



ANNUAL FUND 2019

Dear National MPS Society Friend,

Please support the National MPS Society's 2019 Annual Fund Campaign. Learn why the Society is critical to Jason Madison. Read his story first hand and hear his request for your help.

Carrying on with life, despite...

My name is Jason Madison, and I'm one of the lucky ones. I'm among the 1% of those diagnosed with MPS, who has had an opportunity to participate in multiple clinical trials and thrives at life, despite my progressive disease. I am 42 years old and was diagnosed at the age of six with MPS II, Hunter Syndrome. My mother witnessed four generations of male relatives, including uncles and her brother, suffer from similar symptoms, with little knowledge or medical help. She was determined to find answers and eventually found a diagnosis. Generations before me, MPS II led to rapid health decline and shortened lifespans for my affected relatives.

I've had to face many challenges in life, as all people do, but with the added burden of having to live with a rare disease that negatively affects every part of my body. Many others have it worse, MUCH worse. Still, I'm able to enjoy many things that others with MPS and ML never get to experience. With an attenuated form of Hunter Syndrome, I have attended college, worked and traveled around the country, living independently and playing music. Today, I own a home and am starting a new career. Life has been an adventure I have been fortunate to experience because enzyme replacement therapy has provided me with an improved quality of life.

Paying it forward for future generations after 35 years of support from the National MPS Society.

At diagnosis, my physician recommended that we contact the National MPS Society. Throughout the years, the Society was there to support me and my family. ***They provided me with educational assistance, connected me with valuable doctors and medical researchers, and most importantly, made connections with other families affected by MPS for emotional support.*** The Society provided me with essential educational materials, instructions at Annual Family Conferences on how to advocate and manage my disease and critical support during my participation in clinical trials.

In 2017, I began to pay-it-forward. I joined the Board of Directors and collaborated with others to begin an Adult Resource Committee (ARC), a platform to connect those living with MPS and ML. The ARC program provides support for adults, teenagers transitioning to adulthood and families managing these transitions. ***I understand that many children diagnosed with MPS cannot share their voice and advocate at this level. I shoulder this burden on their behalf and recognize that my voice speaks loudly for others.***

Figuring out the MPS journey can be complex, and each journey is unique. As I struggle with new secondary issues, along with hearing loss, mobility, strength and endurance issues, I know the Society will continue to advocate for approved therapies and support cutting-edge research. They continue to fund research for those who do not have treatments and have evolved to meet the needs of families nationwide.

The Society membership has grown exponentially, from 700 households to over 2,000, in just three short years. We need your support to discover therapies for diseases without treatment, continue the fight to eradicate all MPS and ML diseases and meet the growing financial burdens of the families.

The 2019 Annual Fund supports critical family support programs, ensures the successful delivery of our research program and helps advocate to Congress for key rare disease legislation. Your donation MAKES A DIFFERENCE! Please give to the 2019 Annual Fund—I'm paying-it-forward, will you?

Jason Madison, MPS II Adult & Board Member National MPS Society