

Katy Mom Kristi Wees

How this busy mother of two juggles work and family while navigating the ups and downs of raising a child with mitochondrial disease

Kristi Wees and her daughter Ashlynn, age 3, who doctors suspect has mitochondrial disease



“I don’t see myself as a super mom. I’m just a mom who has been blessed and chosen to care for a child with super unique needs and challenges.”

- Kristi Wees

A Renewed Perspective

I once had an ideal in my mind of what I wanted my life and family to look like, but this journey has taught me that what we envision our lives to be is not always the plan that is laid out for us. My *new* expectation is that my family feel safe, secure, and loved. Material things don’t seem to matter as much as they once did.

The Rough Times

My daughter experiences many episodes of irritability and pain, times when she is inconsolable and sometimes reckless. During those periods, I hold her very tightly in a bear hug, the deep pressure on her joints can help calm her, and I sing as loud as she is screaming, “You Are My Sunshine.” Sometimes it works and sometimes it doesn’t but when she calms, and is later playing with her dolls and pretending to take care of them and I hear her sing this to them, I know that she must find some comfort in this ritual, though it is difficult on us both while in the moment.

The Challenges

One of the biggest challenges has been navigating the medical world of specialists trying to get her help and lessen her pain and symptoms, all while trying to search for the root of what was causing her distress.

Staying Positive

I rely on the strength of my support system; my husband, my son, my family, and my friends who are there to remind me that it is possible to *dance in the rain*. Keeping connected to my special interests such as crafts, staying active, and helping others, helps to channel the chaos and lemons of many overwhelming days into lemonade. Somedays, I just focus on putting one foot in front of the other, taking babysteps to get us all through it.

Natural “Mom Gifts”

I think one of my God-given gifts is my ability to interpret and put complex, scientific, medical, and genetic concepts into understandable terms. Prior to becoming a mom I spent a number of years in a laboratory and in graduate school for chemistry. This knowledge and ability has not only helped out our family, but I hope that it has also helped others.

Advice for Other Parents

Always trust your gut instinct and remember that you know your child better than anyone else on this earth, so you must always be their advocate. You are the one who is more qualified and has more experience for that advocacy role than any doctor, teacher, counselor, therapist, coach, or caregiver. If something feels wrong to you, it probably is, go with your gut, do your research, and never stop asking questions and thinking for yourself. **KM**

WHAT IS MITOCHONDRIAL DISEASE?

Mitochondria are responsible for creating more than 90% of the energy needed by the body to sustain life and support growth. When they fail, less and less energy is generated, causing cell injury and cell death. Some people can live fairly normal lives with mitochondrial disease while others are severely affected, and do not survive past the teen years.

Do you know an amazing Katy person of strength? Email editor@katymagazine.com