When tiny hearts give out

Losing two babies to a little-understood condition prompts a mother to start a foundation

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Look at a photo of baby Bryan taken a month before what would have been his first birthday on July 4, 1999. You can understand why nobody had any inkling this healthy-looking child would die of sudden cardiac arrest.

Look at a picture of his brother, Kevin, born a year after Bryan died, wearing a chubby-cheeked smile while his father nuzzles his ear. He, too, was gone before his first birthday, awaiting a heart transplant.

The brothers died of complications caused by pediatric cardiomyopathy, a chronic condition in which the heart muscle is enlarged or weakened, impairing its ability to pump blood.

An estimated 1,000 children are born in the United States each year with cardiomyopathy - nearly three times the number of children born here with HIV - yet little is known about its cause or treatment.

"Everyone grieves differently," said Lisa Yue, the boys' mother. "For me, I needed a purpose - to make sense of our tragedy. We went through rounds of genetic testing and were told that we might never have an answer, and that if we were to have more children, the risk would always be 50/50."
It was that sense of hopelessness that led Yue, formerly the Asia regional marketing director for Sony Pictures Entertainment, to parlay her business expertise into a full-time venture called the Children's Cardiomyopathy Foundation.

"We knew that nothing was going to happen if we just sat there, immobilized by pain and anger," she said. "If we wanted answers, we had to encourage more research on the disease."

The foundation's mission is to stimulate and fund research toward a cure, educate health-care professionals and patients, and increase awareness and advocacy related to the needs of affected children and their families.

The boys' father, Eddie Yu (his last name is spelled differently from his wife's maiden name, Yue), was diagnosed with hypertrophic cardiomyopathy - one of four forms of cardiomyopathy - at age 15. It's not unusual; about one out of every 500 adults has it. Fortunately, Yu has never experienced any symptoms.

However, the disease progresses more rapidly and severely in children, causing one of the highest death rates of any childhood disease.

The parents had been assured that if Bryan had indeed inherited the condition, it would not be a problem till he was a teenager.

"A pediatrician who is concerned about a child potentially having a heart problem may consult some of today's most popular cardiology textbooks, and he or she will read that it is unusual for a young child to get cardiomyopathy," said Dr. Steven Lipshultz, professor and chairman of pediatrics at the University of Miami School of Medicine.

Lipshultz, who serves as chairman of the foundation's medical advisory board, last year published a study in the New England Journal of Medicine that exploded this myth.

Based on information from the nine-year-old North American Pediatric Cardiomyopathy Registry involving 500 children, the study found that kids are about 10 times more likely to develop cardiomyopathy during their first year of life than ages 2 to 18 combined, and that the condition may occur more often than previously thought.

This is why Yue works most of the day and again in the wee hours, long after she and her husband have put their two healthy little girls, 4-year-old Michelle and 18-month-old Audrey, to bed in their Bergen County home.

She answers phone calls and e-mails from families seeking information - about 100 each year since she and her husband started CCF in 2002 with donations from Yu's co-workers.
With pictures of Bryan and Kevin close at hand, she consults with CCF’s medical advisers while applying for grants and evaluating research projects needing funds. She speaks with government agency officials regarding joint programs. She writes and distributes literature for parents and health professionals, organizes fund-raisers and an annual appeal campaign, and writes a newsletter.

As a result of Yue's efforts, a national blood-and-tissue repository will soon be up and running. Two research studies have been made possible. And CCF helped to establish the Comprehensive Pediatric Cardiomyopathy Program at the Children’s Hospital of New York, the first multidisciplinary treatment center of its kind in the tri-state area.

"In teenagers, we've been able to figure out the cause in 50 percent of the cases," said Dr. Wendy Chung, clinical geneticist for the program.

But newborns with cardiomyopathy usually don't live long enough for geneticists to figure out what's caused the condition so physicians can determine how to treat it. Usually, it's inherited; sometimes it's brought on by a virus.

The CCF-funded biological specimen repository aims to provide geneticists with far more genetic material to analyze. Chung suspects they will find an enzyme deficiency in many infant cases, which would simply call for dietary supplements.

"The good news is that it's potentially treatable by something other than a heart transplant," Chung said.

"Lisa's family is important in that more than one child was affected," said Chung. "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."

After learning of Chung's genetic studies through CCF, Laura and Bill Murphy of Flanders submitted samples from their 9-year-old daughter, Amanda.

Amanda turned blue the night she was born at Morristown Memorial Hospital, and pediatric cardiologists determined that the newborn's heart was enlarged.

"When we got over the initial shock," recalls Laura Murphy, "we understood that she could get sicker over the first year, which would mean she’d need a [heart] transplant, but if it stayed status quo she could be fine and just have some restrictions. That's the course it took." Amanda takes medication daily and may not participate in competitive sports.

It is children such as Amanda Murphy that give Lisa Yue the strength to go on.

"I wanted to do the foundation in memory and in honor of Kevin and Bryan," Yue said. "But once I started working on it, I realized it wasn't just about them. It was also for all
the other kids that are affected by this. When you look at the statistics, it's very hard to walk away."

For more information about pediatric cardiomyopathy or to make a donation to CCF's research fund, visit childrenscardiomyopathy.org or call (201) 227-8852.

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