Bridging the Afib Communications Gap:

Afib Patient Perspectives from the Fourth Annual Western AF Symposium

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I'm an atrial fibrillation survivor. In 2003, I was working in my home office when my heart felt like it skipped some beats and started racing, pounding, and flopping. I felt dizzy and lightheaded, and thought I was going to pass out. My right leg was ice cold, and the vision in my right eye was blurry.

At the emergency room I was told I had blood clots and a close call with a stroke because of atrial fibrillation. I'd never heard of afib. The hospital health-care professionals packed me away with some prescriptions and said, "You'll be fine." But I wasn't fine.

My afib episodes came frequently. And when blood clots are part of the equation, afib becomes terrifying. Since I was never stable on blood thinners, I was literally a stroke walking around waiting to happen. My family wouldn't let me go anywhere by myself for fear I'd be by myself and have a stroke and die. Finally, after almost 2 years, I had a surgical procedure and have been afib-free for 5 1/2 years.

Because of my experiences living with afib, working with health-care professionals and connecting to other afib patients, I created StopAfib.org, a non-profit patient advocacy organization. One of the most important goals of StopAfib.org is to close the gap that's as wide as the Grand Canyon that exists between doctors and patients.

As the founder of StopAfib.org, I hear from hundreds of patients a day as well as speak at hospital-sponsored afib events around the country where I talk to thousands of patients. I have also reached out to the patient community for input, and they have shared many ideas for helping bridge that communication gap.

Grand Canyon Communication Gap

Why is this communication gap like the Grand Canyon? Because health-care professionals and afib patients can see each other, but they can't communicate — sort of like yelling across a canyon at each other!

This communication gap leads to patients being unsatisfied with their care and, what's worse, having a lower quality of life. Afib patients have a worse quality of life than even those who have had heart attacks.[1] Fifty-six percent of afib patients report the condition has had a negative impact on their lives.[2] In addition, about half of the patients I've talked with are not satisfied with their care. Their dissatisfaction is not related to any professional skills, but instead is directly linked to communication issues. Afib patients told me that their health-care providers:

- Don't take patients seriously, or even listen to them
- Don't understand the fear of living with afib
- Trivialize their patients' experiences, and even make jokes about what they are going through
- Use medical jargon and don't explain the terminology
- Blurt out instructions or explanations so quickly that they can't be understood or remembered
- Talk down to patients, or talk only to their family members, not to them
- Have to be constantly re-educated about the effects of afib.

Such attitudes directly affect the timeliness and quality of care. For example, it takes an average of 1.7 years before afib is diagnosed, leaving patients vulnerable, according to *AF Stat*™'s Out of Sync Survey.[3] In Europe, the AF AWARE survey found an average of 2.6 years before afib was diagnosed.[4]

One of the other consequences of the communication gap is that patients don't realize the seriousness of afib. While health-care providers are twice as likely as patients to recognize the seriousness of the condition, the consequences of afib don't register with the patient.[3] And many times, the seriousness of afib isn't realized until after a patient has suffered a stroke.

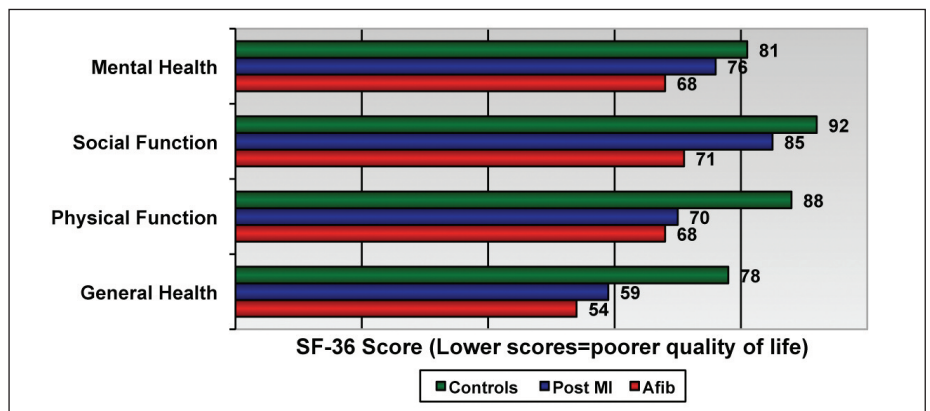
So, just how wide is this gap? Ninety-five percent of doctors and nurses believe patients are at a moderate to severe risk of stroke. Yet only 45 percent of patients believe they have that risk.[3] While most health-care providers discussed stroke risk, only about half of patients heard it, according to both the Out of Sync survey[3] and the National Stroke Association's AFib STROKE survey.[2] While 90 percent of health-care providers discuss preventing stroke, only 43 percent of patients recall hearing about stroke prevention.[3] In addition, when asked to name the most important goal of afib treatment — to restore the heart's normal rhythm, prevent stroke or control heart rate — only 33 percent of patients chose stroke prevention.[2]

One reason for this communication gap may be health-care provider attitudes. Compared with coronary artery disease and heart failure, afib is not typically seen by clinicians as a complex cardiac condition that adversely affects quality of life. Therefore, as stated in a recent article in the *Journal of*

See **AFIB PERSPECTIVES** *page 28*

StopAfib.org raises awareness about atrial fibrillation and strokes. Since launching in 2007, the site has become the No. 1 arrhythmia site and the No. 7 cardiovascular disorder site in the world.

Online forums at StopAfib.org and other media such as Facebook and Twitter allow afib patients to connect and share information.



Afib patients experience a poor quality of life — even worse than those who had heart attacks. Adapted from Dorian et al.[1,9]

AFIB PERSPECTIVES

Continued from page 26

Cardiovascular Nursing, "clinicians may minimize the significance of afib to the patient and may fail to provide the level of support and information needed for self-management of recurrent symptomatic afib."[5]

Such lack of communication may also exist because health-care providers don't fully understand what living with afib is like. Many unique characteristics of afib suggest that the experience of living with this condition may differ from the experience of living with other heart conditions. For example, afib affects a more heterogeneous population than coronary artery disease and heart failure. Afib patients range in age from late teens to the most elderly. Up to 30 percent of patients who have afib have no other cardiovascular disease, whereas others have multiple cardiovascular conditions.[5]

For those who have the condition, it is physically exhausting. When an afib episode concludes, patients feel like a limp dishrag, and often all they can do is sleep. During episodes, the heart feels like a fish flopping around in the chest. And the effects go beyond the individual episodes. Often during their daily lives, patients who are in afib all the time are fatigued, sometimes lightheaded, and unable to enjoy simple physical activities such as riding a bike or even walking.

The emotional toll of afib is heavy as well. The patient feels out of control and will do anything to stop the afib. When asked what it's like to live with afib, patients' most commonly used word is fear. Afib patients live in constant fear of a stroke or a blood clot. They also never know what they will be in the middle of doing when an episode strikes. Those with afib may have to frequently cancel plans with family and friends because of episodes and may feel like failures because afib has taken control of their lives.

The financial cost of having afib is also tremendous. Many afib patients face financial devastation that they may never recover from. Afib may cause sufferers to miss work, potentially leading to lost jobs and insurance. For those self-employed afib patients (like I was), it means you can't work. Many lose cars, houses, and even their families.

The medical costs for those with afib on Medicare were found to be five times higher than for those without, averaging almost $24,000 per year, which could have been even higher for private insurance. Of those expenses, 62 percent was for inpatient care. Afib patients averaged 67 physician visits in the first 15 months after diagnosis, and 61 percent needed emergency services at least once, with an average of three trips.[6]

Not realizing the effects of afib can lead to that Grand Canyon-sized communication gap. That is why I became an advocate for those with afib and founded StopAfib.org.

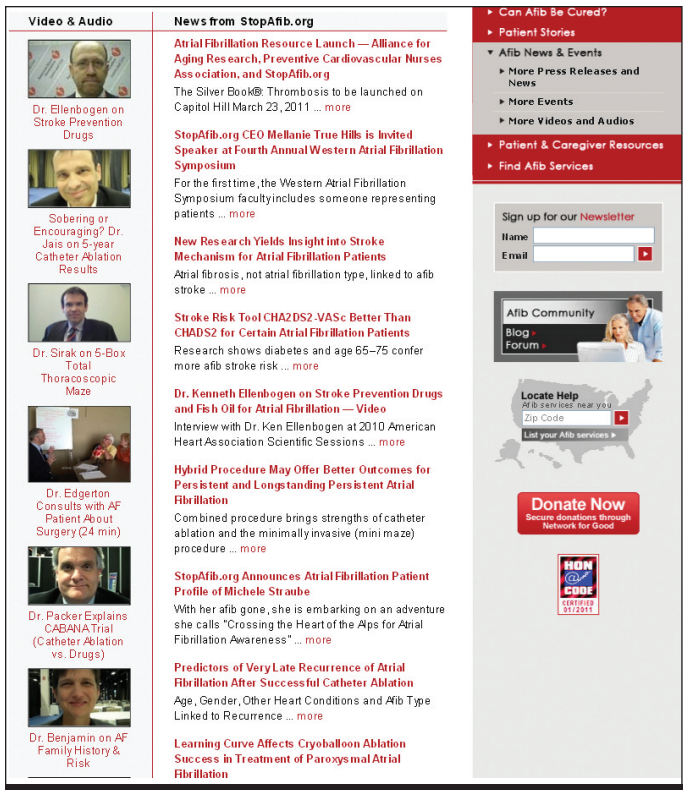
StopAfib.org: The Primary Patient Resource

StopAfib.org launched in 2007. Since then, the site has become the No. 1 arrhythmia site and the No. 7 cardiovascular disorder site worldwide, according to Alexa, a company that tracks website traffic.[7] StopAfib.org has received the HONcode seal, from the international Health On the Net Foundation (HON), certifying it as a trustworthy medical site.

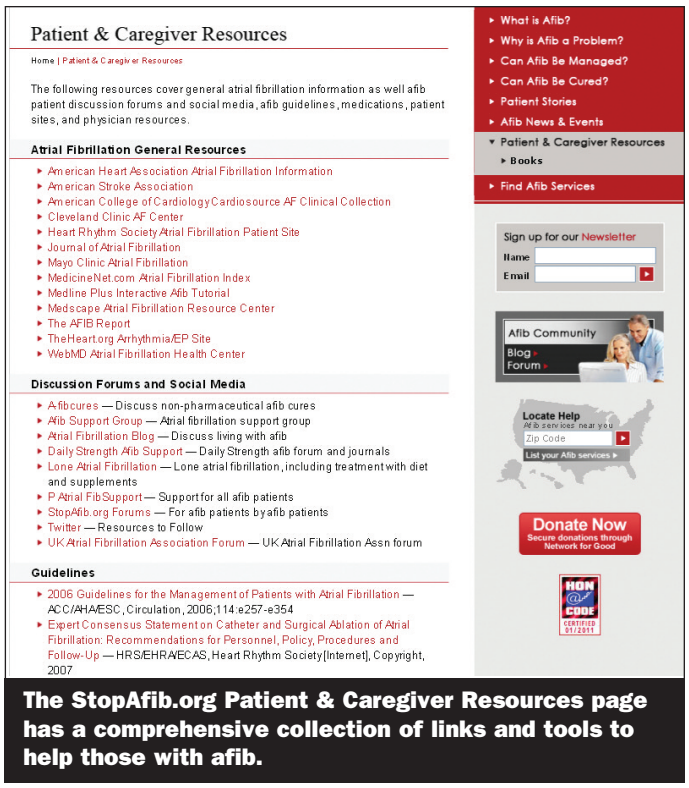
The mission of StopAfib.org is to raise awareness about afib and strokes. Among the organization's successes, it created Atrial Fibrillation Awareness Month, recognized every September. StopAfib.org lobbied on Capitol Hill along with other organizations, and in 2009, the U.S. Senate passed a resolution officially recognizing September as National Atrial Fibrillation Awareness Month.[8] Through ongoing efforts, the organization continues to make the afib patient voice heard in Washington, D.C., and has been involved in policy and awareness-raising coalitions and partnerships in the United States, Europe, Latin America, and Asia Pacific. In addition, StopAfib.org has represented the afib patient perspective to think tanks and the U.S. Food and Drug Administration.

The organization seeks to improve quality of life by supporting and enhancing communication between patients and

See **AFIB PERSPECTIVES** *page 30*



StopAfib.org features constantly updated information about the latest afib research on its News & Events page. The page also offers video interviews with doctors who are on the leading edge of afib research.



The StopAfib.org Patient & Caregiver Resources page has a comprehensive collection of links and tools to help those with afib.

The Quick Response (QR) code on this card provides afib patients access to the StopAfib.org mobile site from an Android or iPhone. StopAfib.org provides these cards to health-care providers to share with patients.

The StopAfib Atrial Fibrillation Blog provides updates about afib-related news and events. A toolbar at the bottom of the page allows the blog to be translated into 11 languages.

Why Don't Patients Take Their Meds?

Afib patients sometimes don't take medications as prescribed. Why is that, and what can you do about it?

Patients may not understand why they are taking certain medications or may have misperceptions about them, such as believing that warfarin is actually a poison. With a perception that afib "won't kill you," they may not have a sense of urgency about taking medications. Health-care providers can help by clearly explaining why the patient needs that medication and what happens if it is not taken as prescribed.

Being aware of cost issues can also help. Costly new drugs can take months for insurance plan approval, so patients who can't afford hundreds of dollars out-of-pocket may not fill prescriptions or may skip doses to stretch them.

Also, the impact of side effects on patients is frequently overlooked when discussing medications with patients. For example, beta blockers are often considered very benign by doctors, but not by patients. Fatigue, brain fog, and other beta blocker side effects can significantly impair quality of life, sometimes keeping patients from exercising, causing weight gain, and making them feel like their brain isn't working.

AFIB PERSPECTIVES
Continued from page 28

health-care providers. Through several outreach efforts, the organization also hopes to decrease afib strokes. Most importantly, StopAfib.org is for patients, by patients. Information about afib is presented in an empathetic, patient-friendly manner.

The organization's website offers a multitude of resources for those with afib. One of the most useful sections on the site is the 'Get Started Learning About Afib Guide,' where patients can learn about the condition, why afib is a problem, how it is diagnosed and treated, and what medication and procedures are used to treat it.

Also among the extensive resources on the site is a patient and caregiver resources page with links to guidelines, medications and other external resources. The site's 'News & Events' page includes video interviews with doctors who are on the leading edge of treatment and articles about the most recent research. The 'Afib Services Locator' helps patients find afib doctors and hospitals with afib centers. Such listings are free, and although currently only offered in the United States, international doctors and facilities will be online soon.

This site is wholly interactive as well. The atrial fibrillation blog features machine-translation into 11 languages, and the patient forums are full of afib patients sharing information. One of the most useful and handy awareness-raising materials the organization has created is the patient card, which doctors can hand to patients. It also features a quick response (QR) code that patients can scan with an Android or iPhone to connect to the mobile website in the phone's browser, which links to StopAfib.org, the blog, discussion forum, Twitter, Facebook, StopAfib YouTube channel, and more.

The Future: Patients and Health-Care Professionals on Same Team

The Grand Canyon-sized communications gap can be bridged. With a greater understanding of afib, health-care providers have the tools to provide more compassionate and better care. Specifically, when talking with afib patients, health-care providers can incorporate these communication strategies suggested by the afib patient community:

- *Think: What if it were me?* When dealing with afib patients, keeping the physical, emotional and financial impact of the condition in mind can lead to more empathetic care.
- *Adjust to patients.* Especially when afib patients are initially diagnosed, they may not be up to speed with the risks posed by the condition. Health-care providers may need to slow the pace of information to ensure the messages are received. Specifically, the elderly, those with hearing loss, or those on beta blockers with "brain fog" have difficulty with speed or accents, so adjust speaking speed to the patient.
- *Decrease medical jargon.* Health-care providers work in the world of abbreviations and medical terminology, but patients don't understand this jargon. Be prepared to offer explanations instead of waiting for questions, because many won't even ask.
- *Write down medical terms.* Patients can gain a greater understanding of their condition and do additional research when they know the precise language used to describe their condition.
- *Set realistic expectations.* Describing the potential outcomes of treatments and medications allows patients to know what to expect and allows them to adjust accordingly. Be honest and don't hide the truth. For example, some patients are not told that they might need more than one catheter ablation.
- *Say "I don't know."* If there is a topic or patient question that health-care providers don't have all the information about, let patients know. Patients know that afib is complex and that health-care providers may not have all the answers, and that's OK. Exploring such answers together creates a team atmosphere when addressing afib.
- *Provide credible resources.* As patients look to research their condition, point them to reputable organizations and reliable sources. Look for resources with the Health On the Net Foundation (HON code) seal, which means that the sites attribute research and are trustworthy.
- *Refer patients to StopAfib.org.* Through the organization's support network, patients can learn about the condition and share their experiences.
- *Request StopAfib.org patient cards.* These handy cards allow patients to immediately connect to afib information.

In addition to sharing information with afib patients, here are a few things health-care providers may consider **not** saying:

- "*Afib won't kill you.*" When first diagnosed, patients are in shock and can't process the deluge of information. Saying "it won't kill you" gets in the way of the real message — that blood clots and stroke can kill.
- *"Just get on with your life."* Afib has hijacked the lives of those who have it, and saying that devalues the patient's experience. It's not something that can be ignored.
- *"Stay off the Internet and only listen to me."* Patients need support from those who have been there. Be open to patients bearing printouts and web research. When patients do such research, they feel empowered.
- *"I'll choose your treatment, not you."* Instead, incorporate patients as part of the decision. Let patients feel in control, because the condition often takes that away from them. They have to live with the end results of treatment.
- *"You're just a hysterical female."* Women are open about feelings, which are often dismissed and thus they don't get treated for afib as quickly. Remember, afib is different for women, especially related to hormonal cycles. And often women's symptoms are dismissed as stress, lack of sleep, or panic attacks.

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

Connecting to the afib community is easy through the organization's Facebook page.

Social Media & Afib

Social media, such as online forums, Facebook and Twitter, has revolutionized how afib patients gather and analyze information about their condition and treatments. Here is how StopAfib.org is using social media:

- The Atrial Fibrillation Blog (http://atrialfibrillationblog.com) — Patients can read and comment on afib news.
- Twitter (http://twitter.com/StopAfib) — Tweets from medical conferences give patients the latest information about treating afib.
- YouTube (www.youtube.com/StopAfib) — Patients can watch videos of doctors explaining treatments on the StopAfib YouTube Channel.
- Facebook (www.facebook.com/StopAfib) — The StopAfib.org Facebook fan page provides updates about the latest afib news and events.

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