



Barth Syndrome
Foundation

Quote of the Day:

“... I firmly believe that the mouse model of Barth syndrome and the collective effort of researchers will result in applicable therapeutic strategies to treat Barth syndrome patients and, perhaps, mitochondrial dysfunction in general.” ~ Zaza Khuchua, PhD, Research Associate Professor, Molecular and Cardiovascular Biology, Children’s Hospital Medical Center, Cincinnati, OH

Featured Story: FEAR IS NOT MY OPTION

By Michael Bowen, Jr.



Michael
12/07/1986 — 12/09/2009

I am a mortal human being. I have no special powers to live forever. From the moment we take our first breath cells begin to die. I have a rare disorder called Barth syndrome. I refuse to let the term life-threatening define me.

Life itself is life-threatening. The greatest of all fears is the fear of death. The irony is death happens to every one of us. Life will always come to an end. People often fret over how they will die or what malady will happen to them. Sometimes things happen to us that are out of our control. We can fear these things or we can be courageous about them.

Some people are afraid of snakes even though they have never encountered a snake. Some are afraid of bats or other silly things like that. When I was old enough to realize death: The worst thing that could happen to anyone is going to happen to everyone. I

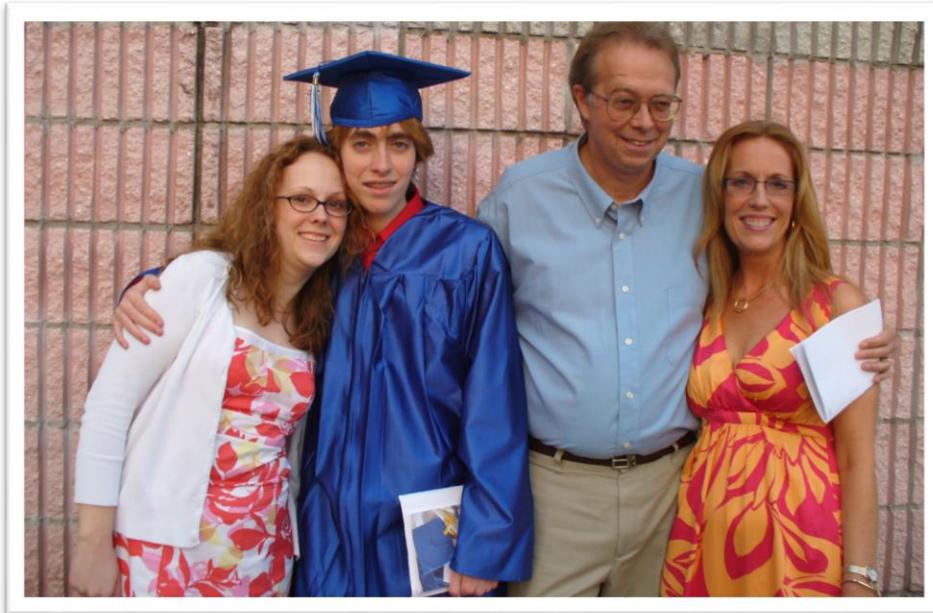
chose not to waste my life by living in fear but moreover to be fearless. Fear paralyzes where courage sets us free.

Barth Syndrome Foundation, Inc.

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I will not waste my time living in fear. I will live my life to the fullest. I will not consider what will come of me because I am not any different than any other mortal human being. I will come and I will go, that much has been defined for me. I have been fortunate enough to draw a first breath that defined the start of my life and I know my last breath will define the end my life. I choose to make the breaths between my first and last the living years. It is not my choice about when the first and last breaths occur but it is up to me to define how I live my life with every breath between. Therefore I refuse to allow fear to define how I live my life.



(L-R) Alanna, Michael, Jr., Michael, Sr., and Shelley on Michael's High School Graduation Day



Michael Bowen visited Dr. Peter Barth in Amsterdam in 1996. During that visit, it was Dr. Barth who told Michael's Mom, Shelley, to go back and find other diagnosed families because he

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