



The Beat

AUGUST 2019

A publication of the North American Thrombosis Forum



Meet Our August 2019 Titan of Thrombosis: Mellanie True Hills



Mellanie True Hills

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

On a rainy night in March 2003, Mellanie True Hills stepped off a plane and could barely breathe as she made her way up the jet bridge. A few days later, she found herself in the ER with a 95% coronary artery blockage that required emergency stent placement. After nearly dying during the procedure, she decided to make some immediate lifestyle changes and was on the road to recovery, or so she thought. Seven months later, she landed back in the ER with a numb leg, blurry vision, and a racing heart. Her workup revealed blood clots in her leg and a close call with a stroke. The doctor told her that these complications stemmed from atrial fibrillation (AFib), a condition she didn't even know she had. Her medical team sent her home with some medications (including warfarin) and assured her she'd be fine.

As Mellanie looks back on her AFib experience, she recalls that "things were *not* fine. When your heart takes off racing and you can't breathe, it's scary. I felt like I was a ticking time bomb. I wasn't stable on my blood thinner and felt like I could have a stroke at any moment. I lived in total fear." Mellanie's family was similarly concerned and traveled with her everywhere she went. "We made sure we were always close to a hospital when we traveled. My AFib just took a toll on all of us."

In the summer of 2005, Mellanie learned that she was eligible for a new, minimally invasive procedure. "That fall, I underwent surgical ablation and had my left atrial appendage (LAA) removed. The LAA is a small sac in the left heart chamber where clots can form," she explained. The surgery stopped her AFib, but her work wasn't done.

"After I was AFib free, I kept saying that somebody needed to do something about this condition. Someone needed to raise awareness and it might as well be me!" In 2007, she launched StopAFib.org, a nonprofit resource dedicated to educating patients with AFib. She

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AFib and Thrombosis: What You Need to Know

- AFib is the most common type of irregular heartbeat. A heart that beats irregularly pumps blood less efficiently, potentially causing blood to collect in the heart. This pooled blood can form a clot.
- These clots can become embedded in arteries or move to the brain, leading to a stroke.
- *The risk of stroke is 5x higher in people with AFib compared to people without AFib.*

Upcoming Events

AFib Awareness Month

September 2019

Visit StopAFib.org to learn more about AFib

2019 NATF Thrombosis Summit

September 12, 2019

The Fairmont Copley Plaza

Boston, MA

Hand-in-Hand Against Cardiovascular Disease:
A Patient and Provider Journey

New Strategies for the Treatment and Management of Anticoagulant-Associated Bleeding

October 3, 2019

Washington DC at the Grand Hyatt Washington

October 24, 2019

Nashville, TN at the Marriott at Vanderbilt
University

December 5, 2019

San Francisco, CA at The Fairmont San Francisco

December 12, 2019

Ann Arbor, MI (venue TBA)

January 20, 2020

Cleveland, OH (venue TBA)

2019 Celebration of Gratitude

November 14, 2019

Museum of Science

Boston, MA

NATF cordially invites you to the Celebration of Gratitude, our premier fundraising event. Our enlightening keynote speaker, Dr. C. Michael Gibson, will discuss the intersection of art and science. Guests will also have exclusive access to the exhibits in the Museum's Blue Wing.

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

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Get to Know Your Heart

The heart has two upper chambers, the right atrium and left atrium, and two lower chambers, the right and left ventricles. The atria and ventricles work together to pump blood through the heart—but it's your heart's electrical system that drives the process.

IT HAPPENS IN A HEARTBEAT

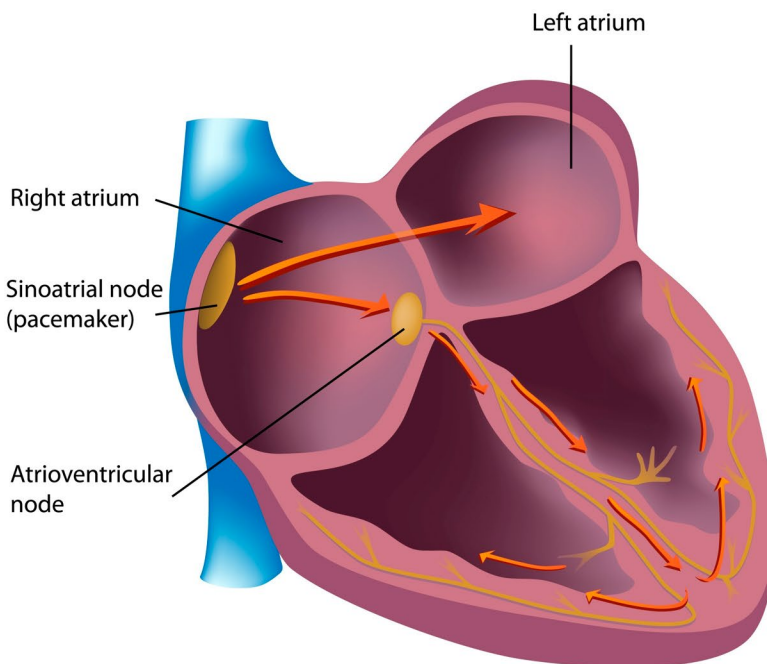
- Two large veins, the superior and inferior vena cava, carry oxygen-depleted blood through the body and deliver it to the right atrium. At the same time, the pulmonary veins carry oxygen-rich blood from the lungs and deliver it to the left atrium.
- The heart's natural pacemaker, the sinoatrial (SA) node, fires electrical signals to both atria, causing them to contract and push blood to both ventricles.

- The electrical impulses move through the atrioventricular node (AV) node and a pathway of fibers, causing both ventricles to contract and move blood from the heart to the rest of the body.
- The SA node fires again and stimulates another heartbeat. This cycle repeats 60-100 times per minute.

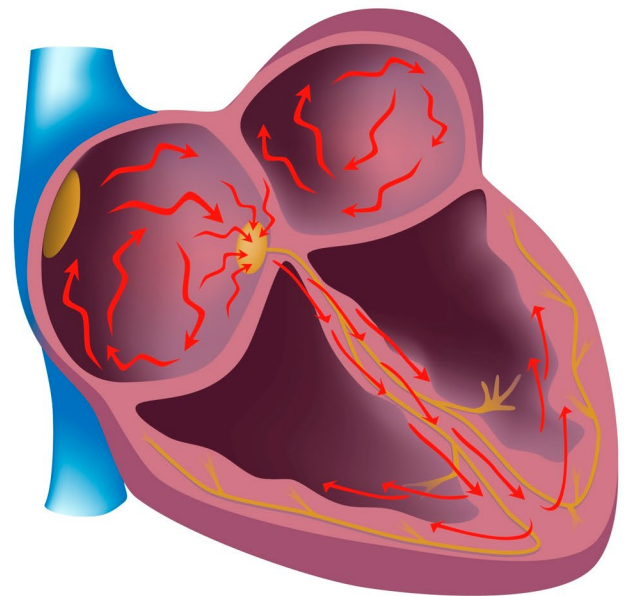
BE AFIB AWARE

- When the heart's in AFib, irregular electrical impulses disrupt the signal between the SA and AV node, and the heart beats irregularly.
- The atria pump less blood into the ventricles.
- Blood can pool in the heart and form clots.
- Irregular heartbeats can strain the heart muscle over time and set the stage for heart failure.

THE NORMAL HEART



THE HEART IN AFIB





continues to serve as the organization's CEO. She then led the charge to institute a national awareness campaign and in 2009, the US Senate declared September as National Atrial Fibrillation Awareness Month. She kicked off the "Get in Rhythm. Stay in Rhythm.® Atrial Fibrillation Patient Conference" in 2013, the first ever multiday, patient-facing AFib conference in the US. The 6th annual conference took place last week in Dallas, TX.

We recently sat down with Mellanie to get her perspective on a few important questions.

Q: Knowing what you know now, what would you tell a patient newly diagnosed with AFib?

I speak at medical conferences around the globe and a key message I deliver to patients and healthcare providers (HCPs) is that because AFib is so complicated, trying to deal with it in a single visit isn't feasible when someone is newly diagnosed. A better approach is to have two visits. The initial appointment should be a "diagnostic debrief," where patients can learn more about what AFib is and what it means for them and their lifestyle. Clinicians can address the patient's most urgent issues and guide them to educational resources. After that, the patient should return for follow-up to discuss pressing questions, management options, etc.

It's also critical to be aware of the link between AFib and stroke. We've taken part in some research that's identified a major disconnect: more than 90% of healthcare providers say that they always tell patients about the risk of stroke in AFib, but half of patients say that they don't remember hearing anything about stroke risk.¹ That's a big issue and I think that the "dual-visit" model could potentially address this communication gap.

Q: How can patients with AFib effectively advocate for themselves?

I tell patients to prepare for a doctor's appointment like you'd prepare for a business meeting. Formulate your goals in advance and think about the following:

- What questions do you have? Make a list.
- What's the priority of those questions? You may not get through your whole list in a 5- to 15-minute appointment, so determine which questions are high-priority.

- What are your values and preferences? What should your HCP know about you so they can devise an appropriate care plan?
- Who's on your healthcare team? Will you be seeing your primary care provider, a cardiologist, an electrophysiologist, a nurse, or multiple HCPs? Become familiar with each clinician's role in your care.
- Who do you want on your personal healthcare team? It's a good idea to have another set of eyes and ears at your appointments, so who will you take with you? A spouse? A son or daughter? A friend? Who will help you by being an advocate and what role will they play in your care?

According to research, more than 90% of HCPs say that they always tell patients about the risk of stroke in AFib—but half of patients say that they don't remember hearing anything about stroke risk.

Q: What's the most significant change that you've observed in the AFib space since you were diagnosed?

The rise of the educated AFib consumer is probably the most significant thing that's happened over the last several years. There's a ton of information out there now specifically *for patients*. When I started my organization, there was nothing—and I mean nothing. We now have close to 800 resources for patients and their families/caregivers on StopAfib.org and nearly 80,000 posts in our discussion forum. We've also partnered with the American Heart Association to create MyAFibExperience.org, an online community for patients. None of this stuff existed 10-15 years ago, so this is a big change and I'm thrilled to be a part of it.

Have a question or comment to share with Mellanie? She can be reached at support@stopafib.org.

¹Out of Sync: The State of AFib in America.
<https://www.stopafib.org/newsitem.cfm/NEWSID/159/>.



Upcoming Support Groups

Let's Heal Together – An In-Person Post-Thrombotic Limb Support Group

[Sponsored by NATF]

August 19, 2019

**NYU Langone Health
New York City, NY**

For more information and to register, please email Heather Paulson-Soussou at hpaulson26@optimum.net

In-Person Blood Clot Support Group

September 10, 2019

October 17, 2019

November 7, 2019

December 3, 2019

**Brigham and Women's Hospital
Boston, MA**

Please visit natfonline.org for more information

All support groups start at 7:00 PM. To register, email info@natfonline.org or call 617-730-4120.

Upcoming Online Blood Clot Support Groups

To register for this online support group, please email info@natfonline.org.

September 17, 2019

Dr. Geoff Barnes

Recent Trials Related to VTE

October 1, 2019

**Drs. Umberto Campia, Jean Connors,
and Gregory Piazza**

Ask the Expert Panel Discussion

November 26, 2019

Dr. David Jenkins

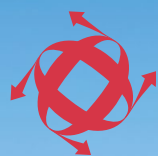
Vitamins for CVD Prevention and Treatment

December 10, 2019

Dr. Arvind Pandey

I've Had a DVT/PE: Now What?

For more information about any of these support groups, please visit www.natfonline.org/patients/support-groups or email info@natfonline.org.



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