

February 12, 2019

“The Cost of Rising Prescription Drug Prices,”

Testimony of Ola Ojewumi
Before the Ways and Means Committee

Good morning, Chairman Neil, Ranking Member Brady, and distinguished members of the Committee. Thank you for the opportunity to testify today. My name is Ola Ojewumi, and I'm honored to speak in front of you today. I'm the founder of a nonprofit organization called Project ASCEND, a disability rights activist and a cancer survivor. I am here today on behalf of Families USA, a non-profit, non-partisan, consumer advocacy organization that has worked since 1982 to promote high-quality, affordable health care for all in this country.

At age nine, I was diagnosed with a severe heart condition. Two years later, I received a heart and kidney transplant. I lived a relatively healthy life for the next ten or so years, but at age 24 I was treated for cancer at the Kimmel Cancer Center at Johns Hopkins Hospital. Thankfully, by then, the Affordable Care Act had been enacted, so I was able to remain on my parents' health insurance and afford the treatment I needed to recover. I'm now 28 and living cancer-free.

Now, in the movies and on television those that recover from organ transplants or cancer tend to bounce back quickly. They never have to receive treatment again. In reality, we have to take medication for the rest of our lives. In order to keep my transplanted heart pumping and kidney functioning, I will be on immunosuppressive drugs until the day I die. Without insurance, that medication alone would cost me \$2,000 a month.

The past few years have proven that affordable prescription medication is a thing of the past.

You can see this for yourselves in the rise in the cost of insulin, EpiPens, and HIV drugs. I've been affected by this. Though it sounds like my list of

medical problems couldn't get any longer, they've grown over the years. I have a unique muscular disorder (mitochondrial disease) that has made me a wheelchair user and a rare autoimmune disease that I had treated with surgery two and a half months ago.

Right now, I have excellent health insurance through my employer, but the costs of my care add up quickly, and insurance doesn't cover everything I need. I take 22 different medications every day, including anti-rejection drugs. In 2014, my health insurance refused to cover a supplement compound to treat my disease. Monthly, I'd pay \$200 for this drug with excellent health insurance, which was in the upward 15% in the country. Imagine how much more expensive it would be without my insurance--I haven't taken the medication in 4 years because I just cannot afford it.

Taken together, I pay over \$3,000 a year in copays and if I were to fill all of my prescriptions, I would be spending over \$10,000 a year out of pocket.

This isn't the only hurdle I've experienced trying to get care. I've faced delays in approval for medical equipment, including a motorized wheelchair. It took seven years for insurance companies to approve a new chair. I paid a \$50 copay for my first motorized wheelchair in 2011. Seven years later, this new chair cost me over \$900 in copays.

And my insurance selectively covers medical treatments. Last year, I had two procedures related to my autoimmune disease. For the surgery, I only needed to pay my \$200 copay, but for a treatment, they charged me \$1500.

All of this is with excellent insurance.

The cost of my care has, in part, meant that I continue to live at home with my parents.

The rise in the cost of affordable medical equipment and drugs and or isn't coincidental or a result of the free market system.

It's corporate greed that's bred from a lack of regulation of the prescription

drug industry. Congress has the power to stop this by changing public policy. Drug makers are granted authority to drive up the cost of drugs to unaffordable and astronomical rates with the consent of the state. Inaction on the part of lawmakers is what's led to this crisis. Drug manufacturers are preying on the needs of our most vulnerable population, the chronically ill and disabled.

To care about the well-being of your fellow man is not only your civic duty but simply the right thing to do. The disabled community isn't asking for your pity. We are asking for compassion and common sense policymaking. Though you may not see us in you, we are one in the same. I may use a wheelchair, but this is your future. We all will experience disability at some point in our lives. The only difference is this happened to my disabled peers and me in our youth. If you're lucky enough to live to old age, you too will experience disability as the human body naturally ages and breaks down. It's a rarity to see senior citizens that aren't living with some type of ailment, physical limitation or health issue. This is not only my future in the balance. It's yours too.

I have health insurance through my employer now, but I'm frightened of the pharmaceutical industry's influence and power on the Hill. If drug companies are allowed to continue to charge people arbitrary prices, I would be unable to afford to live and meet my basic health needs. So many people across our country would be affected negatively by increases in their drug costs. Despite my disability and the obstacles I've faced in life, I've been able to do incredible things, like start my own nonprofit organization at the age of 19, work in the White House at age 20, and graduate college at 21.

The potential of people with disabilities is limitless -- IF they can access the care they need. I don't know how I would survive without affordable prescription drugs. While I'm honored to be testifying before you today, I'm tired of having to tell my story again and again just to show the harmful influence of the pharmaceutical industry on patients like myself.

The United States is one of the wealthiest countries in the world. We should be able to afford health care for everyone who needs it. My life is

not less valuable because I have a disability and people like me have a right to the affordable medications that will allow us to reach our potential, to contribute fully to our communities and society. I welcome the Houses' recent proposals to finally, at long last, hold pharmaceutical companies accountable and protect the most vulnerable patients in our country.

Thank you all.