forum**

*October 18, 2017*

*Joseph B. Martin Conference Center  
Boston, MA*

NATF would like to invite you to join us for the 2017 Celebration of Gratitude, our new premier fundraising event. It will be an exciting night of inspiration, thanksgiving, and fun. First, join us for an evening cocktail hour and then hear from our guest speaker, Olympic medalist and blood clot survivor, Lynn Jennings. The evening will culminate with a dessert and champagne reception.

### **In-Person Blood Clot Support Group at Brigham and Women's Hospital in Boston, MA**

*Oct. 24 and Nov. 28, 2017*

*Brigham and Women's Hospital  
Boston, MA*

All support groups start at 7:00 p.m. and are held at Brigham and Women's Hospital. To register, email Kathryn Mikkelsen at [KMikkelsen@NATFonline.org](mailto:KMikkelsen@NATFonline.org) or call 617-730-4120.

### **Online Blood Clot Support Group**

*Nov. 14 with Dr. Elaine Hylek – "Strategies to Minimize Bleeding Complications"*

*Dec. 12 with Dr. Suresh Vedantham – "An Update on Post-Thrombotic Syndrome"*

NATF's Online Blood Clot Support Group offers patients the opportunity to share common concerns, offer support

to one-another, and to learn up-to-date and accurate information on research in the field of VTE. Dates and speakers for our upcoming meetings can be found at [www.natfonline.org](http://www.natfonline.org). To register for this online support group, please contact [info@natfonline.org](mailto:info@natfonline.org).

### **American Heart Association Scientific Sessions**

*November 13, 2017 7:00 p.m. – 9:30 p.m.*

*(dinner included)*

*Anaheim, CA*

*"Preventing Pulmonary Embolism and Stroke: A New Era of Enhanced DOAC Efficacy and Safety – Focus on Case-Based Cardiovascular Patient Management"*

### **Avoiding the Avoidable: Pathways for VTE Prevention in the Vulnerable Medically Ill**

*December 2, 2017*

*Joseph B. Martin Conference Center  
Boston, MA*

NATF will be hosting a series of **free** programs, designed for medical professionals, that will center on protecting medically ill patients across the United States from VTE. Doctors, nurses, pharmacists, and other healthcare providers are invited to join us for the opportunity to earn up to 2.75 CME credits. The event series will kick-off Dec. 2 in Boston, MA at the Joseph B. Martin Conference Center. Parking at the venue is included.

For more information on any of these events, visit [www.natfonline.org/events](http://www.natfonline.org/events), email [events@natfonline.org](mailto:events@natfonline.org), or call 617-730-4120. We look forward to hearing from you!

*NATF would like to thank our individual donors and corporate sponsors for their generosity: The BMS/Pfizer Alliance, Boehringer Ingelheim, BTG EKOS, Daiichi Sankyo, Janssen Pharmaceuticals, Portola Pharmaceuticals*