

# LONGWOOD MEDICAL ICD SUPPORT NEWSLETTER WINTER 2008



**BRIGHAM AND  
WOMEN'S HOSPITAL**  
A Teaching Affiliate of Harvard Medical School



**Beth Israel Deaconess  
Medical Center**

## Who We Are

The Longwood Medical Area ICD Support Group is a group of medical professionals dedicated to providing education and support to people with implanted cardioverter defibrillators (ICD) and their significant other(s) as well.

Our group includes individuals from Beth Israel Deaconess Medical Center (BIDMC) and Brigham and Women's Hospital (BWH). Our quarterly meetings are held at either hospital with an occasional off-site event.

We are grateful for contributions from the device manufacturers Medtronic, Boston Scientific/Guidant, and St. Jude Medical which enable us to provide this service to you. We'd like to extend a warm welcome to those of you who are receiving our newsletter for the first time.



## “From Active Athlete to Pageant Princess: How having an ICD lead the way to becoming Miss Massachusetts 2006”

Presentation by Michaela Gagne

Summarized By Denisse Peña

On October 10, 2007 Michaela Gagne presented “From Active Athlete to Pageant Princess: How having an ICD lead the way to becoming Miss Massachusetts 2006” to the ICD Support Group at Brigham and Women's Hospital. In her lecture, she spoke about how she was diagnosed with Long QT syndrome as a teenager and how it affected her life thereafter. She talked about her love for competitive sports and how she was unable to continue competing after her diagnosis was made. She concluded her presentation by discussing how her love of competing prompted her to participate in a local beauty pageant. This decision lead the way to her becoming Miss Massachusetts 2006.

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## “From Active Athlete to Pageant Princess: How having an ICD lead the way to becoming Miss Massachusetts 2006”

Presentation by Michaela Gagne  
Summarized By Denisse Peña

Michaela Gagne was diagnosed with Long Q-T Syndrome in her senior year of high school after having a symptomatic episode at a track meet. Long Q-T Syndrome is a genetic condition that can cause the heart to go into an erratic rhythm, meaning the heart begins to quiver rapidly and irregularly, during which time there is no pumping action. Prior to her diagnosis, Michaela was captain of three varsity teams and even had aspirations to become a Division I soccer player. At the suggestion of her High School guidance counselor, she decided to enter a beauty pageant. Although she felt that she was far from a beauty queen, she saw this as an opportunity to continue competing.

The pageants served as an empowering and therapeutic experience. After the implant her doctor confirmed that she could, in fact, play sports again. She felt that the ICD gave her a new sense of freedom. She was able start introducing sports back into her life shortly after receiving her implant. With a lot of work and “heart” she won the title of Miss Massachusetts in June 2006. She had realized that this new role gave her a new forum and voice to spread “heart- disease awareness”. Since winning her title Michaela has traveled all over the U.S. speaking about Heart Disease.



Michaela Gagne pictured speaking at the October 10, 2007 ICD support group meeting.

A video of Michaela’s lecture is available on our website at :  
[www.brighamandwomens.org/icdsupportgroup](http://www.brighamandwomens.org/icdsupportgroup)

“From Active Athlete to Pageant Princess: How having an ICD lead the way to becoming Miss Massachusetts 2006” Presentation by Michaela Gagne

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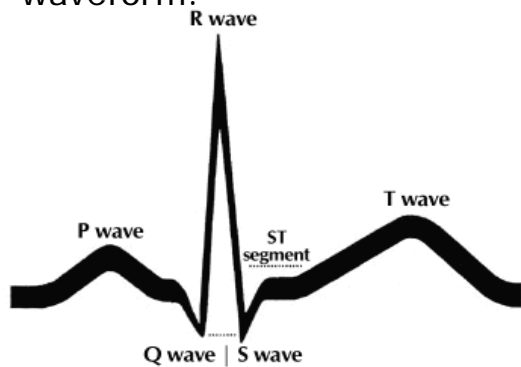
**Additional Information about Long QT Syndrome**

Long QT Syndrome (LQTS) is a disorder of the electrical system that triggers the heartbeat, and regulates the muscle contractions that pump the body's blood supply.

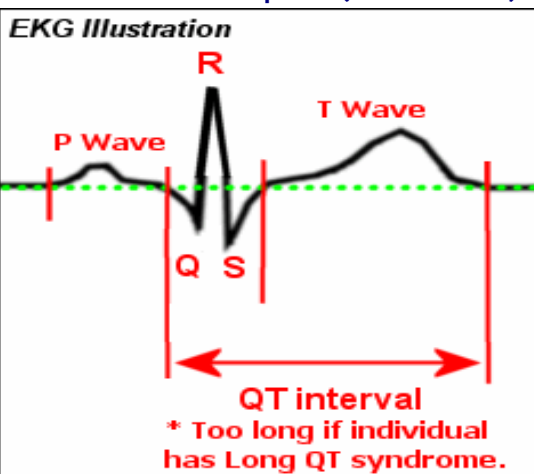
It is not known exactly how many people have LQTS, but the inherited type is thought to be a common cause of sudden, unexplained death in children and young adults

**The QT Interval**

Most people are familiar with electrocardiography (ECG or EKG), a test in which electrodes are temporarily attached onto the chest, arms and legs to record the heart's electrical activity. The electrodes send information to a machine that records and prints a "picture" (an electrocardiogram) of the pattern, or rhythm, of the electrical impulses that pace the heart beat. Each impulse generates a heart beat. The line created for each beat on the ECG is called a "waveform."



**Normal EKG Complex (Heart Beat)**



**EKG showing Long QT Syndrome**

The letters, P, Q, R, S, and T represent different parts of each waveform. The space between the beginning of the Q wave and the end of the T wave (called the QT Interval) is a critical juncture. It represents the time it takes for the heart's electrical system to recharge after each beat (a process called "repolarization") before generating the next signal to activate the ventricles, the major pumping chambers of the heart.

In Long QT Syndrome, the interval between Q and T is longer than normal. People with this syndrome are susceptible to an abnormally rapid heart rhythm (arrhythmia) called "torsade de pointes." When this occurs, the heart muscle cannot contract effectively, and the normal volume of blood is reduced to the body and - most important - to the brain. If the brain is starved of oxygen, the individual faints within seconds.

**"From Active Athlete to Pageant Princess: How having an ICD lead the way to becoming Miss Massachusetts 2006"** Presentation by Michaela Gagne

### **Additional Information about Long QT Syndrome-Cont'd**

If the heart cannot regain its normal rhythm, it may go into spasms that lead to a deadly arrhythmia called ventricular fibrillation. Without immediate emergency treatment, death follows within minutes.

Fainting is the primary symptom - and may be the only warning sign - of LQTS. Once a person has been diagnosed with the LQTS, all family members should be tested, including the parents, siblings and children of the affected individual.

The above information about Long QT Syndrome can be accessed via the Heart Rhythm Society website at <http://www.hrsonline.org>

### **8th Annual - Living With Atrial Fibrillation**

#### **An Informational Workshop for Patients**

**Saturday, November 10, 2007**

The 8th annual Atrial Fibrillation conference was a success! We hosted an estimated 600 attendees and had seven amazing lectures! Please see below for topics and speakers featured.

The next "Living Atrial Fibrillation: 2009 Update" will be held on **Saturday, October 31, 2009** at the Westin Copley Place from 8am -1pm. Save the date!

#### **What is Atrial Fibrillation?**

**Bruce A. Koplan, M.D.**

#### **Medical Therapy of Atrial Fibrillation**

**Usha B. Tedrow, M.D.**

#### **Anticoagulation Update: What you need to know**

**Erin Oliver, PA-C**

#### **Pacemakers for the Treatment of Atrial Fibrillation**

**Kristin Boyt, PA-C**

#### **Living with Atrial Fibrillation: New Treatments**

**Laurence M. Epstein, M.D.**

#### **Undergoing Catheter Ablation: A Guided Tour**

**James Kulig, PA-C**

To view a video of this presentation please visit [www.brigamandwomens.org/livingwithaf](http://www.brigamandwomens.org/livingwithaf)

#### **Successful Living with Atrial Fibrillation- *video***

**William Stevenson, M.D. and Aaron Adler (*patient*)**

To view this interview online please visit [www.brigamandwomens.org/livingwithaf](http://www.brigamandwomens.org/livingwithaf)

If you would like a copy of the syllabus please contact Denisse Peña at 617-732-5842.

**Upcoming Longwood Medical ICD Support**

**Date :** Wednesday, January 23, 2008

**Speaker/Topic:** Dr. Kapil Kumar, EP Fellow Beth Israel Deaconess Medical Center  
"Device Recalls: What this means to you"

**Location:** Kirstein Living Room,  
Beth Israel Deaconess Medical Center,  
330 Brookline Ave., Boston

At this meeting we will be discussing important information and answering frequently asked questions regarding recall issues. The recent recall by Medtronic of their Fidelis ICD lead will be reviewed.

Please see below for the official statement made by Medtronic.

**Please RSVP For this meeting by contacting Denisse Peña at 617-732-5842**

**Important Patient Information- Sprint Fidelis Lead Performance**

October 7, 2007

Medtronic recently provided doctors with important information about our Sprint Fidelis defibrillation leads (Models 6930, 6931, 6948, 6949). We have informed doctors who, according to our records, manage the care of patients with Sprint Fidelis leads. A defibrillator system consists of a device implanted near the shoulder and one or more leads connecting the device to the heart. This information applies to Sprint Fidelis leads only, not implanted defibrillation or pacemaker devices. If you have a Sprint Fidelis lead, your Patient ID card should contain one of the following 4 sets of numbers: 6930, 6931, 6948, 6949. These numbers may be shown at the beginning of a longer set of numbers on your ID card.

We have found that there is a small chance of fractures in particular locations on the Sprint Fidelis lead. If you have a Sprint Fidelis lead, the chance there is a problem with your lead is small. Patients with a Sprint Fidelis lead are more likely to experience complications from removal than from a problem with a Sprint Fidelis lead. However, doctors may choose to change the way a device is programmed to help reduce any potential problems. An independent panel of physician experts recommends against removing Sprint Fidelis leads except in very unusual circumstances.

If you have a Sprint Fidelis lead, you may have already heard from your doctor's office regarding this matter. We encourage patients with Sprint Fidelis leads to contact their doctor's office with any questions about their leads or the information in this letter. The information we provided doctors is more detailed, since they are in the best position to know how to manage patient care in light of specific health considerations.

We sincerely apologize for any difficulties this may cause you and your family. We are committed to answering your questions, keeping you informed, and continuously improving our products. If you have additional questions or would like to inquire if you have a Sprint Fidelis lead, please contact Medtronic Patient Services at 1 (800) 551-5544 x41835 (7am to 9pm CST).

Sincerely,



Reggie Groves  
Vice President, Quality and Regulatory  
Medtronic Cardiac Rhythm Disease Management  
Medtronic, Inc.

# LONGWOOD MEDICAL ICD SUPPORT GROUP NEWSLETTER

## Upcoming Longwood Medical ICD Support Group Meetings

Date : January 23, 2008

Speaker/Topic: Dr. Kapil Kupir, EP Fellow Beth Israel Deaconess Medical Center

“Device Recalls: What this means to you”

Location: Kirstein Living Room,  
Beth Israel Deaconess Medical Center,  
330 Brookline Ave., Boston

Date : April 9, 2008

Speaker/ Topic: Carolyn Ho M.D. “Inherited Arrhythmic Conditions” - Long QT, Hypertrophic Cardiomyopathy, Arrhythmogenic Right Ventricular Dysplasia, and Brugada Syndromes.

Location: Carrie M. Hall Conference Center,  
Brigham and Women’s Hospital,  
45 Francis Street, Boston

Date : June 18, 2008

Speaker/ Topic: TBA

Location: Kirstein Living Room,  
Beth Israel Deaconess Medical Center,  
330 Brookline Ave., Boston

Date : September 24, 2008

Speaker/ Topic: TBA

Location: Carrie M. Hall Conference Center,  
Brigham and Women’s Hospital,  
45 Francis Street, Boston

\* ALL MEETINGS BEGIN AT 5:30PM (Dinner)  
LECTURES BEGIN AT 6:00PM

## Open Face Vegetable Sandwiches

Serves 2

2 to 4 teaspoons Dijon mustard

2 whole grain English muffins, split and toasted

1/2 cup broccoli florets

1/4 cup shredded carrot

1/2 cup shredded low-fat Monterey Jack cheese

Preheat broiler

Spread mustard over the cut side of each English muffin half. Arrange broccoli, bell pepper, and carrot over mustard. Sprinkle with cheese.

Place English muffin halves on the unheated rack of a broiler pan. Broil about 4 inches from the heat for 2 to 3 minutes, or until cheese melt.

Calories: 246 kcal

Protein: 14 g

Carbohydrates: 34 g

Total Fat: 6 g

Saturated Fat: 4 g

Polyunsaturated Fat: 0 g

Monounsaturated Fat: 2 g

Cholesterol: 17 mg

Sodium: 352 mg

For more information and recipes visit:

[www.deliciousdecisions.org](http://www.deliciousdecisions.org)

## ICD Support Group Contact List

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