# **Stopping Atrial Fibrillation** is Big News!

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In recognition of Atrial Fibrillation Awareness Month, author Mellanie True Hills discusses the efforts being made toward the awareness, diagnosis, and treatment of atrial fibrillation.

Atrial fibrillation is making headline news. Capitol Hill is even addressing the concerns of the afib community. Resolutions supporting access to care, afib research, and education have worked their way through Congress this past summer. The timing couldn't be better, because September is also Atrial Fibrillation Awareness Month, when healthcare facilities across the country will announce or hold community afib-related events.

To further bolster the awareness efforts during the month, three public service announcements will be airing in the coming weeks as well. Also, for patients, care supporters, and healthcare professionals, Team AFib, a coalition of organizations that advocate for atrial fibrillation patients, will conduct a Webinar on September 14, addressing the care requirements of afib patients and how the care team can best work together.

In the following article I will discuss the efforts currently being made in atrial fibrillation. I'm so thankful for all of this attention, because it means atrial fibrillation will get diagnosed and afib patients will receive better care. I am also grateful for the many doctors, nurses, donors, organizations and, of course, afib patients who have pitched in on this journey to raise awareness and grabbed those headlines.

## **Afib Legislation**

The biggest news headline came when Congress promoted the link between awareness-raising efforts and the well-being of afib sufferers. This past year, StopAfib.org, along with other organizations, asked Congress to recognize the concerns of the afib community — and they listened. The U.S. House of Representatives is considering House Resolution 295. The resolution was introduced by Representatives Kay Granger (R-TX), Dutch Ruppersberger (D-MD) and Charles Gonzalez (D-TX), and as of early August, it had 30 sponsors of the needed 100. The resolution seeks to raise the priority of afib in the existing research and education funding allocation process. Atrial fibrillation has often been overlooked

for research and funding, so this resolution asks for afib-related research to be included in current budgeting. The resolution does not seek any new funding. For more information about the House resolution, go to http://bit.ly/HRes295.

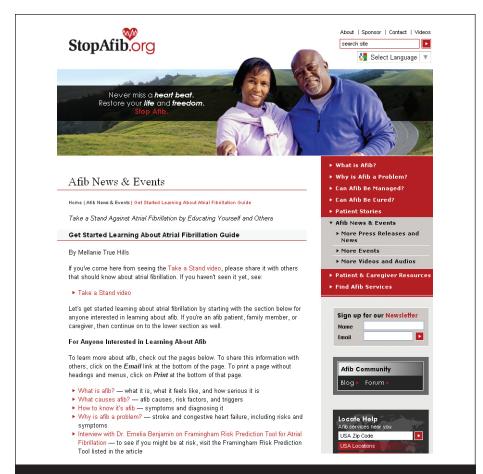
In Rep. Granger's letter to other representatives asking for their support, she straightforwardly stated why Congress should pay attention: "The increased risks for stroke and heart disease associated with atrial fibrillation have significant implications. The cost of atrial fibrillation to the U.S. healthcare system is estimated to be \$15.7 billion per year. Even more tragically, approximately 88,000 Americans will die every year as a result of this condition."

Afib grabbed the attention of the U.S. Senate, too. On July 29, 2011, the Senate introduced and passed Senate Resolution 243 by unanimous consent. For more information about the resolution, go to http://bit.ly/SRes243. The resolution calls for the increased awareness, diagnosis, and treatment of atrial fibrillation to address the high morbidity and mortality rates and prevent avoidable hospitalizations associated with the condition. Senator Michael Crapo (R-ID) introduced and shepherded the resolution through the Senate, and prominent co-sponsors included Sen. Patrick Toomey (R-PA), Sen. Robert Casey (D-PA), Sen. Marco Rubio (R-FL), Sen. Daniel Akaka (D-HI), and Sen. Daniel Inouye (D-HI).

## **Spreading the Word with Passion**

I must confess, as the founder of StopAfib. org, I am pretty proud of the attention afib has been receiving from Capitol Hill as well as from individual patients who are learning more about their condition so they can be diagnosed before having a stroke. For example, many patients (and some healthcare providers) might be surprised to learn that it can take a year or two before some afib patients are diagnosed, and oftentimes, patients can experience a stroke during that time.

Fortunately, with this increased media attention, afib patients are receiving more information to make better decisions.



StopAfib.org's Get Started Learning About Atrial Fibrillation Guide helps consumers, patients, and care supporters learn about the condition, including symptoms and risks of stroke. The guide also explains ways to manage and treat afib.

We have made great progress at raising awareness and encouraging diagnosis and treatment, but more still needs to be done, and I'm more passionate than ever about this mission.

# **September is Afib Month: What Can You Do?**

September is Afib Awareness Month, and to help raise awareness, here are some of the ways you can get involved:

- **Hosting an event.** StopAfib.org can help your healthcare facility conduct an event by helping with speakers, and assisting in preparing and marketing your event.
- **Visiting StopAfib.org.** Along with a wealth of information, several new features have recently been added to the site, including Google search, translation into more than 50 languages, an international afib healthcare provider search, and updated catheter ablation content and resources. Also check out the 'Take a Stand' video at http://bit.ly/TakeStand and the Get Started Learning About Atrial Fibrillation Guide at http://bit.ly/LearnAfib. Both are valuable resources to help patients both understand afib and build a communication bridge.
- **Supporting the House resolution.** Click to http://bit.ly/HRes295 to find the latest updates on the House resolution. You can also use the POPVOX widget at the bottom of the page to express your support, which will be delivered to your congressional representative.

Thanks for your support in our mission to save lives, and thanks for saving yourself and your family as well!

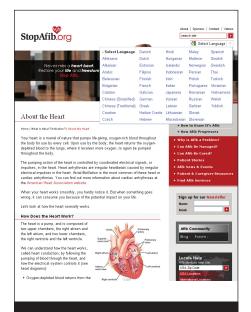
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Public service announcements airing in the coming weeks can prompt patients to ask questions and connect with their healthcare providers. One PSA features daytime TV star Susan Lucci, and in another video, former NBA player and general manager Jerry West explains how he has lived with afib.



StopAfib.org continues to expand. Among the recently added features is Google search, and translation into more than 50 languages.

Additionally, with help from medical professionals, StopAfib.org is striving to empower patients and foster better patient-healthcare provider communication. Such an honest and open dialogue leads to better understanding and solutions. As StopAfib.org and others spread the word about atrial fibrillation, more and more patients can lead better, longer lives.

As we gather steam for a series of events during Atrial Fibrillation Awareness Month (and beyond), I'm reminded of why I started my mission to rid the world of afib and strokes. I founded StopAfib.org for intensely personal reasons: I have felt the fear and uncertainty that comes with afib.

In late 2003, I was sitting at my desk in my home office. I could feel my heart pause and then take off racing. My right leg went numb, and the vision in my right eye seemed blurry. At the emergency room, they said I'd had blood clots and a close call with a stroke because of afib.

That was my first episode of afib. After that, episodes came frequently. I was taking a blood thinner to prevent a stroke, but it was not working. With every afib episode, I felt like a ticking time bomb, because nearly 35 percent of those who have afib will have a stroke. I was literally a stroke walking around waiting to happen. I was



Check out the POPVOX widget at http://bit.ly/HRes295 to express your support of House Resolution 295, which seeks to support and improve access to care and promote afib research and education.

terrified by every afib episode.

I knew I couldn't live with the nightmare of constantly waiting for a stroke for the rest of my life. I discovered a procedure that could stop my afib and remove the source of most clots, and on September 13, 2011, I will celebrate having been afib-free for six years.

Once I was afib-free, I couldn't stand on the sidelines and watch others suffer and have strokes. I had to do something about it. That's why I started StopAfib.org, a nonprofit patient advocacy organization and site to provide information and support for those living with atrial fibrillation.

I knew that we needed to raise awareness so people could get diagnosed and receive treatment before they had a stroke or two. So I declared September as Atrial Fibrillation Month, and after celebrating it, I got it registered in the official register, Chase's Calendar of Events. Then in 2008, I discovered that some other organizations were interested in getting it declared nationally, so StopAfib.org joined together with a num- • AF Stat, "A Call to Action for Atrial Fibrillaber of professional and patient organizations, including the American Heart Association and the Heart Rhythm Society, and asked Congress to make it official. On September 11, 2009, the U.S. Senate passed a resolution officially recognizing September as National Atrial Fibrillation Awareness Month.<sup>1</sup>



Through our collaboration, we have made great progress at raising awareness and encouraging diagnosis and treatment, but more still needs to be done, and I'm more passionate than ever about this mission.

### **New Afib PSAs Help Raise Awareness**

As the mission to raise afib awareness continues to gain more partners, we build more momentum. Recently three fantastic public service announcement (PSA) campaigns from partner coalitions and organizations StopAfib.org is working closely with were released to help raise afib awareness. We encourage you to share these videos with your patients. Here is a brief synopsis of each PSA:

- Facing AFib, "Get Serious about Stroke." Daytime TV star Susan Lucci and her husband Helmut Huber share how they have battled with his afib. The video describes the health risks of afib, including stroke, and explains how the more than two million Americans with afib can care for themselves or a loved one with the condition. Check it out at: http://www. FacingAFib.com
- tion." Narrated by Jerry West, the former NBA player whose likeness was used for the red, white and blue NBA logo, this video describes how afib may go untreated. West, for example, says that he has lived with the condition for many years. Check it out at: http://www.AFStat.com

• Heart Rhythm Society, "A-Fib Feels Like." This public service announcement describes what it's like to live with afib and helps those who may not even know that they have the condition to recognize the symptoms. In the video, dramatizations from afib patients describe what it's like to feel afib and viewers are urged to speak with their doctors if they believe they are feeling the same kind of symptoms. Check it out at: http://bit.ly/HRS-PSA

#### **Medical Community Connection**

In addition to providing more information to those who suffer from afib, another important part of StopAfib.org's mission is to spread afib information to the medical community. For example, I've found that when medical professionals know what it's like to live with afib, it leads to both better communication and care.

This is why Team Afib will be conducting a Webinar for patients, care supporters, and medical professionals on September 14. I'll be hosting the Webinar discussion, which will feature three highly qualified panelists representing the following care team areas:

- · Physicians: Dr. Keith Ferdinand is adjunct clinical professor at the Morehouse School of Medicine, clinical professor in the cardiology division at Emory University, and chief science officer of the Association of Black Cardiologists.
- Nurses: Dulce Obias-Manno, RN is a clinical coordinator in the arrhythmia service at the Pacemaker and Defibrillator Clinic of Washington Hospital Center.
- Afib care supporters: Pegge is a homemaker and mother of two who has been supporting her husband, Mike, in his afib care since he was diagnosed in 2004.

Together, this group will share vital information for all members of the afib care team. I hope you can join us on September 14; for more information please see http://bit.ly/ TeamAFib. If you can't join us, look for the video replay on the Team AFib web site soon afterward at http://www.TeamAFib.com.

> For more information, please visit: www.stopafib.org and www.mellaniehills.com

# Reference

U.S. Congress. Senate. Congressional Record 111th Congress. September 11, 2009. p. S9299. http://www.gpo.gov/fdsys/pkg/CREC-2009-09-11/pdf/CREC-2009-09-11-pt1-PgS9296-2. pdf#page=4



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