

### What Healthcare Providers Can Do About AF Patients Who Research Online

### Mellanie True Hills Founder and CEO, StopAfib.org

### Disclosures

Patient conference sponsorships, unrestricted educational grants, and donations from AliveCor, AtriCure, Bayer, Biosense Webster, Boehringer Ingelheim, Boston Scientific, Bristol-Myers Squibb—Pfizer, Daiichi Sankyo, Janssen, Lohman Technologies, Medtronic, Sanofi, and Topera Abbott



### **Being an AF Patient**

# peartbeat

Close calls with a heart attack and stroke convinced a Texas woman to give up her high-stress life and create a network to help women reduce their risk of heart disease. silinare True Hills of Unservented Team, has described a forcested by Suby a bar stresser also induced the world have may order Web areas. A feet years later, an a high tech, estudying the Calon Pyressa, after them in 2013 Hints and Ady Vox annual med 500 phyrones. His human a high Vox annual and 500 phyrones. His human a high Vox annual and 500 phyrones. His human a high Vox annual med 500 phyrones. His human a high Vox annual high His human a high Vox annual hi

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### **Educate & Empower Patients**



- Learn about AF & treatment options
- Sign up for news alerts
- Translate into 90 languages
- HON Certified

We comply with the HONcode standard for trustworthy health information: verify here.



### What We Have Learned From AF Patients

- How different AF is for each
- AF takes a huge toll on patients and families
- Communication between doctors and patients is challenging
- That patients value different approaches/treatments



## Why Do AF Patients Research Online?

### They still have lots of questions

- Doctors may not have time to answer all their questions
- They may not understand what their doctor said
- They want solutions, not just to live with AF
- They need emotional support from other AF patients



### What Can You Do About Patients Researching Online?

- Accept and embrace patients researching online
- Encourage seeking credible sites with HON seal
- Provide them approved resources and forums

How and where can you find credible resources?



### EHRA Consensus Document on Patient Values & Preferences

EHRA POSITION PAPER



Cardiac tachyarrhythmias and patient values and preferences for their management: the European Heart Rhythm Association (EHRA) consensus document endorsed by the Heart Rhythm Society (HRS), Asia Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de

Estimulación Cardíaca y Electrofisiología (SOLEACE)

Deirdre A. Lane (Task Force Chair, UK), Luis Aguinaga (Argentina), Carina Blomström-Lundqvist (Sweden), Giuseppe Boriani (Italy), Gheorge-Andrei Dan (Romania), Mellanie True Hills (USA), Elaine M. Hylek (USA), Stephen A. LaHaye (Canada), Gregory Y.H. Lip (UK), Trudie Lobban (UK), John Mandrola (USA), Pamela J. McCabe (USA), Susanne S. Pedersen (Denmark), Ron Pisters (The Netherlands), Simon Stewart (Australia), Kathryn Wood (USA), Tatjana S. Potpara (Co-Chair, Serbia)

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ords Quality of He + Cardia: anitytonia + Patienti valaes + Prelevenes + Patient education programme + Patientcentred care + Patient-reported outcome + Shared decision-making

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#### Hypotetice April Hardinan Patient's experimente of long with attrict Berlaton Patient's experimente of anni Berlaton and education estate du carrier Berlaton Rate and Hypote communication Sociale presentant Patient's values and preferences and input of Instatement

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Table 4 Links to patient advocacy groups and foundations, professional societies and organizations, and patient discussion forums\*

#### Patient advocacy groups and foundations

- Atrial Ribrillation Association International, www.afa-international, org.
- · Anthythmia Alliance international: www.aa-international.org
- World Heart Federation: http://www.world-heart-federation.org/ what-we-do/avareness/strial-fibrillation/
- Sign Against Stroke in Atrial Fibrillation: https://www. signapinststroke.com/en
- Heart and Stroke Foundation-Canada; http://www.heartandstroke. com/stelc.MQLcHW(tE/b5052135k.2C86/ Heart\_dvase\_Atrial\_fbrillation.htm
- · StopAlb.org http://www.stopalb.org/
- My ARb Experience: http://mysl/bexperience.org/
- Anticoagulation Europe: http://www.anticoagulationeurope.org/

Professional societies or organizations

- European Heart Rhythm Association: http://www.afbmatters.org/
- American College of Cardiology: https://www.cardiosmart.org/ Heart-Conditions/Atrial-Renillation
- American Heart Association: http://www.heart.org/HEARTORG/ Conditions/Anthythma/AboutAnthythmia/
- AFb-Resources and FAQ\_UCM\_423786\_Article.pp#
   Heart Rhythm Society: http://www.hrsonine.org/
- Patient-Resources/Heart-Diseases-Disorden/ Anial-Floritation-AF6/taxaa3L30TnuT

Patient discussion forums

- Arrhythmia Alliance: https://waithun/odoetcom/ hearthrythmcharity
- AFIB Support Group: https://groups.yshoo.com/neo/groups/ AFIBuapport/info
- Atrial Ribrillation Association: https://healthunlocked.com/ afas.ociation
- StopAfib.org Forum: http://forum.stopa/lb.org
- Atrial Ribrillation Support Forum: https://www.facebook.com/ groups/AtriaFibrillationSupportForum/
- Daily Strength Allb Support: http://www.dailystrength.org/c/ Atrial-Fibrillation-AFb/support-group
- Lone Acrial Reriktion Forum Intelliview allebers orghoboards. htm

This is not an exhaustive list.





### EHRA AF Patient Site — AfibMatters.org



AFIB MATTERS

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ENGLISH

ABOUT ATEIAL FIREILLATION

EIGHS AND STRETORS

TESTS AND INVESTIGATIONS

TREATMENTS.

LINSNO WITH ATRIAL FIGRICLATION

USEFUL LINKS



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LIVING WITH ATRIAL F



AFIB MATTERS

ENGLISH

ABOUT ATRIAL FIBRILLATION

LIGHT AND SYMPTOMS

Boniadion TESTEAND INVESTIGATIONS proventio antagone can incre medicatio LIVING WITH ATRIAL FIBELLATION

Organiza USEFUL LINKS

units of alcohol a day. Click here to find out how many units there are in a clink.

You should also try to have at least 2-3 alcohol-free days per week

Read more about sensible drinking guidelines (PDF)

You should not drink any alcohol, if you develop an episode of the atrial fibrillation within an hour of alcohol intake

DO I HAVE TO STOP EXERCISING?



INC. IN CONTRACTOR

#### USEFUL LINKS

- A Patient's Guide to Living with Atrial Fiboliation
   American Heart Association
   Antocogulation Europe
   Anat Fibritation Association
   Assist Fibritation Association
   Association Association
   WebMID
- Stop Allb
  Stop Stroke
- · Patient co.uk
- NHS
- Anticongulation self-monitoring alliance

StopAfib.org

### **AF Patient Organization Sites**

Provide education & support for patients to:

- Understand what their doctors are telling them
- Communicate more effectively with their doctors
- Make better decisions about their care
- Be adherent to their medications
- Know that they are not alone



### AF Patient Sites — StopAfib.org

#### Get Started Learning About Atrial Fibrillation Guide

#### Home | Allo News & Events | Get Started Learning About Atrial Fibrillation Guide

Take a Stand Against Atrial Fibrillation by Educating Yourself and Others

#### By Mellanie True Hills

If you've come here from seeing the Take a Stand video, please share it with others that should know about atrial fibrillation. If you haven't seen it yet, see:

#### · Take a Stand video

Let's get started learning about atrial fibrillation by starting with the section below for anyone interested in learning about afib. If you're an afib patient, family member, or caregiver, then continue on to the lower section as well.

#### For Anyone Interested in Learning About Afib

To learn more about afib, check out the pages below. To share this information with others, click on the **Email** link at the bottom of the page. To print a page without headings and menus, click on **Print** at the bottom of that page.

- · What is afb? -- what it is, what it feels like, and how serious it is
- · What causes afb? afb causes, risk factors, and triggers.
- · How to know it's afib symptoms and diagnosing it
- Why is afib a problem? stroke and congestive heart failure, including risks and symptoms
- Interview with Dr. Emelia Benjamin on Framingham Risk Prediction Tool for Atrial Fibrillation — to see if you might be at risk, visit the Framingham Risk Prediction Tool listed in the article

#### Video & Audio News from StopAfib.org

Here are recent atrial fibrillation news stories. See previous stories at more News and Press Releases +

#### StopAfib.org Brings Atrial Fibrillation Awareness Month to Broadway and Beyond

For the 9th annual Atrial Fibrillation Awareness Month. StopAfib org spreads awareness and shares vital information ....more

#### Living with Afib Video by Mellanie True Hills

Living with Afib Session, from the 2016 National Atrial Fibrillation Patient Conference ... more

#### Video: Managing AF Risk Factors Panel with Drs. David J. Wilber, Susan Redline, and Mark S. Link Managing AF Risk Factors Panel, from the 2015 National Atrial Fibrillation Patient Conference more

Video: Sumery Panel with fire Jonathan Philoott

#### Video: Surgery Panel with Drs. Jonathan Philpott, Ralph Damiano, Jr., and James Edgerton

Surgery Panel, from the 2015 National Atrial Fibrillation Patient Conference ... more

#### Video: Partnering with Healthcare Providers ---Robert C. Kowal, MD, PhD, FHRS and Mellanie True Hills, CSP

Getting the Best Care, from the 2015 National Atrial Fibrillation Patient Conference .... more

Atrial Fibrillation Medication Study Now Enrolling Study will determine how well medication reduces the





Here are recent

videos and audios. See related News

stories for

transcripts. See

previous videos

and audios at

more Videos

Living with Afib by Mellanie True Hills



Managing AF Risks - Drs. Wilber, Redline, & Link



Surgery Panel - Drs. Philpott & Damiano

## **AF Patient Conference Presentations**



### Get in Rhythm. Stay in Rhythm.

Atrial Fibrillation Patient Conference













AF Patient Conference videos available on StopAfib.org



### Resources

#### Resources for Atrial Fibrillation Patients and Caregivers

#### Home | Patient & Caregiver Resources

The following resources cover general atrial fibrillation information as well afib patient discussion forums, blogs and social media, afib guidelines, medications, patient prescription assistance, patient perspectives, patient sites, industry patient resources, physician resources, popular articles and videos, related conditions, and partner organizations.

#### Atrial Fibrillation General Resources

- American Heart Association Atrial Fibrillation Information
- American Stroke Association
- American College of Cardiology Cardiosmart Heart Patient Resources
- AntiCoagulation Europe
- Ateal Fibrillation Association UK.
- Atrial Fibrillation Association US
- ▶ Cleveland Clinic AF Center
- Clot Care Anticoagulation Resource
- European Heart Rhythm Association
- · Everyday Health Atrial Fibrillation Center
- Healthline Atrial Fibrillation Resources
- Heart Rhythm Society Atrial Fibrillation Patient Site
- Journal of Atrial Fibrillation
- Mayo Clinic Atsal Fibrillation.
- MedicineNet.com Atrial Fibrillation Index
- Medine Plus Interactive Afib Tutorial
- Medscape Atrial Fibrillation Resource Center
- National Blood Clot Alliance
- National Stroke Association Atrial Fibrillation Information
- Society of Thoracic Surgeons
- The AFIB Report

#### Glossary

#### Ablate

A

- Ablation
- Amiodarone
- Angina
- Angiotensin II
- Angiotensin-converting
- enzyme (ACE) inhibitors
- Angiotensin II receptor blockers (ARBs)
- Antianhythmic drugs
- Anticoagulant
- Anticoagulation
- Antiplatelet drugs
- Antithrombotic drugs

- Anterior
   Antrom
  - · Antrum Pulmonary Vein
  - Ablation
  - Apixaban
  - ARISTOTLE Study
  - Anhythmia
  - Asymptomatic
  - Atherosclerosis
  - Atrial remodeling
     Atrial volume
- · Aurian voi
  - Atrioventricular (AV) node
     AV junctional ablation
    - · AV node ablation
    - Second Second Second

Ablate — Eliminate tissue around the pulmonary veins or at other sources of erratic electrical signals that cause the irregular heartbeat.

Ablation — A procedure that eliminates tissue around the pulmonary veins or at other sources of erratic electrical signals that cause the irregular heartbeat.

Amiodarone — An antiamhythmic medication used for atrial and ventricular integular heartbeats. It is considered the most effective antiamhythmic drug, but can cause serious side effects, including thyroid damage, liver problems, or kidney problems or failure. Other possible side effects include lung and breathing problems, respiratory distress, vision problems, diaphragm paralysis, nervous system damage, severe hair loss, speech loss, cognitive problems, and death. Oral dose amiodarone has many brand names that differ in various countries. Brand names in the US are Cordarone and Pacerone.



## **Support Forums**





StopAfib.org

## **Other Support Forums**

### Facebook





### Afibbers.org

LAF FORUM IX A forum for sharing experiences regarding lone atrial fibrillation (ninth in a series).		Q,	Abanted	
Sorren List Son New Topic St RSS		Page 1 of 140	Pages: 1 2 2 4 5	
Subject		Views	Posts	Last Post
0	AliveCorwith a Tablet by Sam	15	1	03/22/2015 11:18AM Last Post by Sam
ø	AF after 2 years (1)	78	7	03/22/2015 03:22PM Last Post by anneh

### Yahoo! Groups





### Patient Empowerment Materials From Sign Against Stroke in AF Task Force



Polish launched World Heart Day English and Portuguese will launch World Stroke Day October 29 Latin American Spanish will launch late 2015 Available at http://www.SignAgainstStroke.com



### How Does Approving of Patients Researching Online Help You?

- Informed patients understand what you tell them
- Patients who engage in shared decision-making
  - Are more adherent
  - Have better outcomes

Empowered patients are easier to manage and treat





For patients by patients

www.StopAfib.org

