To Whom It May Concern:

My name is Madison Bowe, and I am a passionate advocate living with Stiff Person Syndrome and Gastroparesis. Stiff Person Syndrome (SPS) is a rare autoimmune neuromovement syndrome that makes my muscles very stiff, rigid and spastic. It can be triggered by loud noises, touch, my own emotions or at random intervals. The treatment protocol, disease presentation, level of disability and triggers can vary from person to person. Being only 29 yrs old, I hold the patients' quality of life very dear to my heart and, owing to my involvement in the Emergency Services community. I have seen firsthand how the healthcare system needs to evolve for rare disease patients in emergency settings. I am very proud to be a leader in the Rare Disease community with a 1 in 1 million worldwide rare disease, SPS, and multiple rare comorbidities. Just like many other rare disease patients I have faced problems with insurance, transportation, access to care and resources. As a minority, I am passionate about bringing change to this marginalized group because just like Martin Luther King Jr. I have a dream where the color of my skin or someone else's doesn't define what kind of care they receive. I want to become involved in the NV RDAC because I believe I can be a light for the rare disease community as a whole and bring awareness to issues that have yet to be discussed in a proactive manner for Nevada.

I have had the pleasure and responsibility of advocating during Rare Across America and being the first rare disease patient to bring to District 1 information regarding the Safe Step Act along with many other policies. In 11 years, an assistant in the office had never had the material cross their desk and this is an opportunity I take with great passion because it gives light to issues that need to be addressed. I am also an active participant in YARR the Young Adult Representatives of the Rare Disease Legislative Advocates which is based out of the EveryLife Foundation for Rare Diseases. The EveryLife Foundation is an organization working to bring legislative advocates up through their own advocacy journey along with many policies and legislations that are looking to be passed through the House of Representatives and the Senate. The RDLA is a leading initiative effort to bring together advocates across the nation to understand what advocacy needs to be made and coordinate programs to facilitate active change in policy through programs like Rare Across America. I have advocated with Rare Across America for 2 years now. Currently I am a mentee for the RDLA mentorship program, and I have attended many webinars about rare diseases and the impact our own legislative advocacy efforts will have on the future.

Being a student in Emergency Services before my diagnosis of Stiff Person Syndrome I have had the opportunity to relate my diagnosis journey to many problems I have seen with access to care in general as well as in emergency situations. I am actively trying to return to school for Emergency Services Administration. I took a class recently for CEU credits that was focused on specialized patient population access within the Fire Department and my dream is to one day make a program like that exist in Nevada. This program is a book listing of specialized patient groups carried around in the rigs to better assist with care for those patients in collaboration with the medical directors. This type of program could help prehospital care providers to understand how to effectively treat rare disease patients more efficiently and save patients and providers

valuable time and quality of life in emergency situations. Problems don't just occur with access to care but also in transferring patients, continuity and quality of care in both the prehospital and hospital settings, along with dispatch protocols.

I had the incredible opportunity to advocate in the Global Genes Rare Compassion Program. The Rare Compassion Program is an initiative to connect a 2nd year medical student with a rare disease patient and we as rare disease patients have the privilege of educating them on our rare disease and how compassionate care is a driving force through engaged conversation and questions from the students. With the help of Global Genes, I was able to give two medical students a learning experience they will carry with them throughout their medical careers and that's something that makes things like policies within emergency situations still a possibility in my heart. In my spare time I chose to focus my efforts on case management for people I know with disabilities and other rare diseases. From talking to individuals about legal actions they can take regarding neglect or abuse, to helping others get access to food or housing, these are some of the ways I have been facilitating case management to resources in the community. As pediatric care is a priority for the Nevada RDAC, and I align with this initiative through my experience teaching preschool through 10th grade in my parish as well as in a Daycare Center and have a driven passion to help children, adolescents and young adults improve their quality of life.

Equity in the rare disease community is a problem we cannot ignore. I am mixed race and consider myself an ally to the LGBTQIA+ community. Every day in Nevada when I ride my wheelchair around the community, I hear so many different languages and see so many different backgrounds and cultures. I recognize the need for someone who is passionate about helping people from different backgrounds, someone to be their voice. That voice needs to be reflected in the rare disease community, as well. Many rare diseases are invisible, and policies need to reflect those individuals, too. In my personal experience, I had a 5-time journey of application with the RTC Paratransit system. It was only after my physical therapist pointed out to the RTC Paratransit certification system the invisibility of my disability and the deficits in accessing the bus or other means of transportation without having an attack of SPS. I was finally allowed access to RTC Paratransit. When it comes to me being mixed race, I am fearful to point out my ethnic background to medical providers in apprehension of not receiving quality care. I am still very proud to be both Hispanic and African American. I do not want to live in fear for the quality of life I will have for the color of my skin or a disease that is invisible. In Nevada the increasing number of those who speak different languages and the lack of resources to accommodate this population has made access to care even more challenging. For those who have a rare disease and speak a language other than English they may not know that certain programs exist for their condition, potentially delaying diagnosis and treatment, or have greater difficulty connecting with others due to ill-equipped resources. If bilingual perspectives for those with rare diseases were prioritized, the overall burdens would be reduced, patients would know options exist to support them, and diverse populations would be an equal stakeholder in our state. My goal is to create a booklet or event focused on those who have a rare disease and speak Spanish. In this capacity, patients could utilize this resource to help them understand programs available to them, create a community of individuals dedicated to helping partake in

making rare disease patients in the minority community a priority and finding ways to allow these individuals to connect with resources and patients like them.

Once again, I see the progress in the change of the healthcare system and community for rare diseases and I want to be on the RDAC as a means to facilitate change. The healthcare system has the means to facilitate change in emergency situation policies, minority groups, and pediatric care as well as many other areas of the rare disease community that are affected. Although I have Stiff Person Syndrome along with other problems, I want to be a light for the rare disease Community and serving on the Nevada RDAC is the perfect opportunity to combine my passion for change with my desire to help others. Thank you for your time and consideration.

Sincerely,

Madison Bowe
[redacted]
[redacted]@yahoo.com