

Good morning. Thank you for being here today. My name is Kristin Reisch and I am the mom of a child who had half a million dollars in medical bills and four lengthy hospital stays before her first birthday.

My daughter, Anna, is alive because of amazing medical care, but also because we have the good fortune to have employer funded health care. Before she was twelve months old she had amassed half a million dollars in medical care. That is a tremendous amount of money. But that was the cost to keep my daughter alive from the time she was born until her first birthday. By the time Anna was four years old she had had seven surgeries, including heart surgery. She is a miracle and it is my greatest honor to stand before you and say she and her many medical doctors are my heroes.

But my child is no more valuable than any other child in New York State. We must build a society where each citizen and resident of our state has the same level of care as my privileged daughter has, regardless of their socioeconomic or employment status.

I stand before you today to say we must build a society where all people have healthcare. We must build a state where parents and patients can focus on being healthy instead of focusing on cost.

The New York Health Act is critical to the well being of each citizen and resident of New York State. We must demand that each person in New York has the same opportunity to receive medical care.

When my daughter was young so many of our days were filled with fear, worry, almost daily medical appointments, many hospitalizations, frequent new diagnoses. They were some of the darkest days of my life.

I don't know how you focus on your sick child when you don't know how you will pay for her care. I do know when you are worried about the bills it is a lot harder to focus on your sick child. When Anna, was lying in her hospital bed at four months old after heart surgery with so many tubes coming in and out of her tiny body, I had a moment of pure panic. I had forgotten to call the insurance company to ask their permission for her to continue to live. We had come to the hospital on Saturday morning and it was now Tuesday afternoon.

I had not called them within 24 hours to tell them about the admission and surgery, which meant according to our contract they didn't have to cover it. I can still remember the horror and fear I felt for those few moments as I ran *from* my sick child's bedside to leave the Pediatric Cardiothoracic Intensive Care Unit to call our insurance company. I had no idea how we would ever pay for her medical care. Thankfully, when we were admitted, the hospital had informed the insurance company and the stay and surgery were covered after our co-pay.

It is wrong that some moms, right here in our state, in this city, only know that horror and fear because they do not have health insurance for their children or themselves. Yes, even with CHIP, three percent of New York's children have no health insurance. It is wrong that some moms have to work three jobs, be homeless, and manage a multitude of other injustices to pay for healthcare for themselves or their family members. That is not right. You have the power to fix this.

When I first started thinking about what I wanted to share with you today, I planned to tell you Anna's story. However, as I tried to figure out how to contrast my opposing feelings of fear from years of medical drama and almost constant crises with my gratitude for health insurance, I became angry.

I am angry that we live in a nation where it is up to parents of sick children to share our personal and often tragic stories in order to try to convince our elected representatives that all human beings deserve healthcare.

I am so angry that I have to parade my daughter's heroism in the face of medical adversity for the world to see so that other children can obtain the same right to receive treatment for their medical conditions.

I am so angry that it takes medical tragedy for some human beings to realize that leaving people without health care is the wrong thing to do.

We live in New York State, we are sitting in the town of Frederick Douglass and Susan B. Anthony. We are proud leaders in the fight for equality and justice in New York. We have an opportunity to lead our nation, just like Saskatchewan lead Canada, we can pass the New York Health Act and ensure that each person in our state has the same healthcare that my family has because of our good fortune. **You** have the power to do this.

You should not need me to tell you that healthcare is a human right. But if you do, please listen carefully. My child, my beautiful child, is no more worthy than any other child or human being in this state. Each human being must have guaranteed healthcare. The cost of not guaranteeing healthcare is too great whether it is my child, your child, your grandchildren, our parents, ourselves, or our neighbors.

Healthcare is not optional.

As a mom, as a healthcare worker, as a voter, as a human being, I demand that you and the rest of the New York State Legislature pass the New York Health Act this coming year.

The time is now.

## Healthcare Costs for the Insured with Significant Health Problems

I'm here to talk to you today because I would like you to understand my family's health care needs as you make decisions on healthcare legislation. Our story is not short and simple, but neither is the healthcare system. I know that you make policy based on an entire system with many conflicting needs and priorities, and that is necessary, but I think that our situation illustrates key problems with the health care costs in our country.

I didn't fully understand the costs of healthcare until I had a daughter with a few rare, complex and dangerous chronic medical conditions. Not that it's relevant to my message but to provide some background my daughter has dysautonomia, gastroparesis, postural orthostatic tachycardia syndrome (POTS) and complex regional pain syndrome (CRPS). Her medical team also thinks it's likely that she has a form of mitochondrial disease although in a milder form than many who are afflicted with those diseases. Also, the early childhood trauma from her illnesses and surgeries has left her with PTSD. Based on these conditions, Meg is seeing or has seen specialists in four states and had surgery in three. She currently sees two specialists at the Cleveland Clinic, two in Rochester and one at University Hospitals Cleveland. At times she has needed VPAP treatment, alarming overnight oxygen monitoring, and a wheelchair. She needs many medications and at times extensive occupational and physical therapy. To say that her care has been expensive is an almost ludicrous understatement.

To say that I am only worried about insurance for pre-existing conditions would also be ridiculous. The costs of care for someone with a chronic condition are unmanageable even for someone with insurance. Let me illustrate the problem by using my family as an example.

First, you should know that we have the best plan that my husband's job offers, it's highly subsidized by his employer and is a high deductible plan. After a significant employer subsidy, the plan costs our family \$5400 annually. We reach our full family deductible or come very close every year, so our covered medical expenses are \$6000 per year or the amount of the deductible on the plan.

There are also uncovered medical expenses. My daughter takes something known as the "mito cocktail" which is a regimen of high doses of a variety of supplements every month costing about \$660 per year. None of that is covered. We also need to travel to the Cleveland Clinic or the Pittsburgh Children's Hospital, typically spending the night because of the time it takes to see multiple specialists and get the required labs completed. At two trips per year on average the cost comes to about \$400 per year.

So even with the best medical insurance that we have access to our family medical expenses are \$12,460 per year or \$1038 per month. If we had to pay the full cost of health insurance, those numbers would be \$23,460 per year or \$1955 per month. Please let those numbers sink in. Think about what those numbers mean to families. According to the Census Bureau, the median income for 2018 was \$63,179. That means that the cost of health insurance would be over 20% of their income with the employer subsidy and almost 37% without the help of an employer subsidy. How is this OK?

My family is lucky. So far we've been able to afford this. It's a big hit, but at least we do not have to choose to pay the rent or buy our child's medicine. For most parents though that amount of money is totally unsustainable. Their children would go without much-needed