



Barth Syndrome
Foundation

Quote of the Day:

“To discount the importance of a diagnosis for those who have Barth syndrome because targeted therapies have not yet been developed is to discount the portion of the Hippocratic Medical Oath which is... I will use those dietary regimens which will benefit my patients according to my greatest ability and judgment, and I will do no harm or injustice to them...” ~ Shelley, Mother of Diagnosed Sons, Florida

Featured Story: A Personal Message from Shelley



Evan (10/22/1985 – 06/23/1990)
& Alanna

When I was in high school my class was assigned the task to write an essay about the vocation we envisioned in our future. Some female contemporaries wrote about their aspirations to be the first female president, a humanitarian, a human rights activist, a scientist, a doctor, an author, etc. My aspiration was to be a mother. Even then I felt there was no greater responsibility than to lovingly nurture the character of another human being and keep them safe from harm.

My daughter, Alanna came into my life in 1979. The blessing of motherhood multiplied when my son Evan was born in 1985, followed just 13 months later by their brother Michael in 1986. These wonderful

children exceeded my every expectation. It was inconceivable to love anyone any more than I loved these precious souls. Life could not have been any sweeter.

Life suddenly changed on January 7th, 1988 when my youngest child, Michael went into heart failure. Eleven days after Michael was admitted to the hospital with heart failure his brother Evan was admitted to the hospital with an enlarged heart. My life was unraveling as the lives I so cherished were being threatened.

I had not envisioned myself as a doctor or scientist. Yet it was necessary for me to master concepts of science and medicine to make informed decisions. I had not envisioned myself as an activist. Yet when

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(L-R) Michael, Evan & Alanna

there was no way to keep my son Michael safe from the life-threatening aspects of Barth syndrome that claimed his brother Evan's life in 1990 I became one. I had not envisioned myself as the first female president. Yet in 2000 after uniting with families, doctors and scientists from around the world, I became the president of the Barth Syndrome Foundation to serve a cause far greater than my own.

Motherhood had to be redefined at every turn. Throughout it all I always considered myself as a mother. My son and daughter became adults possessing great strength of character. Everything I had accomplished was fueled by my passion to be the

best mother I could be for them. I was a mother who had moved heaven and earth to keep my children safe from harm. When I first read about the disease that claimed Evan's life it had no name. It was considered to be uniformly fatal in infancy. I wouldn't concede to losing another child. If there was any solace to be gained after Michael's death in 2009 it was in knowing I had seen my son grow to be a great man.



(L-R) Alanna, Evan, Michael,
Michael Jr. & Shelley

After Michael's death my identity had been quaked to the core. Even the simplest question, "How many children do you have?" no longer resulted in standard response. Now I realize motherhood is not defined in terms as I once thought. I still consider myself as a mother to many who have Barth syndrome because I love them as if they were my own family.



Michael & Alanna



Shelley with Dr. Toniolo and some of the Barth boys/young men at BSF's 2010