Testimony of Nikki Lyons

Before the U.S. House of Representatives Committee on Oversight and Reform

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My name is Nikki Lyons, thank you members of the House Oversight Committee for taking the time to hear me. I'm here to speak today because for the second time in my 20's, my entire life is on pause while I'm in organ failure and waiting for an organ transplant. This loss of control regarding so many aspects of my life has had me thinking about what I would say to you, those with the power to make changes in the place decisions are made. Like so so many Americans, Medicare for All would have changed the course of my life and provide comfort for my future.

The first time I found out I was sick, I was at a hospital in the middle of college midterms week, waking up from an emergency appendectomy. The diagnosis was not adequately explained and there was none of the follow up care we should expect. As a struggling college student, I didn't have the luxury to see a doctor anywhere besides the emergency room. Because of this, I didn't know how sick I truly was, and because of my illness, I failed out of school, which delayed my career, and cost thousands of dollars. Years later, I'd learn i should have already been looking for a transplant because I was in the end stages of kidney failure. Had I had access to regular care, the extent of my organ failure could have been stalled or even prevented.

While waiting for that first transplant, instead of focusing on conserving the little energy I had, I worked 50+ hours a week on my feet at a bar and a gym to afford doctors' appointments and medication. Potential transplant patients are evaluated for stability in many aspects of your life - housing, economics, compliance with doctors. Not being able to afford medication or appointments could have disqualified me from the organ I needed to live. Medicare for All would have meant not deciding if I needed to skip meals to afford to qualify for a kidney.

I received a transplant in 2016 but am again in organ failure. This current round of organ failure, I can say with certainty, would have been prevented by Medicare for All. I wasn't able to get regular transplant checkups because the resources I had allotted for healthcare went towards attempts at mitigating long covid symptoms. Because of that lack of care, I did not know my body was rejecting my transplant as a complication of long COVID. I haven't been able to properly work or attend class adequately since winter of 2020. The covid symptoms transitioned into kidney failure symptoms seamlessly to the point I didn't realize what was happening. A simple blood test would've told me. Rejection caught earlier is treatable. I wasn't that lucky. It was amazing I was alive, for the second time in my life. Since June, I've had 6 long-term hospital stays, with the longest being 7 weeks, traveled 12 hours a week to dialysis for 3.5 hours, had blood transfusions and chemicals that made me feel even worse infused into my blood. I've had days where I'm only able to be awake for 4 hours a day. There's no way for me to work, finish school, or thrive at all in this condition.

On top of that, I had no insurance until Medicare kicked in. This took 6 months from the time I applied. I was told their system did not important my application, and several times that my physical paperwork had been lost; never filed. For 6 months, I couldn't access care unless I went to an ER. I went into heart failure during this time. It took 4 ER visits to catch, but had I been able to go to a cardiologist for an Echo, it would've been spotted immediately. I was told peritoneal dialysis would be a better option for my heart but had to endure hemodialysis because no surgeon would place the needed catheter if I couldn't pay.

I spent 6 months having my blood sucked out through a tube in my neck,cleaned, and returned to my body while often going into shock where a loss of fluid makes the heart unable to pump blood to the body, having horrible insomnia, deep pain, and fatigue. 6 months of suffering due to a lack of access to care for a medical situation that should have been prevented in the first place.

Medicare eventually kicked in, and now 229 AGONIZING days after my first dialysis session I am finally switched over to the in-home peritoneal dialysis I should have gotten in the first place. 229 days of my life were robbed from me, for reasons out of my control but that are preventable for the next person by the elected officials sitting in this room. The experiences I briefly shared are a drop in the bucket compared to my full story. I want to thank you for taking the time to listen to me, and I implore you all to also take the time to fully absorb the words I said. This situation is happening all across the country, and Medicare for All would prevent it. It is inhumane to present any human being a situation where they must choose between eviction or healthcare.

Thank you.