

ELMIRA



Upstate New York Hearing 10/10/19

New York Health Act (A5248/S3525)

Becca Forsyth

Thank you for the opportunity to testify before you today. My name is Becca Forsyth and I am an organizer with the Poor People's Campaign: A National Call for Moral Revival. We are building a moral fusion movement among the poor around this country. We make up more than half of New York State with a total of 9.9 million who are within a \$400 emergency of finding ourselves in poverty.

The emergency that landed my own family in poverty was caused by the bite of a mosquito. Due to the ecological devastation we have reaped, my husband was stung by a mosquito in Upstate NY that transmitted viral encephalitis. While 30% of those who contract this illness don't survive, he was one of the 'lucky' ones. He spent three weeks in intensive care, hooked up to more medical equipment than I have ever seen in one place...and that includes medical dramas on TV. His body was sold to specialists of every kind, including a neurologist, pulmonologist, cardiologist, infectious disease specialist, a nephrologist, a few different hospitalists, the list went on and on. He underwent a spinal tap. He was placed on two different anesthetics to keep him

in a medically induced coma while we waited for the brain activity to slow from the seizures. I have never been so overwhelmed and scared.

When he was discharged, the care was completely fragmented and uncoordinated. I literally went back to college to try to understand what happened and who we needed to call for what side effects. He left the hospital with this list of prescriptions, intended to treat the seizure disorder he was left with, the constant migraines he has suffered all day every day, the vertigo that made the world spin every time he moved his head, the PTSD he still struggles with, the emotional dysregulation, and a CPAP machine for sleep apnea. He also experienced problems with cognitive functioning. He has had a few grand mal seizures but he has also developed myoclonic and absence seizures, not as severe as a grand mal but incredibly disruptive. He was instantly disabled, unable to perform any of the jobs he used to have before he got sick. He became a distinctly different person and I became a full-time caregiver and student.

While I am grateful that New York Medicaid did respond to a majority of our needs, there were gaps. We were among those who have had to skip or delay multiple types of care due to cost. There are prescriptions that would help to alleviate some of his symptoms but they weren't covered and with no income, we had to pass. There were many cutting edge diagnostic tools like PET scans and functional MRIs, which could have provided clues about the degree and type of damage that happened, but these tests were not covered so we went without. We had to travel to Rochester, two and a half hours away just for a neuropsychological assessment. The co-pays of just his general meds left us at the mercy of the generosity of our family and friends. Over the years, we've borrowed thousands of dollars with no idea when we could pay it back. We struggled to gain access to critical mental health treatment because we only had one provider in

Elmira who accepted Medicaid and the waiting list was months long. This has added dramatically to the stress and strain felt by family and friends. It also likely contributed to the heart attack he suffered two years later, at 42 years old. The incredible number of specialties we needed to see ensured that our needs exceeded the list of approved providers and services. The fragmentation of the system created barriers that stopped our providers from being able to work together on his complex case.

I come to you and ask that you legislate based on right versus wrong, not left versus right. My husband's story has been hard to live...but we aren't alone! Too many New Yorkers are missing out on living a full and healthy life! We need health coverage to be universal — everyone needs to be included with full benefits and choice of providers. We need equity in care — making sure that all of us have access to high quality care regardless of our wealth or where we live. We need participation — we need to be able to have a voice in our own healthcare. We see the corporate interests being represented in Albany when it comes to our critical need for care. We can't afford the status quo! We are begging you to put people over profits and fighting to pass the New York Health Act during the 2020 legislative session.

