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## Tenaflly mom's loss of sons leads to activism award

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**STAFF WRITER**

TENAFLY - Four years after her infant sons died, Lisa Yue is still trying to figure out what happened.

She still doesn't understand how the boys developed cardiomyopathy, a rare condition in children in which the heart muscle is abnormal.

The pediatric form was virtually unexplored when her kids had it, so Yue established a research grant to search for answers. Then, frustrated by the lack of advancement, she started the Children's Cardiomyopathy Foundation.

The Tenaflly resident's efforts keep her awake until 2 a.m. most nights and sometimes away from her two healthy daughters, 4-year-old Michelle and 22-month-old Audrey.

Her sleepless nights were acknowledged this week, when she received a Good Housekeeping "Heroes for Health" award, along with four other women. About 50 women across the country were nominated.

"The recognition is great," said Yue, who will also receive \$10,000 for her foundation. "This gives you fuel to keep going on."

When Yue and her husband, Eddie Yu, started trying to have children, they told their doctor about Yu's hypertropic cardiomyopathy, which means his heart muscle is enlarged. The doctor assured them that if the baby inherited the condition, he wouldn't have problems until later in life.

But the child, whom they named Bryan, died when he was 11 months old. That day he went limp like a rag doll, Yue recalled. On the way to the hospital he shuddered and slumped over.

"I think that's when we lost him," she said.

Her second child, Kevin, was diagnosed with the condition a week after he was born. He needed a heart transplant, but died waiting for a donor.

Yue rechanneled the energy she had spent searching for treatments for Kevin into her foundation.

"You can shrivel up or you can do something about it," Yue said.

The small foundation has contributed big things. It helped fund establishment of a tissue repository for research, a cardiomyopathy center at the Children's Hospital of New York and a patient registry that follows children with the condition. An estimated 1,000 children are born in the United States each year with cardiomyopathy.

One of its biggest contributions was formation of an online support group for parents about a year ago "I just had to talk to somebody," said Jennifer Ghandour, a Michigan resident who came across the foundation a year ago, after her two kids were diagnosed with the condition.

Ghandour started holding fund-raisers for the foundation to support its research ambitions.

"It's so undetectable," Ghandour said of cardiomyopathy. "There needs to be a test that right when the baby's born."

Yue's devotion astounds the physicians who serve on the foundation's medical advisory board.

"Lisa is remarkable," said Dr. Wendy Chung, from New York-Presbyterian Medical Center. "Even though she lost two children, she is a tireless advocate."

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