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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)
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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.

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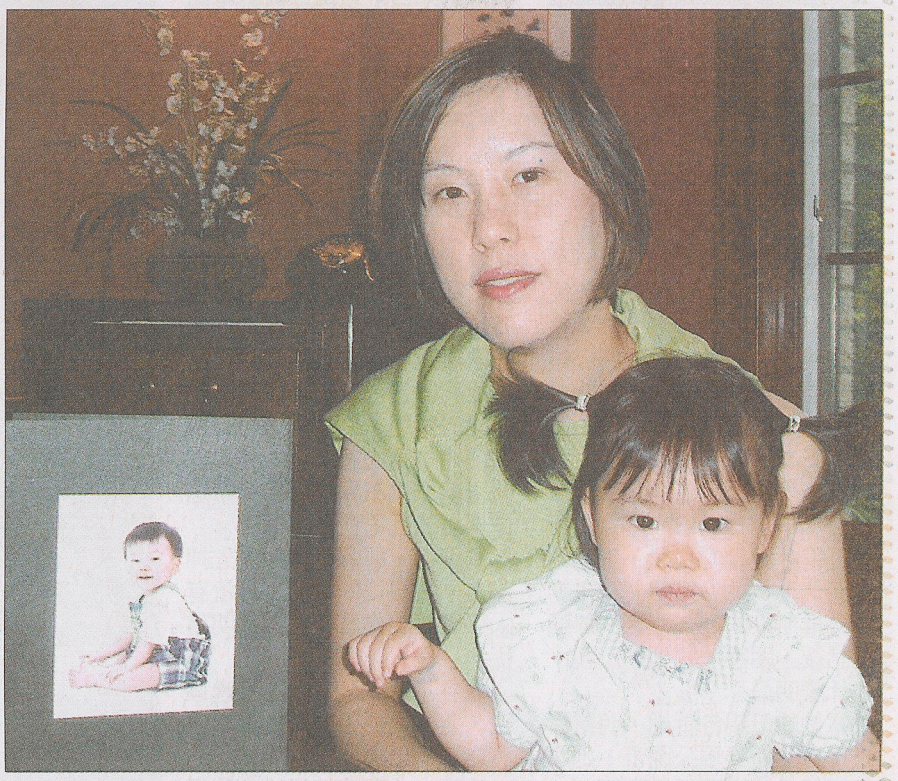

余文清(Lisa Yue)身受喪子之痛，促使她成立兒童心肌症基金會，籌款研究病因及治療之道，圖為她抱著奧黛麗，身貼布來恩留下的珍貴照片，她呼籲社會重視兒童心肌症的研究，並踴躍捐輸。（本報記者方文章攝）

余文清矢志發掘兒童心肌症

喪子之痛促使成立基金會 籌資研究絕症成因及醫治方法

【本報記者方文章新澤西報導】四、五年前眼睜睜看著心肌症狠心奪走兩位稚子寶貴生命的余文清，凝視著照片中他們留下的燦爛笑容回憶說，經歷這兩次錐心泣血的打擊，她在2002年成立了兒童心肌症基金會 (Children's Cardiomyopathy Foundation)，矢志發掘心肌症的造成原因及醫治之道，因研究費用龐大，她籲請大家踴躍捐輸。

住在新州田納福來市的余文清表示，長子余皓東表面上完全正常，但1999年只有11月大的余皓東，卻在毫無預警的情況下病發去世，經過數月的研究與調查，終於在解剖驗屍後確認致命元兇是心肌症。

余皓東去世後一年，次子余成龍於誕生後一週，也被診斷罹患心肌症。有了上次的慘痛經驗，余文清及丈夫余健中不再坐以待斃，想方設法卻無力回天，余成龍也以九個月稚齡因心肌併發症而辭世。

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，目前全美約有一萬名兒童心肌症患者，每年約新增一千名兒童患者，約是新增愛滋兒童的兩倍。

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) 爲例，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液及肌肉 (tissue)樣本蒐集計畫爲例說明，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。第一年單是與六家醫院合作蒐集50個樣本，花費即高達15萬元，未來此項開銷年年都會發生，她不希望這項研究因爲資金不足導致半途而廢。

余文清堅決一定要找到病因，她放棄了在新力電影娛樂公司 (Sony Pictures Entertainment)亞太地區行銷主任的高薪工作，一面照顧四歲大的領養女兒余晴希及19個月大的親生女兒余晴恩，一面推廣兒童心肌症基金會。

由於人手不足及資金有限，所有的公關、行銷及募款工作，幾乎是余文清一手包辦。雖然每天工作到凌晨二、三時，但是她依然無怨無悔，繼續服務廣大的兒童心肌症患者。

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。如欲瞭解兒童心肌症或是捐款，可電 (201) 227-8852，或上網 www.childrenscardiomyopathy.org查詢。