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# The Beat

A publication of the North American Thrombosis Forum



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## Patient Perspective: Brenda

Brenda is a dedicated mother and hardworking professional that experienced a deep vein thrombosis (DVT or a blood clot in the leg) after surgery. She attends NATF's in-person blood clot support group in Boston, MA. Brenda's story highlights the importance of knowing your family history and how it can interact with additional risk factors.

### Q: When did you first have a blood clot?

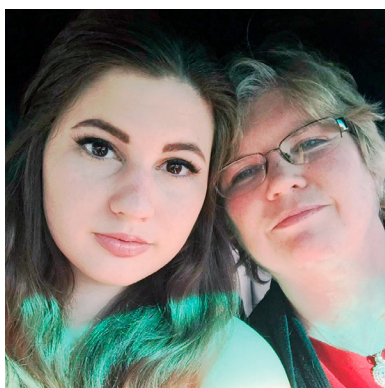
I had it following surgery. I had had a double mastectomy and was undergoing reconstruction.

Probably within three days after surgery, I could feel a pain in my leg. I thought nothing of it. I kept doing my thing and basically, I thought it was a charley horse. On the third day of it not getting any better, I decided to call my primary care doctor.

He ordered an ultrasound. I was kind of surprised when the tech told me that I had a blood clot.

### Q: Did you know what a blood clot was before you experienced one?

I knew what it was because my dad has had blood clots for years. His always went to his lungs.



Brenda (right) and her daughter



## Genetic Risk Factors for Blood Clots and the Role of Genetic Testing



The blood clotting system plays a vital role in stopping bleeding in case of open damage to blood vessels. This vital function is accomplished by the coordinated work of platelets and a set of circulating inactive clotting factors. When the wall of a vessel is damaged, platelets clump together



## Upcoming Events

### Online Blood Clot Support Group

**December 11 with Dr. Samuel Berkman – What's New? An Update on Bleeding While on Anticoagulants**

*Dates for 2019 will be announced soon. Please check [natfonline.org](http://natfonline.org) for more.*

NATF's Online Blood Clot Support Group offers patients the opportunity to share common concerns, offer support to one-another, and learn up-to-date and accurate information, including new research on blood clot prevention and treatments. Dates and speakers for our upcoming meetings can be found at [natfonline.org/patients/support-groups](http://natfonline.org/patients/support-groups). To register for this online support group, please email [info@natfonline.org](mailto:info@natfonline.org).

**In-Person Blood Clot Support Group at BWH**  
**December 5 – Brigham and Women's Hospital, Boston, MA**

*Dates for 2019 will be announced. Please check [natfonline.org](http://natfonline.org) for more.*

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

**Independence from Blood Clots – an NATF Sponsored In-Person Blood Clot Support Group**

**December 20 – Kansas City, MO**

Independence From Blood Clots is a newly-formed, monthly support group for blood clot patients living in Independence, MO and the Kansas City area. Blood clot patients, family members, and caregivers are encouraged to attend. For more information and to register, please email Tess Jenkins at [undiscoveredcountry@msn.com](mailto:undiscoveredcountry@msn.com).

### Cardiology Updates with Pri-Med

**December 5 – Boston, MA**

NATF is working with Pri-Med to bring you CME designed by cardiologists for cardiologists. As a cardiologist, your knowledge of and expertise on the latest clinical guidelines is crucial for optimizing the care of your patients with cardiovascular comorbidities and risk factors. Participate in this complimentary CME program that meets your specialized educational needs by providing you with the most up-to-date clinical evidence from respected thought leaders in cardiovascular medicine. Check the NATF website ([natfonline.org](http://natfonline.org)) for more dates and keep an eye out for NATF in a city near you.

Register for Boston: <https://bit.ly/2xO1sMN>

**New Strategies for Preventing PE, DVT, and Stroke in Hospitalized Medically Ill Patients**

**January 10, 2019 – Los Angeles, CA**

**January 17, 2019 – New York City, NY**

This program will provide insight into the latest research and newest developments in venous thromboembolism and what healthcare providers can do to protect their most vulnerable patients. For the NYC program, you will get an exclusive look into New York University's Venous Thromboembolism Center and Pulmonary Embolism Response Team.

Register for Los Angeles: <http://www.cvent.com/d/tbqmf>

Register for New York City: <http://www.cvent.com/d/bbq3py>

For more information on any of these events, please email [events@natfonline.org](mailto:events@natfonline.org). We look forward to hearing from you!



### PATIENT PERSPECTIVE

*Continued from page 1*

It's in the family, so I was aware of it. I just wasn't aware that I would actually get one, because I had had so many surgeries prior to that one. For me, this surgery was so simple. All of the other ones I'd had were long and major. That's when I would have expected to have one.

**Q: Were the doctors able to explain why this surgery triggered a blood clot?**

It was explained to me that the type of surgery I had involves a lot of inflammation. It's not uncommon, even though it was such a small surgery. The inflammation that it brings on can actually put you at a greater risk for a blood clot.

**Q: How did you feel after your diagnosis? Were you concerned?**

I was kind of concerned. I was concerned because when my dad had blood clots, they had travelled to his lungs. So, whenever I felt anything strange I would think, "Man, did this go to my lungs?"

But, I had a lot of faith in my primary care doctor. When I went back to see him a couple of weeks after my diagnosis, we had some good conversations and my leg was feeling great. I felt like I was wasting his time. During my visits to him, I was able to ask my questions without feeling rushed. That was pretty comforting.

I figured I was pretty safe at that point.

**Q: Has your blood clot impacted your life at all since your diagnosis?**

It's always kind of in the back of my mind, wondering if it's ever going to happen again.

*Brenda had a scare in January of 2018 when she broke her foot.*

When I broke my foot, that was a concern. I had been in the emergency room (ER) in January for pneumonia and a collapsed lung. Then, I broke my foot. My other leg developed a pain similar to when I'd had my blood clot. I remember thinking, "What are the odds this would happen again?"

*Continued on page 5*





## GENETIC RISK FACTORS

*Continued from page 1*

to form a plug and activate the clotting factors to form a mesh that strengthens the plug itself. This system is tightly regulated so that a blood clot (also called a thrombus) forms only when needed. However, at times clots form when there is no breach of the vessel wall, causing potentially life-threatening conditions such as a deep vein thrombosis and pulmonary embolism (a clot that travels into the veins and then reaches the lung circulation causing a dangerous obstruction to blood flow).

Some individuals have genetic variations in one or more of their clotting factors that may predispose them to the development of a clot, usually in a vein. These genetic variations are collectively called "inherited thrombophilias" (from the Greek words for "clot" and "predisposition"). In the general population, about 10% of people have an inherited thrombophilia, a proportion that increases to about 40% among those who have already developed a clot.

The 5 most common inherited thrombophilias are called Factor V Leiden (V is the Roman numeral for factor number 5), which affects 3-7% of the population, the prothrombin gene mutation G20210A, which affects 3-7% of the population, and deficiency of protein C, protein S, and antithrombin, each affecting less than 1% of the population. The presence of these genetic mutations increases the risk of a first clot several-folds, but once a patient has had a clot the risk of a second clot in the future is not much higher than that of a patient without thrombophilia who has developed a clot.

Most people at this point would be asking the experts: "If these genetic conditions predispose to clots, shouldn't we all get tested?"

Surprisingly, the answer is "no," for a number of reasons. Screening (testing in the absence of the disease) in the general population is not recommended because:

- 1) There are few symptomatic people in the general population and few people with the common thrombophilias develop symptoms from it.
- 2) We don't have a safe and cost-effective long-term method of preventive treatment if an abnormality is found.

In simple words: the preventive treatment would expose a patient to more risk (such as bleeding) than the possible benefit of not developing a clot.

As these conditions are genetic and may affect more than one member of the same family, another frequent question that experts are often asked is: "My sister had a clot and has thrombophilia: should all family members get tested?"



Commonly, as thrombophilias are autosomal-dominant diseases, 50% of relatives will carry the same abnormal gene. If the family member also has the genetic abnormality but has not developed a clot, then the above considerations for the general population also apply. However, in specific high-risk situations (trauma, surgery, immobilization >7days, delivery) prophylactic treatment may be considered.

Finally, another common concern that the expert is asked to address is: "I have had a clot, should I be tested?"

In general, the evaluation for thrombophilias in all patients with a diagnosis of clots is not recommended. However, testing is considered appropriate in specific populations:

- 1) Patients with a family history of clot in a first degree relative before age 45.

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## Bring Support to your Community!

NATF is looking for patients or healthcare providers that would like to start a blood clot support group in their area.

With short appointment times, it can be difficult for patients to get the answers and support they need to understand and process their blood clot diagnosis. Starting a blood clot support group with the North American Thrombosis Forum can help!

Don't take our word for it! One Boston support group member described their experience as, "Very encouraging. It became very clear that life after a blood clot is certainly a possibility and a real positive possibility."

*If you, or someone you know, may benefit from starting a blood clot support group, email [kmeredith@natfonline.org](mailto:kmeredith@natfonline.org) to learn more.*



## Gaining Independence From Blood Clots



Tess Jenkins

Tess Jenkins is launching a new blood clot patient support group in Independence, Missouri. Located near Kansas City, MO, Tess' group has opened a new channel of healing for those diagnosed with a blood clot.

Tess is a blood clot survivor herself.

"I have had two pulmonary emboli. I didn't have any of the risk factors. I hadn't been traveling or sedentary," explained Tess, who had many of the same

questions others face after being diagnosed.

"The doctors don't give you a lot of information. Whether it's because of the time constraints or they just don't think about it, they just don't," Tess said. "So, people are left with a lot of questions and they struggle to figure it out on their own. A lot of people are left without finding something like a support group."

After her diagnosis, Tess found support through a Facebook group of fellow blood clot survivors. From here, she connected with NATF and felt the need to step up and help those in her community.

"I'm not the leader type. I've never led anything in my life," Tess explained. "I'm more of a follower, but something just came to me and said 'this is something I need to do.'"

Tess' support group is a monthly support group that will meet at 7:00pm at The City House, 14300 E US Hwy 40, Kansas City, MO. It is open to blood clot patients, as well as caregivers, friends, and family. Attendees will get to share their first-hand experiences and hear from other blood clot survivors. The group is designed to increase knowledge, help survivors develop confidence, and help survivors cope with the challenges that come with blood clots.

"The awareness needs to be out there," Tess stressed. "I want to let people know they're not alone, the survivors, the families, and the caregivers. There's others out there, and there are people that care."

NATF would like to thank Tess for helping NATF start more in-person blood clot support groups.

If you are in the Kansas City area, please consider attending Tess' group. Upcoming dates will be released shortly on the NATF website. Please email [info@natfonline.org](mailto:info@natfonline.org) for more information.

*The next "Independence From Blood Clots" support group session will be held on December 20.*



### Independence From Blood Clots

is a newly-formed, monthly support group for local, Independence, MO blood clot patients, family members, and caregivers.

Join us for the opportunity to:

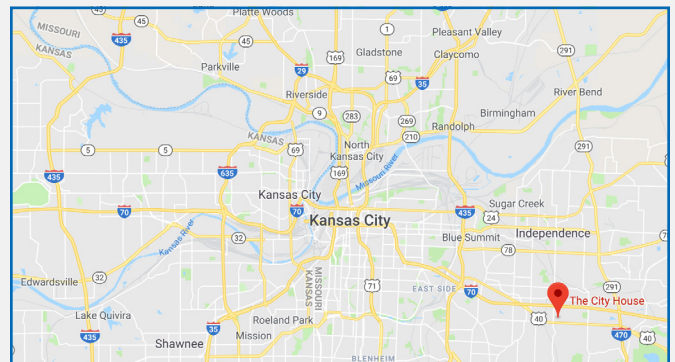
- Share first-hand experiences with others
- Help one another cope with challenges
- Increase knowledge, develop confidence, fortify hope



For more information, or to sign up, please contact Tess Jenkins at [undiscoveredcountry@msn.com](mailto:undiscoveredcountry@msn.com)

This support group is sponsored by the North American Thrombosis Forum, a non-profit that focuses on unmet needs and issues related to thrombosis and other cardiovascular diseases.

[www.NATFonline.org](http://www.NATFonline.org)







## PATIENT PERSPECTIVE

Continued from page 2

I went to the ER thinking I had another blood clot, but then I was told it was negative. It turned out to be fine.

### **Q:** Do you have any advice for other blood clot patients?

I was very fortunate with my experience because I had such great medical care. I really think that if you have caring, intelligent doctors that make you part of the team, instead of just seeing you as a patient, you're fortunate. It's important to ask questions.

I think it's also important to have a good support system. There are other people out there that have had similar experiences, and people don't always know that. I think the NATF in-person support group is a wonderful thing, and it has helped quite a bit. It's nice to hear from different people.

*Thank you, Brenda, for sharing your story!*



## GENETIC RISK FACTORS

Continued from page 3

2) Patients without a family history of clot who present with: age <45 years; recurrent thrombosis; with thrombosis in multiple veins or unusual veins (abdomen, brain).

*If you are concerned about your genetic risk for developing a blood clot, the best thing you can do is discuss your concerns with your healthcare provider. Only your healthcare provider can give you the personalized advice and individualized treatment that you may need.*



**By Umberto Campia, MD, MS**  
Brigham and Women's Hospital  
Harvard University



## EAST ANNUAL CONFERENCE

**December 6-9, 2018**

**Boston, MA**

Together with world renowned faculty members and practicing primary care physicians, Pri-Med will deliver a curriculum designed to empower you as a primary care professional and provide the necessary knowledge and tools to give your patients high level care.

**NATF is offering a special discount code for attendees. Register with the code NATFVIP to receive all 4 days of the conference for \$70, which includes the preconference day. Register at: <https://bit.ly/2xN169I>**



## AC FORUM 15TH NATIONAL CONFERENCE

THE DIPLOMAT BEACH RESORT

FORT LAUDERDALE

APRIL 11-13, 2019

This national conference brings together more than 900 physicians, pharmacists, and nurses for presentations by the leading experts in the field of anticoagulation.

The program includes special lectures focusing on recent advances and important issues in anticoagulation therapy, meet the experts lectures, poster presentations of original research, and exhibitors.

### Session Highlights

- Combined Therapy – Afib, Coronary and Peripheral Disease
- Optimizing Anticoagulation Clinics
- Controversies and Challenges in VTE
- Moving the Needle – Creating Change at the National Level
- Improving Safety and Quality in Anticoagulation Care
- What Is the Anticoagulation Provider To Do? Real-World Dilemmas

### EARLY BIRD REGISTRATION

Now open at [www.acforum2019.org](http://www.acforum2019.org)





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