Lisa Yue's Commitment to Curing Cardiomyopathy

A painful loss led to the establishment of a foundation to raise research funds for the cause and cure of this fatal disease.

By Paul Fang (Wen Chang Fang)
Published: July 30, 2004; English translation from Chinese article

Five years ago, Lisa Yue experienced the loss of her two infant sons, their cause of death: cardiomyopathy. Looking at the photos of her smiling boys, she recalls the pain of losing them and explains how it provided the impetus to find the cause and cure for a relatively unknown disease called pediatric cardiomyopathy. In 2002, Yue founded the Children’s Cardiomyopathy Foundation, and she asks for everyone’s generosity and support in helping to fund such a large research undertaking.

Yue currently lives in Tenafly, New Jersey. She explains that before their elder son Bryan died suddenly at 11 months in 1999, he looked completely normal and showed no symptoms. After months of exhaustive research and investigation, it was discovered in an autopsy that the cause of Bryan’s death was cardiomyopathy.

A year later, they were blessed with the birth of their second son, Kevin. Tragically, Kevin was also diagnosed with cardiomyopathy. After suffering the lost of Bryan, Lisa Yue and her husband, Edward Yu, became proactive in finding the proper treatment for Kevin. Unfortunately Kevin passed away at 9 months before a cure was found.

Yue explains, very little is known about cardiomyopathy, a chronic disease that causes the enlargement and weakening of the heart muscle, which impairs the heart’s ability to pump blood. The disease has proven far more deadly to children than to adults. Currently, there are approximately 10,000 children suffering from this disease in the United States. Each year, this number is increased by 1,000, which is approximately double the number of children born with HIV.

In spite of the spread of the disease, government and private organizations have done very little on researching cardiomyopathy. Yue cites the National Heart Lung and Blood Institute as an example. The institute has mainly concentrated their funding on the research of adult and geriatric heart diseases, whereas only $68 million was allocated to the research of congenital heart disease. Out of that, only $4 million is dedicated to pediatric cardiomyopathy, which is
considered to be a small amount of funding to be spent on research. This is one of the main reasons why information on pediatric cardiomyopathy is severely lacking.

For example, the current collection of a national blood-and–tissue sample is the first step to finding the cause and cure. Collaborating with six hospitals in the first year to gather 50 such samples will cost $150,000. Such expenses will increase each year. Yue hopes that the lack of funding will not lead to the discontinuation of this kind of research initiative.

Yue is determined to find the cause and cure of cardiomyopathy. In her pursuit, she has given up her high paying job as the Asia regional marketing director for Sony Pictures Entertainment. She now cares for her 4-year-old adopted daughter Michelle and 19-months-old birth daughter Audrey, all the while managing the Children's Cardiomyopathy Foundation.

With insufficient resources and limited funding, Yue alone takes on the work of the foundation's public relations, sales and fund raising. It is common practice for her to work until 2 to 3 in the morning. Still, she remains relentless in her care for the many children and families with pediatric cardiomyopathy.

Yue hopes to raise the general public's awareness of pediatric cardiomyopathy, provide a forum for patients and family to exchange ideas and support, and assist families in finding the best medical resources. If you would like to learn more about pediatric cardiomyopathy or to make a donation, please call (201) 227-8852 or visit www.childrenscardiomyopathy.org.

Original Chinese article attached below.
余文清弁志發掘兒童心肌症
喪子之痛促使成立基金會 籌資研究絕症成因及醫治方法

余文清表示，原因不明的心肌症，屬於慢性疾病，由於心臟逐漸放大或衰竭而損害輸血功能，對兒童的殺傷力遠高於成人。她說，目前全球約有一萬名兒童心肌症患者，每年約新增一千名兒童患者，約是新增愛滋症的兩倍。

儘管如此，政府及民間對心肌症研究的贊助卻少之又少。余文清說，以美國心臟、肺暨血液學院 (National Heart, Lung and Blood Institute) 為例，該院提供補助金集中在成年及老年心臟病，兒童先天性心臟病只占6800萬元，其中兒童心肌症只分到四百萬。對於費用龐大的心肌症研究，根本是杯水車薪，難怪相關的資訊付之闕如。

她以正在進行中的兒童患血友病及肌肉 (tissue) 樣本蒐集計畫為例說明，採樣計畫是發掘病因及治療的第一步。可說是兒童心肌症研究的關鍵。第一年費用約為600萬元，第二年費用約為500萬元。每年費用約為1100萬元。她希望提高社會對兒童心肌症的重視，提供患者家屬交換心得與經驗，並協助尋找最佳的醫療資源。如欲了解兒童心肌症或捐款，可電 227-8852。