

Testimony of Kate Barnhart
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New Alternatives for LGBT Homeless Youth
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My mother, Patricia Barnhart, came to NYC from Kansas in 1961 to attend Barnard. Like many creative people, she was drawn to New York and once she got here, she never left. She wrote for one of the daily newspapers until it folded, and after that she was freelance. Being freelance, she had no health insurance. I don't know when she discovered the lump in her breast, but by 1993, my senior year of high school, when I walked in on her changing, her breast was visibly deformed. Afraid of bankrupting the family with medical bills, she continued to ignore her cancer for another two years, until I came home for spring break and found her bluish and gasping for breath. I dragged her to the hospital, but of course it was too late. She died in 1999, age 56.

Fast forward to 2015. I work for a small non-profit serving homeless LGBTQ youth. Since I am the only full time employee, we don't have enough people for a group, so I have an ACA plan. In Nov. 2015 I developed back pain so severe that moving in my sleep made me wake up screaming. To get out of bed, I had to roll onto the floor, get to my knees and stand up from there. The day after thanksgiving my right foot went numb. The next day my left foot went numb. I couldn't stand on my toes. Then the right foot turned outward and I could not bring it in. I started staggering like I was drunk. When I tried to walk my legs would cross. And then I started to fall. I needed a neurologist, but there weren't many who took my plan. I wound up with this strange neurology practice where you never saw the same doctor twice. I needed MRIs of my brain and my whole spine, but my insurance would only pay for one at a time, so that meant four trips, which is a major challenge when you can't walk. Months were going by and I was progressing from a cane to a quad cane to a walker. My agency had to send a car to bring me to and from work because the subway was out of the question. The sketchy neurologists could not diagnose the problem. A close friend of mine, himself a doctor, wanted me to see a friend of his, but he was not in network. I had to wait until the open enrollment period, switch to a plan he took, and then wait until Jan 1 for it to take effect. He took 15 tubes of blood the first time I saw him, but he was able to diagnose the problem – my immune system was attacking my spine. The treatment he proposed was Rituxan, which at that time was mainly used to treat b-cell lymphoma – using it in autoimmune conditions was new. My insurance company said no. My doctors and I had to fight them to get it approved. Once my immune system was under control, the next hurdle was learning to walk again. I had lost a lot of muscle and my feet and lower legs were numb. Physical therapy would have been the obvious solution, but my plan, like most ACA plans only covers it for people who have had surgery or been hospitalized, so that left me out. Luckily a volunteer at my agency is a pilates instructor and she offered to work with me and that is how I got to walk again. I could go on for days about all the strange and ridiculous things I have encountered from our insurance system, but here's the latest – last year I signed up for the same plan I'd had the year before, after checking that none of my doctors were planning to stop taking it. Since neither they nor I had changed anything, I thought things would be fine. But without any notice, my insurance

company changed which of their provider networks ACA patients had access to, making my specialists out of network. When you have a complicated medical situation, changing doctors is a mess.

Our current system is not working for anyone – not for the uninsured like my mother, not for people who are struggling with their insurance like me. We need to take the profit motive out of paying for healthcare, and get rid of the tiered system where the quality of health care depends on whether and what kind of insurance you have. We need to end a system where people have to choose between bankruptcy and death. We need a single payer system. We can't rely on the federal government. New York needs to protect all new Yorkers, and the way to do that is the NY Health act.