Lisa Yue fights back
Tenafly mom works to defeat the disorder that took her sons’ lives

BY DONNA NITZBERG

Okay, so most moms are heroes to their kids: wiping tears; stuffing cookies into lunch boxes; staying up to the wee hours waiting for the fever to break; or the dance to be over. That’s why we honor them on Mother’s Day. But some women are heroes to more than their own kids—by doling out care and compassion to other people’s children too. Tenafly’s own Lisa Yue is one of these special women. She suffered through terrible personal tragedy, losing two baby boys to the rare and incurable heart disorder, pediatric cardiomyopathy. But instead of crumbling under the weight of unbearable grief, she turned her anguish into hope for other kids.

Today, Lisa Yue and her husband, Eddie Yu (Lisa kept her maiden name when she married), an executive director at Morgan Stanley, are blessed with two healthy little girls, aged 4 1/2 and 2, who keep the couple plenty busy. In addition, they have started a national foundation run out of their Tenafly home, called the Children’s Cardiomyopathy Foundation (CCF), to fight the disorder that killed their sons. Lisa works full time now for the organization. And helping other children suffering from cardiomyopathy has allowed her to both honor her boys every day, and to mend her wounded heart.

“There are few parents that can muster the personal strength and vision after living through such a terrible, terrible situation, and turn it into something amazing,” says Dr. Wendy Chung, the Director of Clinical Genetics at New York-Presbyterian Medical Center who is on the board of the CCF. “Lisa is literally up at midnight talking to families going through this, talking to scientists working on cures, and talking to families going through this, talking to scientists working on cures, and sometimes it becomes sick and doesn’t work as it should,” explains Dr. Hsu. “A heart that doesn’t work well affects everything in your body. The heart muscle needs to pump blood to get the oxygen into your body.”

The disorder is extremely rare in children, only affecting about 1,000 babies a year in the United States, with an incidence of 1.2 cases per 100,000 children, according to a recent study by Dr. Steven Lipshultz of the University of Rochester, published in the New England Journal of Medicine. And although rare enough to get little research funding or attention, it still afflicts about three times as many children as those born with AIDS each year in the United States.

In babies, symptoms of cardiomyopathy can include: poor appetite and failure to thrive; upset stomach/gastrointestinal distress; fainting; chest pain; heart murmur/irregular heart beat; coughing; and excessive sweating. While children can be afflicted at any age, 65% are diagnosed under the age of 1, a fact that many pediatricians are only now being made aware of, due in no small part to efforts by the Yu family foundation.

“The disease can be very deceiving, because the children can look fine,” explains Yue. “They’re not blue, they’re not really weak. Some are a little bit smaller than the average kid, but they meet all the developmental milestones. So doctors sometimes don’t realize how serious it is.” And since in most cases (68% of the time) there is no known cause, like a family history or a viral infection, the disorder is often not diagnosed until the child dies.

After Bryan’s death, the Yus were told that his condition was so rare that it wouldn’t happen again. And they desperately wanted to have more children. “No one ever suggested we go to see a geneticist,” Yue explains sadly. “We didn’t know enough back then. We were just in shock over what had happened.”

CONTINUED ON PG. 24
Pediatric cardiomyopathy is one of the world’s most deadly childhood diseases, with a higher death rate than even cancer.

And nearly half of the children undergoing transplants have pediatric cardiomyopathy.

Some of the therapies that the Yus considered included giving medications that ease the heart’s workload; implanting a defibrillator into the baby’s heart that would automatically shock it back into action if it stopped suddenly; using a feeding tube to try to get his weight and strength up; and putting him on a waiting list for a heart transplant. But each time it was a guessing game about whether and when to do the procedures. The defibrillator went in at six months, and the feeding tube shortly thereafter. Deciding on a heart transplant was particularly difficult.

“New Hope

In the midst of their heartbreak, the Yus had a glimmer of joy which gave them reason to go on. Their daughter Michelle’s adoption was finalized a few months after Kevin died. “You feel very very empty after you lose a child,” Yue says. “So it was really a blessing that we continued on page 25.”
had already started the adoption process.

Two years later, after much soul searching, genetic testing and blind faith, Audrey was born. “We really took a chance,” Lisa says quietly. “When you lose two children and then become pregnant again, the joy of being pregnant is not really there. You just don’t tell anyone. It’s very nerve racking, and definitely not for everybody.” But it seems that Audrey has dodged the CM bullet definitely not for everybody.” But it seems that Audrey has dodged the CM bullet and is perfectly healthy.

“It’s hard not to be over protective,” notes Yue. “And after having children with heart conditions, I guess I’m a little more careful about the girls’ health. But I try hard to let them be kids.”

One of the most important lessons that Lisa took away from the boys’ short lives is that she’s learned to trust her intuition. “Anytime you think that something is wrong, you have to listen to your inner voice,” she says. “You have to constantly push to feel comfortable about things like medical treatment. Don’t worry about what the doctor thinks or if you’re just being paranoid. You have to be your child’s advocate and constantly push.”

“One of the problems with rare diseases, especially when the children die, is that there aren’t ‘poster children’ to advocate for themselves,” notes Dr. Chung. “All that’s left are grieving parents. And ghosts. And Lisa has taken on the difficult role of speaking for the missing children.”

In between their two daughters’ arrivals, the Childhood Cardiomyopathy Foundation was born. The Yus didn’t set out to “save” anyone, only to find a way to remember their sons.

THE FOUNDATION

“It started out as a small project,” Lisa says with a chuckle. “In talking with doctors and through our own journey we knew that there were no support groups, not many specialists and almost no research being done on the disease. But as we got more and more involved we found out that we couldn’t just do this in a small way. We decided to properly start up a foundation with a proper medical advisory board, so that we could control where the money would go.”

Over the past three years, the Childhood Cardiomyopathy Foundation – which is still very small with a full time staff of only three – has focused on a couple of different projects. Among them is an on-line family support group; a lobbying effort to get a bigger piece of the National Health/research pie allocated to the disease; an education project which tries to increase awareness of the disease to both the general public as well as pediatricians and cardiologists; and contributing to the establishment of a cardiomyopathy tissue bank and registry, which collects tissue from afflicted children all over the world for future research projects.

“Lisa is absolutely correct in her vision about creating the tissue and DNA repository so that scientists from all over the world can study the disorder,” notes Chung. “No one has had enough of their own patients to do the research. Now scientists don’t have to spend a lot of time finding all of these cases on their own. They can get the data from the repository.”

Most experts say that in order to learn how to treat this disorder, its first necessary to figure out what causes it. As there are so many different causes, there are probably many different treatments. Even now they have had some small triumphs, especially when a child’s heart problem is linked to certain diseases, the best-known of which is called Pompe’s disease, called “inborn errors of metabolism.” In these diseases, the child lacks certain enzymes that safely break down chemicals, usually in food, and the unprocessed chemicals can cause a lot of damage throughout their bodies, including the heart. If these types of disorders are caught at birth, the children can be treated and often cured. That’s why many states, including New York, have recently expanded their newborn screening tests to include Pompe’s disease and similar “fatty acid oxidation” disorders.

Donna Nitzberg is a New Jersey mother and writer.

---

The Barbizon Message

★★ How does your teen stand up to peer pressure?
★★ Does he or she have confidence and high self-esteem which is what it takes to say NO!
★★ Barbizon has the tools to make this happen!

Since 1939 Barbizon has been the leader in the acting and modeling school industry – now with a special emphasis on helping one’s confidence and giving the life skills it takes to succeed in today’s world.

Don’t Wait!
Call the Barbizon of Paramus Today (201) 727-1034
www.barbizonmodeling.com/paramus