



From the Heart

Lisa and Eddie Yu '85 Establish Foundation for Children

■ By Susan James ■
Chronicle Editor

Lisa and Eddie Yu of Tenafly listened to the pediatrician when their 11-month-old son came down with a cold – babies often get sick so their bodies can develop strong immune systems.

But, several days later Bryan woke up crying and seemed drowsier than usual. Within a few hours he was lethargic and refused to eat and, knowing something was wrong, they rushed him off to the emergency room.

Bryan was already experiencing heart failure in the car, as he shuddered and slumped over in Lisa's arms. It wasn't until the autopsy after Bryan's death that the Yus learned that Bryan suffered from hypertrophic cardiomyopathy (HCM), a disease that affects one in 100,000 children born in the U.S. and is the leading cause of heart transplants in children over the age of 1.

"To this day, I blame myself for not reacting more quickly," said Lisa, who now has two healthy girls. "Two hours after the ordeal, the doctors still did not know the cause of his death. They thought it might have been a virus that affected his heart. We had so many questions, but were too consumed by grief to ask."

But grief was only beginning. Three years later in 2001, the Yus lost



Photos by Jim Inverso

▲ Lisa and Eddie Yu '85 with Michelle and Audrey outside their home in Tenafly, N.J.

a second child, 9-month-old Kevin, while he waited for a heart transplant.

Eddie also has HCM, but doctors never took the genetic component of this disease seriously. When Eddie was 7 years old doctors found a septal defect in his heart. Later, in his sophomore year at Peddie, Eddie had an echocardiogram and doctors found the wall of his heart had thickened. At the time, they believed it was insignificant.

"I am asymptomatic," said Eddie, who has regular check up and takes

medication, "but it's a constant reminder of my sons' condition. I would do anything to have prevented them from having this disease."

Cardiomyopathy Foundation

In 2002, angry and determined, the Yus founded the Children's Cardiomyopathy Foundation, a grass-roots organization dedicated to supporting parents and funding education and research. Today, they reach out to 1,800 doctors and 100 families worldwide and are the only public interest group devoted to battling the pediatric form of the disease.

"When we were going through all the pain with Kevin, there was no support and no information on the disease, especially in infants," said Eddie, an executive with Morgan Stanley. "Our motivation has been to help others and maybe one day find a cure."

Led by a distinguished medical advisory board, the foundation just received a grant to establish a national tissue and blood repository at Baylor College of Medicine. The lab

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Eddie with Kevin at nearly 6 months old. ▼

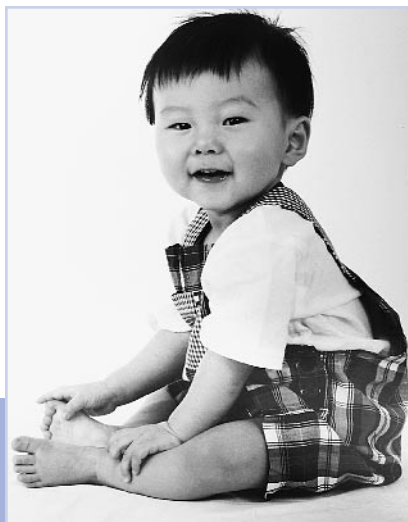
will collect samples of blood and tissue for molecular studies on the disease to better understand its mechanism and to find better therapies. This one-of-a-kind repository and database allows doctors throughout the United States and Canada to accelerate research on the disease by making high quality samples available so investigators do not need to spend years collecting samples and data.

The Yus hope the center will be up and running by the end of this year with major children's medical centers in New York City, Miami, Boston, St. Louis, Chicago, Philadelphia, Los Angeles, Arkansas and Texas participating. The goal is to improve survival rates, find genetic causes and eventually a cure.

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What the Yus learned is cardiomyopathy is a rare and chronic condition in which the heart muscle is enlarged and weakened, and the pumping ability of the heart is impaired. About 1,000 children a year are diagnosed nationally, triple the number who suffer from AIDS. Many die undiagnosed of sudden cardiac arrest or go on to require a heart transplant.

This rare disease has no known cause or effective treatment. When children are diagnosed young, fami-



lies face a lifetime of anxiety. The only available treatment is medication to relax the heart so it does not need to pump so hard, as well as implantable defibrillators to prevent sudden death.

Studies on the children's form of the disease are under funded, as most cardiac research is devoted to adults; only five percent of the budget of the American Heart Association is spent on pediatric research.

The disease comes in four different forms. The most common form, hypertrophic cardiomyopathy, is hereditary. The disease can also be acquired through a viral infection or associated with other diseases.

While the first symptoms can occur in childhood, as with Bryan and Kevin, often those affected can go years symptom-free, then suffer fatal arrhythmias, rapid beats that paralyze the flow of blood from the heart.

Kevin's Story

Behind a frame in the entryway of the Yus' home in Tenaflly, is a tiny embroidered jacket, one of many collectibles they brought home from Hong Kong, where they met and married. It was there that Bryan suffered his fatal heart attack and Kevin was born. In searching for answers the Yus asked top cardiologists if it would be safe to conceive again. Doctors downplayed the genetic component of the disease, and no one advised seeing a geneticist.

There were no support groups, little information and no recommendations for participating in research. The Yus had always wanted to adopt a child and began the process to adopt Michelle, now 4. But, in 1999, Lisa unexpectedly got pregnant with Kevin. A week after he was born, they discovered he, too, had hypertrophic cardiomyopathy.

"I was overwhelmed with emotion and felt so helpless," said Lisa. "We were determined to do all that we could to save Kevin from the same fate as his brother."

◀ Bryan at 11 months old.



That meant giving up high-powered careers and comfortable life in Hong Kong, where they had been living for eight years. Eddie was with Morgan Stanley and Lisa was Asian regional marketing director for Sony Pictures Entertainment – but they decided to move to the U.S. to get medical care.

At six months old, Kevin was the youngest patient ever to receive an implanted defibrillator while being treated at Children's Hospital/Columbia Presbyterian, which sees about 150 children with cardiomyopathy a year.

"It was so big that it stuck out from his abdomen," said Lisa. During the surgery, there were complications, and he even survived cardiac arrest. After two more months of feeding problems, medicine and countless doctors visits, Kevin was admitted to the hospital with low blood sugar and close to death.

Kevin was put on a wait list for a heart transplant, but his condition deteriorated. One month later, after being put on a heart-lung bridging device, the Yus were informed that Kevin had suffered brain damage from being on the machine. Kevin had lived most of his young life in hospitals, and so the Yus made a tough decision.

"We decided to pull the plug and let Kevin die in our arms," she said.

Supporting Research

But in 2003, the Yus took a chance again and Audrey, now 19 months, was born. Geneticists had told them they had a 50/50 risk, but they were lucky, Audrey was healthy.



Eddie is also participating in research studies at the Seidman Laboratory at Harvard University and is undergoing clinical genetic screening to see if they can identify the genetic mutation causing his cardiomyopathy and determine if it is the same as Kevin and Bryan's. This would tell doctors more about how the disease could manifest so differently in children and in adults.

The foundation's medical board includes Dr. Steve Lipshultz, chairman of pediatrics at Holtz's Children's Hospital at the University of Miami School of Medicine. He recently published a study in the *New England Journal of Medicine* that shattered old myths about cardiomyopathy.

Based on a nine-year study of 500 children suffering from cardiomyopathy, Dr. Lipshultz found that children are 10 times more likely to develop the disease during their first year of life than ages 2 to 18 combined. In fact, about 40 percent of those diag-

nosed under age 1 are likely to die or need heart transplants.

This was the case with Bryan, said Lisa: "The pediatrician said it was rare that Bryan would have the disease, but if he had read this study he might have had him screened by a specialist earlier."

"In the past, children were lumped in together with adults, and so there is no hard data available on pediatric cases," said Lisa, remembering that Kevin did not seem sick enough to receive a heart transplant until it was too late. "Knowing that, parents and doctors can get children on the list earlier."

Dr. Lipshultz now runs a national registry that studies the course of the disease in 10,000 children at 252 participating pediatric centers, and is partnering with the Children's Cardiomyopathy Foundation to link the tissue and blood repository to existing clinical data. This would be a valuable resource made available to all interested researchers.

According to Lipshultz, there are no



▲ Audrey Yu, 19 months, is healthy.

pre-natal or diagnostic genetic tests for the disease. Despite new drugs and implantation devices, no cure exists today, and a damaged heart cannot be repaired. Registry data and repository samples could help spearhead studies into developing a low-cost diagnostic test and improved therapies.

Dr. Wendy Chung, a clinical geneticist at Children's Hospital of New York, is hopeful the blood and tissue repository will give researchers more genetic material to analyze. The Yus have donated their samples, as well as tissue that was saved from Bryan and Kevin.

Peddle Families Suffer from Cardiomyopathy

Cardiomyopathy often strikes young people in their prime. It took the lives of two other members of the Peddie family. Matt Weiner '98 of Medford, N.J. died while playing a game of pickup basketball at Princeton University in 1999; Joe deLaurentis '00, son of Falcon football coach Frank deLaurentis, died during a community service project at Ursinus College in 2000. Both boys were only 19.

"I don't know if we have ever come to terms with Joe's death," said Coach deLaurentis. "We have good days and bad days. Because Joe was symptomless, it was obviously not discovered. The coroner and the doctor said there was nothing we could do."

Like the Yus, now that a family history has been established, cardiologists can test the other deLaurentis children, Mike '03 and Julie '05, for signs of the disease. So far, both are healthy.

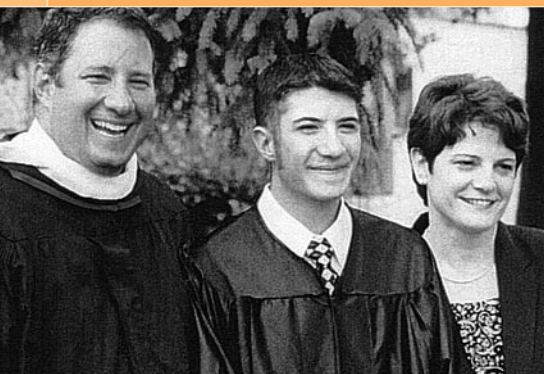
Peddle parent Kim Blakeslee-Sexton, 47, of Bordentown, N.J., who has been diagnosed with the disease, suffered a sudden death arrhythmia in June and survived. The heart races so fast that the blood is not adequately pumped, and without intervention, death occurs. Kim knew there was a family history of cardiomyopathy – her father had died at 36, and she lost

two sisters at ages 17 and 22.

Her 18-year-old daughter, Courtney '04, was diagnosed with the pediatric form of the disease at the age of 2. Both mother and daughter were part of a controversial experiment at the National Institutes of Health. Cardiac surgeon Dr. Lameh Fananpazir put pacemakers in 68 children between 1992 and 1996. Several patients died, and there was at least one lawsuit surrounding the study.

Both Kim and Courtney now have defibrillators – about the size of a deck of cards – surgically implanted in their chests. Those electrical devices – part stimulator, part pacemaker – automatically charge in an attack, reprogramming the way the heart beats. They both say the devices have saved their lives.

Kim had never had an attack, but all that changed this summer.



◀ Joe deLaurentis '00 with his parents, Frank and Betty.

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—Eddie Yu '85

"Lisa's family is important in that more than one child was affected," said Dr. Chung, who also serves on the foundation's medical advisory board. "Finding another 20 families like that would enable us to determine the genetic factor that causes it, because the problem is getting enough genetic material to analyze."

The Yus' foundation helped establish the Comprehensive Pediatric Cardiomyopathy Program at Children's Hospital of New York, the first multi-disciplinary treatment center in the tri-state area.

For parents who turn to the Yus' foundation for advice and information, "there is constant anxiety when a child has a chronic condition," said Lisa. "One mother called me and her child was fine. In a year the child was

dead. It can progress that quickly. When a parent loses their child, the pain really is unbearable."

Yu hopes the Children's Cardiomyopathy Foundation might one day change that. But the biggest hurdle they face is money, to carry out their work and to maintain and expand the tissue repository. The foundation depends on public contributions.

Lisa is tired these days, talking to doctors, writing her newsletter, prepping up on the latest research and reassuring parents who are traumatized by knowing their children's condition. The phone calls from frantic mothers come late at night, after she's had a long day focusing on the foundation work and taking care of her two young girls. The younger one, Audrey, reminds her of Kevin.



"Sometimes I tell Eddie that this is too much work, but then I get e-mails from families saying how important it is to them, and I can't walk away from them," said Lisa. "If this organization did not exist, what would these families do?"

Their generosity also helped establish the Yu Child Care Center at Peddie in memory of Kevin and Bryan.

"Peddie prepped me well for all the difficulties in life," said Eddie. "This was one of the worst things that could happen as a parent. Being a boarding student [Eddie's parents lived in China] helped me be self-reliant. The spirit of our foundations is that it is important to make a difference."

For more information about the Children's Cardiomyopathy Foundation, visit www.childrenscardiomyopathy.org or call (201) 227-8852. On Sept. 14, CCF held a golf tournament at the New York Country Club in Hempstead, N.Y. to raise funds. Last year's tournament raised more than \$160,000 for the foundation.

Walking down the hall at the high school where she works as a teacher for the learning disabled, she fell unconscious hitting her head against a wall. Her defibrillator kicked in and restarted her heart after 13 seconds.

"I'm having a hard time right now," she said. "I have lived with this all my life, but now I am scared. I am usually so much stronger than this. I've got that guilt, because of what Courtney goes through every day. I can't be afraid if she is not afraid."

Courtney, who attends Villanova University, understands better than anyone what her mother is going through. She has suffered numerous sudden death arrhythmias, including one on a treadmill during a heart check-up when she was 8 and another recently while surfing on Long Beach Island.

"How do you explain to your 8-year-old classmates what a pacemaker is, let alone the fact that you have one sitting just under the skin next to your heart?"

said Courtney, remembering back to elementary school. "And how do you convince them that the monitor with wires running in all different places isn't

some sort of alien robotic mechanism."

Courtney has been active in volunteer work for the American Heart Association.

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