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Public Hearing May 28<sup>th</sup> 2019 Health Committee's Senate and Assembly

Distinguished Committee Members, Senator Riviera, Assembly member Gottfried,

My name is Mary Somoza and I am the mother of four children which include my 35-year-old twin daughters Alba and Anastasia, both of whom have cerebral palsy, are quadriplegic and motorized wheelchair users. Alba is non-verbal and uses sophisticated technology - (Dynavox) to communicate and is fed via a feeding tube.

Alba paints three days a week at a studio in Chelsea for artists with developmental disabilities, teaches art at IHope school in Harlem, a school for children with multiple disabilities where most of the children are non-verbal and use some sort of assistive technology to communicate. She also lectures to graduate students at New York University, Bank Street College, Fordham University, Cuny School of Graduate Education, Teachers' College at Columbia University and so on.

Anastasia is a graduate of Georgetown University and studied at the London School of Economics and Political Science for a Masters in Human Rights. She worked on Senator Hillary Clinton's New York campaign, and interned with her in the Senate, and later on her presidential campaign. She presently works for the Speaker of the New York City Council Cory Johnson and is the disability coordinator for the whole council. The first one in their history.

Our lives, since my twins birth has been dominated by their health care needs. The first two years of their lives were spent in and out of hospitals, and from then on multiple surgeries to hips, ankles, and various medical procedures related to their cerebral palsy. All of this required eligibility – meaning, my husband and I could not pursue the American dream, but had to keep our income low in order for our girls to qualify for Medicaid. Unless you are independently rich, it would have been impossible to pay for all of their medical care, and eventually their homecare. I could not work for 22 years. That meant that when I turned 65, I did not qualify for Social Security. I also had a huge gap in my resume making it extraordinarily difficult to get a job. Eventually my daughters were eligible for the Home and Community based Waiver and their services were not tied to our earnings.

I learnt to live on 4 to six hours of sleep each night, seven days a week. That is still the case.

I am an Irish immigrant, and grew up between Ireland and England. Medical coverage was universal and free. I believed this was true in most western democracies, until my daughters were born in New York 35 years ago and we entered into the netherworld of the medical bureaucracy. I thought that because I was an immigrant perhaps I just did not know the system, but it became clear to me that nobody knows the system when you have a child or children with significant disabilities. And, I had an advantage. I spoke English as my primary language, unlike the many families I encountered in the Medicaid clinics and hospitals.

And so, I took to writing to everyone about the problems with the medical system, and how to improve them. I have done that to this day, and that is why I am here today. After meeting a couple of months ago with Assembly member Gottfried along with a group of other parents of adult children with disabilities about an emergency we were facing with our Consumer Directed Personal Assistant homecare program, he spoke to us about the New York Health Act. We were all incredibly impressed and sent the information out to our listserv. Then I attended, along with a few of our parents, an informational session at the 92<sup>nd</sup> Street Y in New York, with a panel of experts that included Assembly member Gottfried and Senator Gustavo Riviera. I was overwhelmed with the thought that this could become a reality! I left the meeting filled with hope and a commitment to do all that I can to help this legislation become law. It would change so many lives, it would be incredibly important for people with disabilities who face all types of obstacles to try to lead a dignified life, and give us families the peace of mind that when we are no longer here as a safety net for our children – they will be okay.

My worst nightmare is the thought that my daughters will have to live their entire lives fighting every day for that basic human right – healthcare. It is the same for all families, but especially families of children/adults with disabilities whose care is lifelong, who do not get cured because their disability is permanent, who need help getting out of bed every day, taking a shower, getting dressed, and heading off to school or work.

I thank you for all you have done to get the legislation this far and look forward to working with you to ensure its passage.

Respectfully submitted,

Mary Somoza