SB 188 - Public Health - Rare Disease Advisory Council
Sponsored by:
Senators Lam, Rosapepe, Salling, Muse, Carozza, Kramer, and Benson
In the Senate - Hearing 2/07 at 1:00 p.m.

Thank you for the opportunity to speak with you today.

My name is Mary Morlino. I have been advocating, volunteering and working professionally in the rare disease space for over 16 years. I am the Patient Services manager at Global Genes, a global non-profit advocacy organization for individuals and families fighting rare and genetic diseases. I am also the (FSR) Foundation for Sarcoidosis Research, Global Sarcoidosis Clinic Alliance support leader at Johns Hopkins.

Previously, I worked at the EveryLife Foundation for Rare Disease, a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.

In 2021, I co-created MarylandRARE, a support and advocacy organization for the rare disease community of Maryland. but I need help. We (the Maryland rare disease community) need help, we need more support, more research, more champions and more action to help improve the lived experience for the Maryland Rare Disease community.

I am both motivated by and frustrated with the lack of information, research and access to effective medical treatments available for the rare disease community. I am a rare disease patient, for over 16 years I have been living with chronic Sarcoidosis, a debilitating multisystem rare disease of the immune system. In 2007, I was a very healthy and active mother of two young children.

While visiting my sister's family in CA, I unexpectedly collapsed and lost consciousness and got my first ride in an ambulance. 3 weeks and 3 different hospitals later, after extensive testing and evaluations I was told I needed a pacemaker because my AV node was severed, the electrical system of my heart was broken. No explanation, no diagnosis, but a solution. I recovered and restarted my life with Vivian. I named my pacemaker Vivian, her name means ‘full of life’.

Fast forward about 6 years later, My heart function was starting to rapidly decline. My cardiologist began preparing me for a heart transplant which included visiting all the transplant teams within 4 hours from where I was living. I’m wearing an external

defibrillator vest 24/7. Things are pretty scary. After another test, a lung biopsy, I finally got a diagnosis, Cardiac Sarcoidosis. Within 1 week I was upgraded to an ICD - pacemaker/defibrillator. Vivian II.

6 months later I was about to drive my 15 year old daughter to her friend's house and I had a cardiac arrest in my kitchen. I was shocked, literally. I came back, I came back to my daughter screaming ‘Mom!”. Had it not been for the diagnosis, I would not have gotten the upgraded ICD and I would have died for good in my kitchen that day.

Had I been diagnosed and received effective treatment in 2007, or even 2008, this disease would not have had 7 years to spread throughout my body and do irreversible damage to my heart and other organs. I am rare, but I am not unique in that there are hundreds of thousands of Maryland constituents living with rare and undiagnosed diseases, facing medical financial bankruptcy, devastating families, and increasing the economic burden of our communities.

This is why we need a rare disease advocacy council in Maryland. We need a task force, a team, a council who works together to improve the time to diagnosis, who works to increase research opportunities, who works collaboratively, efficiently and effectively to improve access to treatments as well improving the lived experience for the rare disease community of Maryland.

I respectfully ask all of you to support Senate Bill 188, and to champion the establishment of the Rare Disease Advocacy Council for the betterment of the Maryland Community.

Thank you for your time, and your attention.