

JOHN TAYLOR BABBITT FOUNDATION

NEWSLETTER

October-November 2008

A MESSAGE FROM THE BABBITT FAMILY

If you are like most people, you expect each day to be pretty much like the last one. Sure, experiences vary from day to day...some days are good while others leave a lot to be desired. Although you know life isn't perfect, you kind of assume things will continue on an even keel. What you don't expect is to experience a life shattering event – one that, in the blink of an eye, changes you forever. This is what our family experienced when our 16 year old son and brother, John, passed away suddenly, and without warning, while playing basketball with his friends. Within a matter of days we learned John suffered a heart arrhythmia triggered by Hypertrophic Cardiomyopathy – a genetic disease involving thickening of the heart muscle.

Soon after John's death, we decided the most appropriate way to honor his memory and to increase awareness about the severity and prevalence of Hypertrophic Cardiomyopathy within the young adult community was to establish the John Taylor Babbitt Foundation. We are pleased to share with you some of the initiatives we have been working on as well as other news about events the Foundation has been involved with over the past few months.

Finally, but most importantly, we would like to thank all our friends and family for their love and support. Your strength, inspiration, and kindness keep us focused on our journey to help eradicate the risk of sudden cardiac death.



With much gratitude,
Dave, JoAnne and Andrew Babbitt

JOHN'S STORY



John was 16 years old when he collapsed and died from an undiagnosed heart condition while playing basketball with his friends. He was a 2003 graduate of St. Patrick's School in Chatham N.J. and a junior at The Pingry School in Martinsville. An avid sports fan, John played football, basketball, soccer and baseball. His knowledge of sports was legendary and he loved nothing more than sharing that knowledge with his friends and family.

Born in New York City, John lived in the United Kingdom before moving to Chatham when he was 9 years old. He loved to travel and especially enjoyed ski vacations with family and friends in France, Vermont and Utah. An active member in St Patrick Youth Ministry, John was a team leader for the freshman retreats and immensely enjoyed participating in the annual Appalachia outreach trip to Preston County, West Virginia. He was also passionate about all types of music, Sting and The Police being among his favorites.

Virtuous, decent, kind and caring, John was a great friend, brother, son, and grandson. He always listened when people wanted to talk and had the ability to bring a smile to the faces of those he touched.

John Taylor Babbitt Foundation

GOALS AND OBJECTIVES

The John Taylor Babbitt Foundation is a nonprofit 501©-3 organization founded in John's memory and dedicated to preventing sudden cardiac death. The specific goals of the foundation are to:

- Install **defibrillators** in schools, athletic venues, and public gathering places.
- Establish **JTB Heart Clubs** in high schools and universities to raise awareness and save lives.
- Support **research** on genetic cardiac disorders that increase risk of sudden cardiac death.

Defibrillators:

- Proposing legislation and lobbying for state-level laws on defibrillators
- Working on municipal policies and procedures to support the purchase and maintenance of defibrillators
- Sponsoring local training programs in CPR/AED

JTB Heart Clubs:

- Establishing campus JTB Heart Clubs at high schools and universities
- Club activities are focused on: Advocacy, Education, Defibrillators and Fund Raising

Research:

- Supporting research on genetic cardiac disorders, including Hypertrophic Cardiomyopathy and other diseases, that increase the risk of sudden cardiac death
- Research focus areas include improving the accuracy and cost effectiveness of screening programs and investigating promising treatments.

WHAT IS HYPERTROPHIC CARDIOMYOPATHY (HCM)?

Hypertrophic Cardiomyopathy is a genetic condition affecting the heart muscle. The main feature of HCM is an excessive thickening of the heart muscle caused by the genetic mutation. HCM is normally recognized by its structure, for example the thickness of the heart. The electrical function of the heart may also be abnormal and cause life-threatening arrhythmias and sudden cardiac arrest. HCM also causes the cells in the heart to form incorrectly.

For additional information about HCM, please visit the Hypertrophic Cardiomyopathy Association web site at www.4HCM.org

LEGISLATIVE UPDATE..... HOW TO MAKE A DIFFERENCE....

One of the key goals of the JTB Foundation is to propose and lobby for state level legislation for the placement of defibrillators (AEDs) into schools, athletic venues, and public gathering places. In the State of New Jersey, defibrillators are only required in nursing homes, state buildings, and health and fitness clubs. Currently there are 14 pieces of legislation pending in the New Jersey State Legislature all relating to the placement and training of defibrillators. The Foundation is in the process of reviewing the open legislation in an effort to learn what goals and objectives are included in each bill. This includes how the bill specifies placement of the AEDs as well as responsibility for placement, education, coordinating and funding.

Members of the Foundation Board met with Lisa Salberg, Founder of the Hypertrophic Cardiomyopathy Association to discuss the current status of legislation in states throughout the country. Board Member LeeAnne Lan states "the Foundation Board plans to continue the assessment process, as well as meeting with the various bill sponsors, with the goal of developing and supporting a comprehensive bill that will involve a coalition of the multiple bills currently pending."

"WALK WITH HEART"

.....an annual event to support HCM awareness and research and defibrillator legislation.....

Over the past two years, hundreds of walkers and runners have gathered on beautiful sunny days in May at The Pingry School, both to honor the memory of a friend and to raise funds in support of the John Taylor Babbitt Foundation. The walk is organized each year by members of Pingry's senior class and includes a two mile competitive run, a two mile walk, raffle, music, food, and prizes. While there was a solid community, family and friend representation, many of the attendees were students from local area high schools. Most touching perhaps this year was the return of many of John's friends who have gone on to college.

The 2007 and 2008 Walk With Heart events have raised over \$150,000 in support of our efforts to install **defibrillators** in schools, athletic venues and public gathering places, establish **JTB Heart Clubs** in high schools and universities to raise awareness and save lives and support **research** on genetic cardiac disorders that increase risk of sudden cardiac death.



DID YOU KNOW.....

- Hypertrophic Cardiomyopathy affects 1 in 500 people in the USA and is the leading cause of sudden cardiac death in the young, especially young athletes. HCM affects people of all ages (from birth to 90). It is an equal opportunity disease affecting all ethnicities and both genders equally.
- Every year approximately 125-200 athletes will die and 1/3 will have HCM. This means approximately every week a young athlete dies from HCM.
- Although there is no cure for HCM it is very possible to live a LONG and ACTIVE life as there are many treatment options that aim to improve symptoms and prevent complications.

(from the Hypertrophic Cardiomyopathy Association)

JTB Foundation Board of Directors

Our deepest thanks and gratitude to our Board who have given so selfishly of their time and effort:

David C Babbitt – President
JoAnne Taylor Babbitt – Vice President
Gerald P. Scales – Treasurer
Diane Duffy – Secretary
William Babbitt
Sean Donovan
Kathleen Donovan
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Warren Kimber III
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Tufts New England Medical Center

JTB FOUNDATION YOUTH BOARD

The following interview with Sean Donovan was conducted by Elizabeth Entwistle, a sophomore at Boston University and press liaison for the foundation. Sean is a student at Fairfield University and currently co-directs the youth board with Andrew Babbitt.

What is the John Taylor Babbitt Foundation Youth Board?

The John Taylor Babbitt Youth Board is a group of young adults (students) assembled by the Executive Board members. The Youth Board and its members will concentrate on the goals of the Foundation, specifically in the young adult community. The primary focus is to raise awareness as well as potentially establish a club or chapter in high schools and universities.

Why did you volunteer to co-direct this Youth Board?

I have known John and the Babbitts since they returned to the United States so many years ago. Growing up, the Babbitts became more than just friends or acquaintances. They were like family. After witnessing the tragic event that took John from both his friends and family, I felt the need to do whatever I could to continue the relationship I developed with John and his family. I feel that the part of myself I lost when John died lives now because of what he had given me. If there was a way I could advance the foundation I was more than willing to help, and I thank the Babbitts for allowing me to be a part of this Foundation.



What are your responsibilities?

Currently our job is to raise awareness and continue to forward the mission statement of the Foundation. It is my hope that the Board will soon bestow more responsibilities on both Andrew and I so that we might be more aggressive in pursuing the goals and objectives of the Executive Board.

What JTB events and functions have you helped with in the past or are there any you will help with in the future?

I have helped at both "Walk with Heart" with fundraising and awareness. I also attended the HCMA (Hypertrophic Cardiomyopathy Association) meeting with a few Board members and heard from a few doctors that are on the Executive Board. I have also participated in the first annual JTB Golf Outing and will be coming home this Columbus Day weekend to attend the second.

SUMMER BBQ TO LAUNCH YOUTH INITIATIVES

On August 21st, 60 friends and schoolmates of John and Andrew's gathered at the Babbitt's home for a JTB Foundation BBQ. The purpose of the evening was to bring the young adults together before they started classes at their various high schools and colleges to discuss ways they could help increase awareness and prevent sudden cardiac death within their communities. Dave and JoAnne spoke about the formation of a JTB Youth Board (see related article) as well as plans for launching "JTB Heart Clubs." JTB Heart Clubs are founded, organized, and run by students on a high school or college campus. A club contributes to the foundation mission to prevent sudden cardiac death by focusing on four goals: **Advocacy, Education, Defibrillators and Fundraising.** "It is all about empowering the students to help make a difference...they decide what is important on their campuses and we support them in helping to achieve their goals," says board member Sarah Kimber.

Dave and JoAnne were so thrilled with the great turnout and enjoyed catching up with all the students. Everyone enjoyed the food, a swim in the pool and a chance to see both old and new friends before starting the new school year. Since the BBQ, JTB Club Toolkits have been sent to everyone via email and a few campus initiatives have been started. As Dave mentioned that evening, "We have made great progress but we still have a way to go...it is our goal to start six JTB Heart Clubs by the end of 2009. We are also looking for more students to be more involved with the Foundation by participating on the Youth Board."



For more information about the JTB Heart Clubs or the Foundation Youth Board, please contact the Babbitt's at www.jtbfoundation.org.

What part does the Youth Board play in the new "campus chapter" endeavor?

The current major goal of the Youth Board is the "campus chapter" endeavor. It is the hope of the Youth Board that we might advance the goals of the JTB Foundation to high school and college campuses through the young adult community. We hope to accomplish this by reaching out to family and friends.

Do you have any goals for the future?

I most certainly do. The goal I am currently working towards is putting defibrillators in the corporate headquarters of Mercedes-Benz USA. This past summer I interned at their headquarters, located in Montvale, NJ, in the budgeting and controlling division, and proposed a business plan that would be cost effective in putting defibrillators in all the buildings. I also hope to move the "Walk With Heart" to a larger scale effort involving universities and their extensive alumni networks for further support. Ultimately, I would like to see if we can do this at other places as well.

GENETICS DAY ON THE HILL

On July 10th, Genetic Alliance hosted the third annual Genetics Day on the Hill, where individuals from all areas of genetics came together to bring about change in the policies affecting every one of us. Christine Willinger, a graduate of St. Patrick School in Chatham and a senior at The Pingry School attended the event which helps to educate policy-makers about legislation needed for genetic testing oversight and health information technology, among other topics. Christine has always been interested in the field of genetics and very supportive of our desire to fund additional research ...especially in the area of genetic cardiac disease.

Each year we discover more and more about the genetic mutations associated with cardiac diseases but there is so much more to discover. This year we celebrate the approval of the Genetic Information Nondiscrimination Act (GINA). Under the bill, employers cannot make decisions about whether to hire potential employees or fire or promote employees based on the results of genetic tests. In addition, health insurers cannot deny coverage to potential members or charge higher premiums to members because of genetic test results. Hopefully more

SUPPORTING THE HYPERTROPHIC CARDIOMYOPATHY ASSOCIATION (HCMA)



In May, the JTB Foundation Board voted unanimously to present the HCMA a gift of \$10,000.00 to support their efforts in providing support, advocacy, and education to patients, the medical community and the public about hypertrophic cardiomyopathy. The gift was presented to Lisa Salberg, President of the HCMA, at the 11th Annual HCM Meeting in June of this year. "Lisa and her staff have been so supporting of our efforts", says Dave Babbitt "her work has helped so many people ...including the medical community.... become better educated about hypertrophic cardiomyopathy".

The HCMA serves thousands of families and medical professionals from 32 countries every year. Some of the services include: physician referral, peer support, educational materials, annual national and regional meetings, insurance advocacy and legislative advocacy.

people will now be willing to participate in clinical research for treatments of specific genetic sequencesso we can better understand the nature of genetic diseases, such as HCM.

"I am so appreciative of the time and effort given by Christine and her mother, Diane Duffy in helping our Board more fully understand the issues in the field of genetic research and what we can do as a organization to help make a difference" says JoAnne Babbitt.

**To learn more about
Hypertrophic Cardiomyopathy
and the JTB Foundation
contact:**

**JoAnne and Dave Babbitt
72 Buxton Road
Chatham, NJ 07928
Phone 973.701.0920
www.jtbfoundation.org**

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