Code Talkers

***Genome* readers honor genetic counselors who interpret complexity with compassion.**

L TO R:
MARY-FRANCES, CARI

Mary-Frances Garber

A Debt of Gratitude

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Listening, Reflecting, Healing
Supportive Genetic Counseling
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Mary-Frances Garber by Cari Cornish

From our daughter's diagnosis over a decade ago to this past December, when she visited our home to kiss our girl's sweet forehead for the last time, I have been honored to call Mary-Frances our genetic counselor and friend.

I first met Mary-Frances through a fellow college alumna shortly after my 2-year-old daughter was diagnosed with Sanfilippo syndrome. That was 11 years ago now, and Mary-Frances was with us throughout my daughter's life, and even after her passing.

My husband and I were in shock when we first met Mary-Frances. Our daughter had just been diagnosed with a terminal disease, and I was pregnant with our next child, who we were concerned would have the same disease. Our perfect life had disappeared in an instant, and we didn't know where to turn.

At our first meeting in Mary-Frances' welcoming home office, we discussed our heartache but also tackled the pressing concern of prenatal testing for Sanfilippo. It was not a straightforward path to follow. Because our daughter had just been diagnosed, the mutations had not been identified, and a prenatal enzyme level needed to be done. Mary-Frances explained the difficulty with this test and recommended a doctor who had previously done this rare test in his practice.

When you have a child with a rare genetic condition, your need for genetic guidance seldom ends at diagnosis. We depended on Mary-Frances throughout the years.

The wait began. I remember this as being one of the worst parts of the diagnosis. It is devastating to hear the news that your 2-year-old daughter has a rare genetic condition, but then to have to wait to hear if the baby you are carrying will also be stricken with the same disease is beyond comprehension.

Many tears were shed. I remember calling Mary-Frances regularly during this time and expressing my fears and concerns. What would I do if this baby that I was carrying had this same terrible disease? The wait was excruciating, and I'm sure that I wouldn't have survived without the guidance and support of Mary-Frances.

After several weeks of waiting, we found out the good news that our new baby did not have Sanfilippo syndrome. Mary-Frances shared our relief and helped us to focus on the hope that remained in our lives. Through these first few months, a lasting relationship was formed.

When you have a child with a rare genetic condition, your need for genetic guidance seldom ends at diagnosis. We depended on Mary-Frances throughout the years. I attended a small support group that she ran for several years. Through that group, I met other moms with children who had Sanfilippo, and we supported each other through many aspects of life and with the many deaths of our precious children. We cried together and tried to put the pieces of our lives back together with caring support from Mary-Frances.

It was with her gentle encouragement that I became involved with the New England Regional Genetics Group — first as a speaker at their annual conference, and then as our state's consumer representative on the board. It has been rewarding to voice my views as the mother of a child with a genetic disease to the wider community and help guide education and support for genetic counselors. My continued connection and involvement is due to Mary-Frances' influence in our family's life.

Our family has been blessed to have support from a genetic counselor throughout our daughter's lifetime and beyond. We have survived what no mother and father should have to endure, and we owe Mary-Frances a debt of gratitude for helping us navigate this journey.