

## New Consensus Document Embraces Patient-Centered Approach to Atrial Fibrillation

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This year, Atrial Fibrillation Awareness Month (September) is a time to celebrate a recent breakthrough in the way AF patients and healthcare providers can interact in the future. Healthcare providers from around the world created and endorsed a patient-centered view of the management of atrial fibrillation and other tachyarrhythmias. This evolution in patient and clinician interaction is important because patients with these arrhythmias are often highly symptomatic and the psychological impact can be significant.

This unique consensus document from the European Heart Rhythm Association (EHRA), Cardiac Tachyarrhythmias and Patient Values and Preferences for Their Management, [<http://bit.ly/PatientValues>] was presented at EHRA Europace-Cardiostim 2015 this past June and published in the journal *EP Europace*.<sup>1</sup> Coordinated and produced by EHRA, a branch of the European Society of Cardiology (ESC), this consensus document is endorsed by the Heart Rhythm Society (HRS), the Asia Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología (SOLEACE).

One significant step forward is that patients and patient organizations worked alongside clinicians to develop this groundbreaking consensus statement on patients' values and preferences. As an AF patient and founder of StopAfib.org, a patient advocacy organization for those living with afib, it was a privilege to be a co-author.

The task force provided consensus



**Figure 1:** StopAfib.org helps patients and clinicians manage atrial fibrillation in order to improve patient quality of life, support the patient-clinician relationship, and rid the world of afib-related strokes. To further this mission, the organization created Atrial Fibrillation Awareness Month and worked with other organizations to get the U.S. Senate to officially designate September as National Atrial Fibrillation Awareness Month.

recommendations for use in clinical practice based upon patient input and the latest medical research into patients' experiences of living with various cardiac tachyarrhythmias. This statement identified patients' treatment preferences and gaps in knowledge to inform clinical practice and future research.

The consensus statement is intended to be useful on a day-to-day basis in clinical practice as it summarizes issues clinicians can address with patients regarding AF and its trajectory, treatment goals and options, and potential outcomes. The consensus statement also provides links to useful resources for patients and clinicians such as patient advocacy groups and professional societies relevant to each cardiac tachyarrhythmia.

For clinicians, this consensus statement may inform decision-making processes related to strategies for

treating patients with afib, supraventricular arrhythmias, and ventricular arrhythmias. And while this article focuses on the afib sections of the consensus document, reading the entire document will help clinicians understand patient values and preferences for each of these arrhythmias.

### IN-DEPTH FOCUS ON ATRIAL FIBRILLATION PATIENTS

This consensus document could have a dramatic impact on clinical practice. One of the most crucial issues addressed is how highly symptomatic heart rhythm disturbances can cause a significant psychological impact on patients. Far too often, this psychological aspect of afib is ignored by healthcare providers because they simply have not experienced it and cannot understand how debilitating the condition can be.

Afib (and other cardiac arrhythmias)

can have a huge impact on quality of life. Research has shown that those with AF have a lower quality of life and can suffer from anxiety due to the unpredictable nature of AF. Treatments can also lead to fear and psychological distress. As many as half of AF patients with symptoms suffer from depression and anxiety, and some are even stressed and panicky due to the effects of their medications.

Patients' knowledge about their condition and medications may affect their adherence, influence their responses to their illness and treatment, and ultimately, impact health outcomes.

Two particular examples of patient preferences cited in this consensus document are worthy of mention:

- Afib patients prefer normal sinus rhythm, including those without symptoms or who are only mildly symptomatic, even when research says there is no significant difference between rate and rhythm control.
- Afib patients prefer preventing strokes over preventing bleeds. In fact, AF patients were willing to endure 4.4 major bleeds to prevent a single stroke, according to the consensus statement. Therefore, AF patients need to know that they are at risk for a stroke even without symptoms, and need to understand that they will need oral anticoagulants throughout their lives.

### RECOMMENDATIONS FOR HEALTHCARE PROVIDERS

The consensus statement is a valuable resource for any healthcare provider who treats AF, but especially for electrophysiologists and the EP lab

**Figure 2:** The consensus document on Cardiac Tachyarrhythmias and Patient Values and Preferences for Their Management was presented this past June at the European Heart Rhythm Association (EHRA) Europace–Cardiostim 2015. As an innovative step forward that involved patients and clinicians, the EHRA task force developed the consensus statement, which was endorsed by the Heart Rhythm Society (HRS), the Asia Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología (SOLEACE). This consensus statement recommends patient-centered care that considers patient values and preferences in the management and treatment of arrhythmias.

team who contend with more difficult and complex atrial fibrillation cases. In addition to identifying patient concerns, the consensus statement suggests ways that clinicians can better work with AF patients.

One of the primary recommendations was that education is an essential component and that all patients should receive individually tailored information about their condition, treatments, and possible outcomes. In addition, patient values and preferences should be discussed, documented, and incorporated into decisions about care.

Using a shared decision-making approach to reaching decisions about care received special emphasis throughout.

“Patients live with the consequences of treatments so it’s reasonable that they should have some say,” says Dr. Deirdre Lane, task force chair. “Patients may have different priorities to doctors, particularly with regards

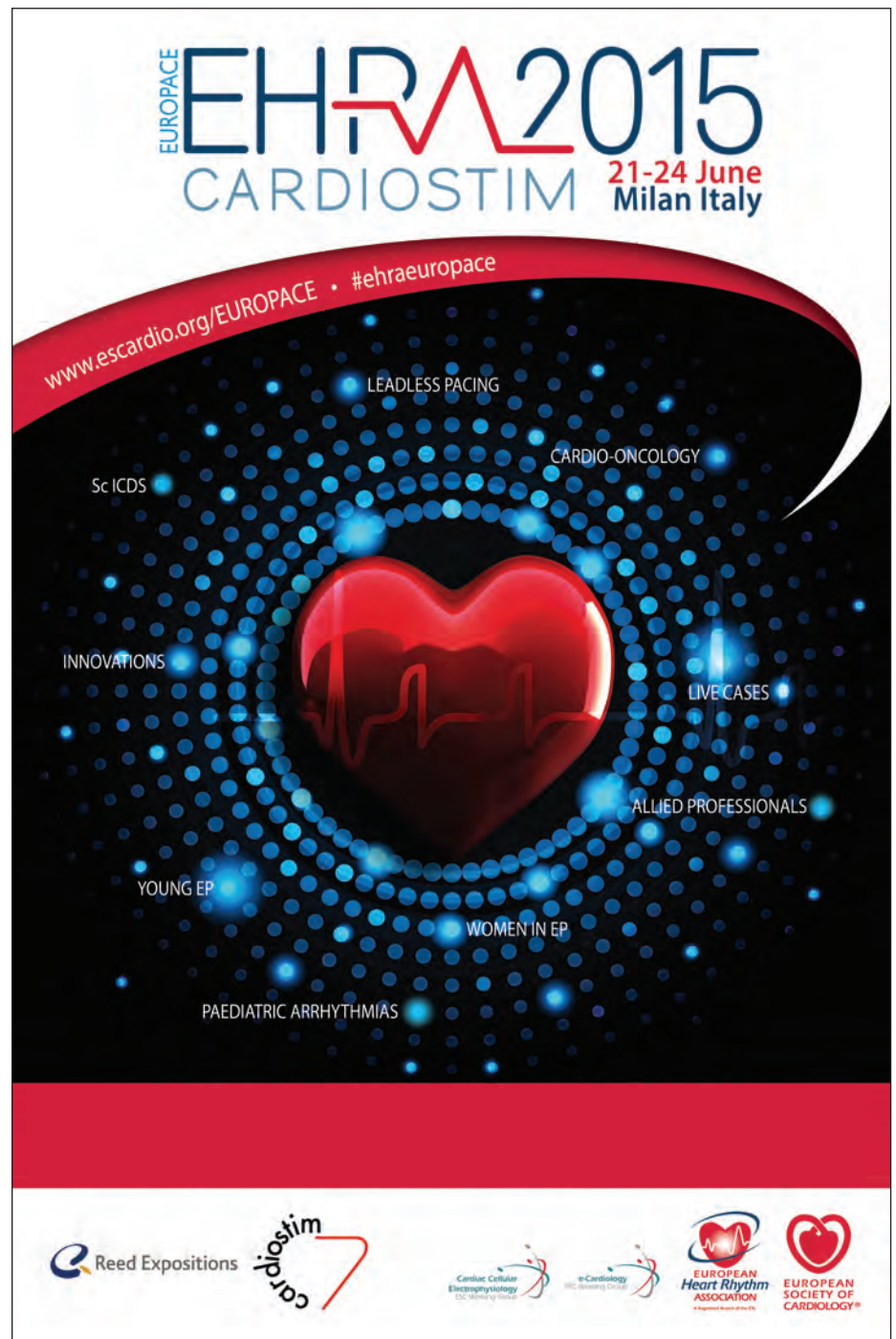
to anticoagulation therapy to prevent stroke in atrial fibrillation. Patients should be told the pros and cons of the different treatment options so they can make an informed decision for themselves.”

**ATRIAL FIBRILLATION-SPECIFIC FINDINGS**

For electrophysiologists, the statement’s specific cases and information about how atrial fibrillation affects individual patients could be extremely valuable. Among the many AF-related themes are:

- *Making an AF diagnosis can be difficult.* Transient and non-specific symptoms are frequently attributed by healthcare providers to other conditions, and an AF diagnosis may be delayed because of incomplete diagnostic procedures. This may cause patient frustration and

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## AF Approach

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put patients at risk for stroke due to delayed referral to an expert for evaluation.

- *Short appointments inhibit AF assessment.* Because of time constraints, healthcare providers may not fully comprehend the impact of afib on a patient's lifestyle, which may also lead to the underutilization of rhythm control strategies.
- *Patients desire better communication.* Patients want their healthcare providers to understand what they are experiencing with AF, to provide patient-specific education, and to use shared decision-making approaches.
- *Understanding AF treatment is daunting.* Patients seek quality information about AF and believe they need repeated educational opportunities. A vital part of AF care is referring patients to high-quality websites and other resources tailored specifically for AF patients.
- *Families of AF patients are affected, too.* Families of those with AF may not understand the significance of the symptoms, so education that includes family members can help relieve some of the stress.
- *Lack of knowledge affects treatment.* Many afib patients lack sufficient knowledge to manage their condition. Studies have found that many AF patients are not aware that they have atrial fibrillation, and that almost half of AF patients don't realize that atrial fibrillation increases their stroke risk. Many also do not realize that AF can occur without symptoms. Patients need to be educated about their stroke risk, and that AF-related strokes are more disabling or deadly. They also need to understand treatment options and stroke prevention.
- *Educational resources are difficult to acquire.* Healthcare providers report

having difficulty finding quality sources of AF education, even though professional societies and patient advocacy groups such as StopAfib.org provide the written and video educational resources that patients prefer. Often lacking is how healthcare providers can best educate patients about how to manage their AF.

### LOOKING TOWARD THE FUTURE

In addition to providing guidance for a more patient-centered view of arrhythmia diagnosis and treatment, the consensus document also sought to identify opportunities for future research. Among the recommended areas for additional AF research are:

- *Add quality-of-life assessments.* For AF patients, the extent of impairment and quality of life aren't routinely assessed. Researching existing, or creating new, AF-specific questionnaires to assess quality of life will aid clinicians and patients in evaluating how to manage AF for each patient.
- *Study anxiety and depression.* While anxiety and depression may be more frequent in those with AF, the actual prevalence and incidence of anxiety and depression is largely unknown and should be determined. Also, appropriate interventions should be developed.
- *Value educational programs.* Because patients have insufficient knowledge about AF, the development of educational programs should be considered.
- *Evaluate the effect of ethnicity and culture.* Many patient preferences related to education and treatment may have an ethnic or cultural basis. Evaluating patient values in different ethnicities and cultures as they relate to AF and other arrhythmias may facilitate more effective education and patient management.
- *Increase the use of patient-reported outcomes.* When patients provide

### FIVE ESSENTIAL TAKEAWAYS FOR PATIENT-CENTERED CARE.<sup>1</sup>

To help better serve patients, here are the five most important takeaways from the consensus document:

1. Education enables patients and family members to better understand and manage the condition, treatments, and long-term effects.
2. Information from the healthcare team should be tailored to the specific patient, and be repeated and reviewed when new treatments are discussed.
3. Management of the condition should include discussing and documenting patient preferences.
4. During the course of treatment, reviews and evaluations of management should take place with patient input.
5. Patient representatives should participate in guideline development and implementation.

### VALUABLE AF RESOURCES FOR HEALTHCARE PROVIDERS.<sup>1</sup>

The consensus statement provides clinicians with valuable resources. Healthcare providers who treat patients with AF, supraventricular arrhythmias, and ventricular arrhythmias may want to read the entire document and consult suggested resources to take advantage of the valuable wealth of information included about all of these conditions.

Valuable AF resources for electrophysiologists and EP lab team members include:

- Key topics to discuss with AF patients at consultations (Table 2 in the consensus statement)
- Discussion points for oral anticoagulants (Table 3 in the consensus statement)
- Links to useful afib-related patient advocacy groups, professional societies, and patient discussion forums (Table 4 in the consensus statement)
- Questions for AF patients to ask their doctors (page 18 in the consensus statement)

direct responses and interpretations about their health and healthcare, clinicians can gain a better understanding of the impact of interventions on patients. Also, the increased use of patient-reported outcomes can aid in assessing the effectiveness and adherence of the new oral anticoagulants.

- *Develop multidisciplinary, integrated care programs.* Research is needed to develop and validate ways to manage afib through integrated care programs that involve multiple disciplines and standardized patient education to determine

best practices for efficacy and cost-effectiveness. ■

#### Reference

1. Lane DA, Aguinaga L, Blomström-Lundqvist C, et al. 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). *Europace*. 2015 Jun 24. pii: euv233. [Epub ahead of print]

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