

Rev. Lauren Ouellette - Bruchez

Good morning ladies and gentlemen of the Senate of New York State. Thank you for taking the time this morning to discuss the state of healthcare in New York.

I am a priest for The Nemeton of the Ways. We are an Earth-based interfaith church based out of Troy, NY. The community I serve suffers from severe poverty and much of the poverty I see is a result of medical debt. Many of my community members are fighting a losing battle between addressing their serious medical needs and paying for rent and food. Some of these people are on Medicare and Medicaid and still struggle to make ends meet. The people who live next door to me for example have lived in the city of Troy for almost their entire lives. They've worked here and served this community in providing vital services such as childcare, care for the disabled, trucking and serving food. I have on a number of occasions paid for their medications because they didn't have enough money to pick up a script with a \$5 co-pay and pay their phone bill. They have been subject to the decline of care extended to the poor and working class. As they attempt to recover from the myriad health concerns they battle, they may also be losing their home as they can't afford to pay the taxes on that home. I have held their hands as they suffer from anxiety attacks reading the stacks of bills that have piled up over time. Many of them are dying without dignity as a result of our morally-bankrupt private insurance systems.

My family is no exception to these hardships. My partner who is epileptic constantly fights with whatever insurance he has, save for the Medicaid he had during a time of unemployment. He suffers from focal onset aware seizures. As a child he underwent a week-long series of epilepsy tests at Strong Memorial Hospital in Rochester and it was discovered that he had up to 30 of these seizures a day without medication. Through his last neurologist, he was prescribed a combination of Vimpat and Keppra. He's a big guy so he takes quite a bit of these medications but they regulated him for many years without incident.

Recently he took a new job with a small business which repairs garage doors. The owner does everything he can to provide his employees with the best benefits he's able but that also means that he cannot afford to be covered by the same insurance he offers his employees and is on a bare-bones plan himself. He's a husband and father of two children with another one on the way. If anything were to happen to him, his family would be in dire trouble. His wife told me just the other day that the medical bills keep flooding from her current pregnancy which has landed her in the hospital multiples times and they've begun to stack up leaving them vulnerable as well despite their best efforts.

The insurance my partner is provided has fought us tooth and nail on him receiving the medications he is prescribed, as prescribed. Many years ago his previous neurologist tried him on the generic version of Keppra and he continued to have seizures. Since then he was given Keppra as Dispensed As Written (DAW) and was well-regulated.

When he switched to this new insurance plan provided by MVP suddenly we were fighting for him to receive the DAW medication without paying an exorbitant price. With insurance coverage the DAW medication goes for \$3,172.79 a month for the 12, 500 mg tablets he must take twice a day, at a quantity of 360 pills a month. That is more than he brings home in pay a month.

We were unable to purchase his medications.

On February 19th of this year at approximately 1 in the morning, my partner suffered his very first ever tonic-clonic seizure. I was terrified. He fell off the bed, and nearly hit his head on a side table. He was

foaming at the mouth and non-responsive for about 10 minutes. As I held his head to be certain he didn't smash it into furniture, I wasn't sure that he was not about to die. Luckily our local emergency responders were amazing and got him to the hospital in a timely manner.

Later that night he was released from the hospital. The next day he should have been recovering from this traumatic health incident but instead spent the entire day with our family fighting with MVP on the phone as we were passed from one customer service representative to another. We asked that his case be reviewed for exception. He was denied that exception just after the end of the business day that day by some unknown higher-up. We were told that a prior authorization from his current neurologist was not sufficient and that he would need additional documentation proving he needed this medication. After discussing this with his doctor she explained that she sent every bit of documentation that was requested and this was still deemed insufficient.

As of right now he is still not completely regulated. He is only experiencing focal onset aware seizures as of right now, but until he is regulated for 6 months, he can't drive. This means he cannot operate at his full capacity at his job where onsite work is a requirement. This past week he was informed that he was being let go from this job leaving him once again with no insurance sometime in the near future. His employer has done everything within his power to provide reasonable accommodation but his finances are suffering and cannot maintain another employee, let alone a relatively new employee who now cannot go out on repair calls.

I myself, on a much smaller scale, am experiencing similar difficulties with my insurance Cigna and Express Scripts. I have depression and ADHD for which I've been taking the generic for Zoloft, Sertraline and Concerta. While taking these medications I have made incredible strides in functionality. Two years ago, before I began taking these medications, I was suffering from suicidal ideation and severe executive dysfunction. It was like night and day when my chemical imbalances were finally regulated. I had the focus to continue my work as a priest and serve my community.

For medication management I began working with the Psychiatric Department at Albany Medical Center upon referral from one of my other doctors. The experience I had there was fantastic. My psychiatrist was very responsive and with her assistance, I was able to address many of my needs.

Recently I found out that my insurance would not cover care provided by this doctor. I have stacked up over \$1000 in debt in the meantime and am scrambling to find another provider I trust who can also see me in a timely manner as one of my meds is a controlled substance and requires constant monitoring. For now my ADHD is unmanaged. As is the case with most millennials I know, I am looking for additional sources of income considering I receive no pay for my work as a priest. My community simply does not have the means but that does not negate the importance of my work. But as my chemical imbalances continue to wreak havoc, I worry that I will not have the functional capability to maintain work.

Unfortunately I have been experiencing these challenges for quite some time.

In 2009, a little more than a month after my wedding I rushed to the hospital with abdominal pain so severe I couldn't keep food down or walk. It was discovered that I had ruptured an ovarian cyst that we had no clue I'd had. I required surgery and lost both my right ovary and fallopian tube. During the course of that surgery my surgeon accidentally nicked my colon extending what should have been an overnight observational stay in the hospital to a week.

As you can imagine this came with a great deal of debt.

My husband was given a high-deductible plan through his job at the time and didn't worry about it initially because until that point we had both been in fairly decent health. This emergency situation destroyed our finances.

Despite our best efforts we have not been able to recover well enough to improve our credit to own a modest home. We live within our means. Our household shares a car. Not a new or fancy car either – a 2008 Chevy Malibu. We don't go on vacations. We don't buy new clothes or furniture. Almost everything in our home has come from Goodwill and garage sales. We grow our own food where possible. We aren't people who live lavish, stylish lives.

It should not be considered radical to expect that as a civilized society we would take care of the people who hold our communities together. These people aren't just the politicians who are guaranteed a lifetime of healthcare the moment they assume office. These people aren't simply the wealthy entrepreneurs and CEOs. These are the wait staff and janitors. They are the bus drivers and daycare providers. They are our teachers, customer service representatives, repair specialists and dog walkers. They're our loved ones and neighbors. They're people – worthy of dignity, respect and support for all they do, regardless of how much money they bring home. Living should not be a pay-to-play scenario and we have the chance to change one of the grand inequities of our time, starting right here in New York, right now.

Be the pioneers of a new standard of life for the people of this state. You have been entrusted with the power to improve the lives of millions. Be brave. Challenge this regressive existing healthcare payment model and show the people who've put their faith in you that you deserve their trust.