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ON THE WEB

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## After Tragedy, Resolve to Battle a Heart Disease

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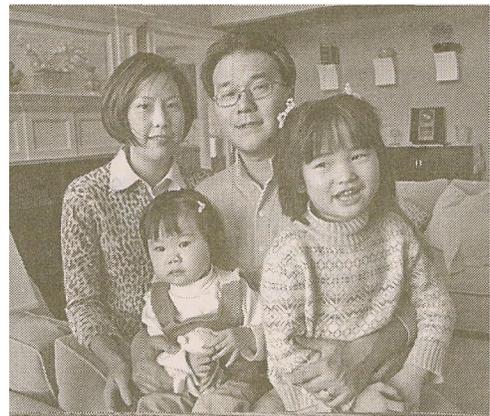
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Lisa and Eddie Yu of Tenafly listened to the pediatrician when their 11-month-old son came down with a cold – it's nature's way of allowing babies to develop strong immune systems.

But several days later Bryan woke up crying and seemed drowsier than usual. Within hours he was lethargic and refused to eat and, knowing something was wrong, they rushed him to the emergency room. Bryan was already experiencing heart failure in the car, as he shuddered and slumped in Ms. Yu's arms.

The autopsy revealed Bryan died from cardiomyopathy, a disease that strikes one in 100,000 children nationally. It has one of the highest death rates of any childhood disease – about 40 percent, yet no pre-natal tests exist, it is often misdiagnosed and those studying it feel their research is under funded. Fewer than 10 regional pediatric clinics serve 10,000 children who have the disease.

"To this day, I blame myself for not reacting more quickly," said Ms. Yu, 39, a former marketing director. "We had so many questions, but were too consumed by grief to ask."



Lisa and Eddie Yu of Tenafly, with their daughters, Audrey, left, and Michelle.

Photo: Timothy Ivy for The New York Times

But their grief was only beginning. Three years later in 2001, the Yus had another child die with the same disease; 9-month-old Kevin died as he awaited a heart transplant. Angry and determined, they founded the Children's Cardiomyopathy Foundation, a national organization dedicated to financing research and education.

Cardiomyopathy is a chronic condition in which the heart muscle is enlarged and weakened, and pumping is impaired. There is no cure, and as the disease progresses it can require a heart transplant. When the disease is diagnosed in young children, families face a lifetime of anxiety. The only treatment is medication to relax the heart's pumping or implantable defibrillators to jolt the heart back from fatal arrhythmias. Many children lead seemingly healthy lives, then unexpectedly die as teenagers.

Cardiomyopathy often strikes athletes: Hank Gathers, a Loyola Marymount basketball star, and Olympic figure skater Sergei Grinkov dropped dead in their prime.

When Mr. Yu, 37, a financial executive, was a teenager, it was determined that he had cardiomyopathy. Mr. Yu and his wife lived for eight years in Hong Kong, where Bryan died and Kevin was born. They consulted top cardiologists, but doctors played down the genetic component of the disease and never recommended further testing. Even after returning to the United States to seek treatment for Kevin, they found no support groups for advice.

Today, Mr. Yu is monitored annually, but remains symptom-free. He also participates in genetic screening at Seidman Laboratory at Harvard University. "It's a constant reminder of my sons' condition," he said. "I would do anything to have prevented them from having this disease."

In 2003, the Yus took another chance, and Audrey, now 22 months, was born healthy, despite 50/50 odds. They adopted Michelle, who is now 4, shortly after Kevin's death.

As the Yus struggled with understanding why the disease could be so benign in one parent and yet lethal to their children, the Children's Cardiomyopathy

Foundation took shape. Today, it reaches out to 1,800 doctors and 100 families as the only public interest group devoted to battling the pediatric form of the disease. For her efforts, Ms. Yu was recently named a “Hero for Health” by Good Housekeeping magazine.

"Everyone grieves differently," Ms. Yu said. "I needed a purpose – to make sense of the tragedy. We knew that nothing was going to happen if we just sat there, immobilized with pain."

Led by a medical advisory board, the foundation is working with the National Heart and Lung Institute funded Pediatric Cardiomyopathy Registry to establish a national tissue and blood repository. The lab will collect biological specimens from leading medical centers for molecular studies to find better therapies and perhaps a cure.

Dr. Wendy Chung, a clinical geneticist at Children’s Hospital of New York and foundation board member, is hopeful the 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.

"Lisa's family is important in that more than one child was affected," said Dr. Chung. "Finding another 20 families would enable us to determine the genetic factor that causes it.”

One Bordentown family has been devastated by cardiomyopathy. Kim Blakeslee-Sexton, 47, lost her father and two sisters, ages 17 and 22. After their deaths, she took her son Ryan, then 6, and her daughter Courtney, 2, to the National Institutes of Health.

It was determined that Courtney, now 18, had cardiomyopathy. Her mother was a suspected case, even though she showed no signs of the disease. Both were part of a study with Dr. Lameh Fananpazir, a cardiac surgeon who implanted pacemakers in 68 children between 1992 and 1996. Both Ms. Blakeslee-Sexton and Courtney have defibrillators – about the size of a deck of cards – surgically implanted. Those devices – part stimulator, part pacemaker – automatically charge in an attack, reprogramming the heartbeat.

That device saved Ms. Blakeslee-Sexton's life last summer when she had her first near-fatal attack.

"I have lived with this all my life, but now I am scared," she said. "But I can't be afraid if Courtney is not afraid."

Courtney has had many sudden-death arrhythmias. Her defibrillator is replaced every five years in a risky procedure. A three-hour surgery in September turned to six hours, when she developed life-threatening complications.

Ms. Yu, who fields late-night phone calls from parents, said: "There is constant anxiety when a child has a chronic condition. One mother called me, and her child was fine. In a year the child was dead. The pain really is unbearable."

Ms. Yu hopes the Children's Cardiomyopathy Foundation might one day change that. They now have a partnership with the American Heart Association and other organizations to develop patient materials. But the biggest hurdle is money, as the foundation relies on public contributions.

"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," Ms. Yu said. "If this organization did not exist, what would these families do?"