



ANNUAL FUND 2021

Dear Friends,

The National MPS Society is more than just an organization. It is a source of hope, peer support, education, and inspiration, as well as a platform to dream big about how we can be “change agents” in the course of a devastating disease.

Our first-born daughter, Annabelle, was diagnosed with MPS at six months old. Our lives pivoted that very day and took on a purpose that we could never have imagined. Physicians told our family how this disease would damage and dramatically limit her life. With fierce determination, this news led us to be a force for change and not wait to accept the inevitable. *As my mother would say, “time to take the bull by the horns!”*

Annabelle is courageous. She has undergone several surgeries to correct the severe impact of MPS damage and orthopedic challenges. She flourishes each day of her life. Annabelle was the youngest participant in a clinical trial for MPS IVA enzyme replacement therapy, the honoree of many successful fundraisers, and an advocate to lawmakers to improve access to treatments. Today, she is a 15-year-old thriving high schooler with excellent grades (cue the proud parents!)

But we are not alone on our journey. The National MPS Society and an extensive community embrace our family each day...

As parents, we knew we needed a community to launch our fight forward by taking significant and strategic action to alter the course of the disease. The Society is the organization that provides the platform, resources, support, and comradery we need to wage our fight for more research, treatments, and, eventually, a cure!

I have sat on the National MPS Society Board for over a decade to take the inside position. I needed to further immerse and educate myself for the benefit of my daughter and stand as a steward for all families and individuals living with this rare degenerative disease. Being a part of the Society mission to support, cure, and advocate has genuinely been one of the most humbling and inspirational experiences of my life.

Looking ahead, the National MPS Society must continue to lead the way in funding innovative research, educating key stakeholders, providing supportive assistance to those in need, and setting the stage for “change agents” to dream big. Our horizon includes newborn screening, second-generation therapies, and breakthrough science for those diseases that do not yet have treatment. Your support is crucial for these changes to be successful.

I humbly ask for your support by donating to the National MPS Society Annual fund, which is critical to funding mission-driven programs and our collective ability to dream bigger and create lasting change for years to come.

Thank you to those that have loyally contributed year after year. You are a valuable contributor to an outstanding four-star rated organization. For first-time donors, we graciously welcome and thank you! The National MPS Society fulfills its mission each year because of your gift and the belief that we can and will make a difference.

Sincerely,

**Stephanie Bozarth, MPS IVA Parent of Annabelle Bozarth
Board Member National MPS Society**