

Hello,

My name is Mary Bridget House and I am a kitchen manager from Syracuse New York.

I am here today to testify in support of the New York Health Act. I am a 33 year old woman who is seemingly in good health, but I have what is called an invisible disorder. I was misdiagnosed with Von Willibrans at the age of 11 and was formally diagnosed with Ehlers Danlos Syndrome 7 years ago.

Ehlers Danlos is a rare collagen disorder and there are 13 types of Ehlers Danlos, I have type IV which is a vascular form. Type IV has many symptoms which include but are not limited to; post surgical, post traumatic hemorrhaging, neurological issues, numbness in my extremities, digestive issues, uterine issues, chronic pain and joint dislocation. The older I get, the worse the symptoms can become. Type IV is also the only fatal form of Ehlers Danlos, the cause of death is usually caused by main aortic valve failure or organ failure, and the life expectancy for type IV is around 50 years of age.

There is no cure for Ehlers Danlos. The best way to treat Ehlers Danlos is through preventative care which I thankfully have a good control on. But also it is necessary to have yearly check ups with specialists. With preventative care and yearly checkups I have the potential to live past 50 and have as normal and easy a life as possible.

When I had insurance I was already seeing a hematologist, my primary care, and was on my way to see a neurologist, reumatologist, dermatologist, and was getting ready to look into seeing a cardiologist. I have now been without insurance for just over 2 years, and have not seen a specialist in that time since. Health insurance is too expensive for me to afford through my employer, and the state plans are just as expensive. A market place plan is around \$400 a month.

Being without insurance has me living in fear. I am scared because I don't know what tomorrow is going to bring. At this moment I am living a healthy life. I am able to work, and do normal everyday activities. Although some days can be hard I am not held back in any major way. I see other people who have Ehlers Danlos who are younger than me who have lost all or most of

their mobility, had to go through surgeries for numerous reasons, or suffer from such chronic pain that they can barely get through the day. If I get a cut I get nervous, and when one of my legs go numb I worry if I should go to the doctor or just ignore it and hope with some exercise and stretching it will go away.. I always end up choosing the later because I don't have the money to have it looked at properly. I also have been dealing with chronic digestive issues which thankfully for the most part I have under control. But what will happen when what I am doing is not enough.

I am a 33 year old healthy woman aside from my invisible disorder, and every day in the United States I live in fear that I am going to die from something that could have been prevented if I had access to affordable health care or that I will go bankrupt due to emergency hospitalization without insurance. Either of these outcomes would mean my life would be over.

There are many people like me, who despite working full time, have very specific and ongoing healthcare needs. Please fight to pass the NY Health Act next session so that all New Yorkers can have peace of mind and the healthcare we need to live happy, dignified, and productive lives.