



ANNUAL FUND 2024

In a world where hope can seem elusive, some stories reignite our belief in the power of community and compassion. Carl Kapes' journey with MPS is one such story—a testament to resilience, the strength of the human spirit, and the incredible impact the National MPS Society can have on lives. As we embark on our 2024 Annual Fund campaign and 50th anniversary, the National MPS Society is honored to share Carl's inspiring story with you and invite you to join us in climbing to new heights to improve the lives of countless families facing similar challenges.

Carl is a father of four children, including two boys, Ryan and Brayden, affected by MPS IIIA (Sanfilippo syndrome). Carl and his family faced what so many feel is unimaginable: receiving Ryan's diagnosis with no treatment or cure options, then reliving that nightmare again, within weeks, with Brayden. They first dealt with the grief and pain. Then Carl decided to take the weight of the mountain he was carrying and forge ahead.

I always knew we weren't alone in our diagnosis, but living daily with the struggles of Sanfilippo syndrome can be an extraordinarily isolating experience. The disease becomes your life, and you begin to feel like it is your complete existence—managing medications, balancing nutrition, and giving baths and physical support with every step. We watched Ryan and Brayden grow and gain skills and abilities, and we struggled alongside them as this relentless disease took those abilities away.

Taking the First Step – A Mountain of Information

How do you even begin processing that not just one, but both of your sons have a terminal disease and the array of information that follows? I was flooded with a range of emotions but eventually realized I needed to take action and do something about it.

Sanfilippo was not a disease we had ever heard of, and although it's now been part of our lives for well over a decade, there are still no treatments or cures. I found some solace in the small community I connected with and dove into reading and learning what I could from the medical information provided to us. I started to listen and work through a mountain of stories and shared experiences from parents of children with all MPS diseases.

Through the National MPS Society, I received support. I joined as a member of the Society, and the force that continued pulling me through the mountains of emotions and information was seeking answers and a cure. I wanted to raise awareness and needed to raise funds for medical research. Step by step, I would focus on bringing about a cure, or at least a treatment, even if it was not in time for my boys.

Training for a Mountain – The Challenge of the Climb

It may seem counterintuitive, but I wanted to dedicate my time and efforts to something that would challenge me. It needed to be "big." I needed to reach people I didn't know and ask for money. Mentally and emotionally, I needed to push myself to my limits to work through all I had experienced. I decided to climb the 19,341 feet to the summit of Mt. Kilimanjaro, Africa's tallest peak.

I found sponsors, friends, and equipment donations to make the climb possible, and spent hours in the gym training my body for a grueling climb and altitude adaptability. On August 3, 2012, I began the trek to my first summit.

I couldn't help but think about the parallels between mountain climbing and life as I went on this arduous journey. There's a goal in front of you, and to reach that point, there is no choice but to keep pushing. Sometimes you take your next steps in complete darkness, as you're waiting for the sun to rise. You may take a moment to recognize the beauty the sunrise brings and admire the snowy peaks above and flatlands below that are now miles away. Then, your body aches with each step, the exhaustion that set in hours before mirrors the clouds surrounding you in your mind, your lungs are yelling for oxygen, and the only thing that keeps you going is the purpose that made you want to do this to begin with. Thoughts of Ryan and Brayden filled my mind during these times. My purpose was finding treatments and cures for those to come with MPS. And wow, what a feeling when I reached the summit! There is hope, and hard work pays off.



More Mountains Ahead

Mt. Kilimanjaro was such a success I continued to train and went on to summit Mt. Ranier (Washington, 14,411 ft) and Pico de Orizaba (Mexico, 18,491 ft) to keep raising funds and awareness for Sanfilippo. While each mountain and experience were wildly different, the mission remained the same—raise awareness and funds to find a cure for MPS.

We lost Ryan to MPS in 2021. Brayden continues his fight daily. I joined the Board of Directors of the National MPS Society in 2022 because, though I know how high the mountains are for all of the MPS and ML diseases, I have seen firsthand the impact of raising funds and awareness. There are many clinical trials seeking treatment and cures. Much of the research benefits multiple disease types, even outside the umbrella of MPS diseases. Tests are becoming more accurate, our voices are being heard, and a cure is at the summit.

The National MPS Society guides the climb by funding crucial research, educating key stakeholders, and guiding patient families. What initially brought me to the Society and has fueled my desire to be more involved is the integral support provided to families and the unwavering voice to advocate.

Contributions to the Annual Fund enable the Society to continue the mission to cure, support, and advocate. We help those around us through fundraising, providing resources and family support, and funding research. I humbly ask for your support to fund our critical work to make this happen. We are incredibly grateful for the support donors like you provide each year as part of this Annual Fund.

We need your support to reach the summit to find cures for MPS and ML. Will you join me on my climb?

Thank you,

Carl Kapes
Father of Ryan and Brayden, MPS IIIA
National MPS Society Board Member