

Dear Family Caregiver,

On behalf of the NYMAC Advisory Committee, I would like to thank you for registering for the 2024 Annual NYMAC Conference, “Expanding Access to Genetic Services by Engaging with Communities”. We’re so happy that you can join us.

Like you, I am the family caregiver of someone with a genetic condition. My children were diagnosed in 2010 with a “non-specific connective tissue disorder” after a lengthy search for answers that took us to four hospitals in three states. It is a diagnosis that may have saved our oldest son’s life because he was diagnosed with an aortic aneurysm at age seven. The kids also have a variety of behavioral health issues such as ADHD and autism. Our journey has been crazy at times but we have learned a lot along the way. I share my own family’s triumphs and struggles in hopes of educating and empowering other family caregivers and learning from them as well.

Your experience as a family caregiver is valuable to this conference because your real world, lived experience can provide valuable feedback on how the systems we are discussing work for the people who use them. For this reason we ask that you share your “expertise” to the degree that you are most comfortable during our discussions. There will also be opportunities for you to ask questions and expand your own understanding of genetics as well as the ability to network with providers and other families to build your personal resources.

If you need anything during the conference, feel free to send me a direct message in the chat. I am also available via email outside the conference space at linperry73@gmail.com.

I look forward to meeting and learning from you.

Lin Perry