Oversight Hearing: Impact of the Administration's Policies Affecting the Affordable Care Act

Wednesday, February 6, 2019 10AM-12PM

Labor HHS Committee Hearing Room – 2358-B Rayburn House Office Building

TESTIMONY

Peter Morley – Disabled Patient and Patient Advocate

Thank you, Chairwoman DeLauro, Ranking Member Cole and Members of the Subcommittee, I am honored and humbled to speak with you today about the critical importance of the Affordable Care Act and the Trump Administration's ongoing efforts to undermine it.

My name is Peter Morley. I live in New York City. I appreciate the opportunity to share my personal healthcare journey with you. In 1997, I had an injury during a lapse of insurance coverage. The costs of my physical therapy, epidural steroid injections, and medications were paid out of my own pocket. Consequently, when I needed surgery after securing health insurance at a new employer, my injury was considered a pre-existing condition and all my claims were denied for the procedure. It was an incredible financial burden for years; totaling in tens of thousands of dollars.

In 2007, I was permanently disabled from a fall off a ladder and unable to work, I was fortunate to be spared the entire cost of my medical bills because I had continuous insurance coverage. Since then, I have had 10 surgeries in 11 years, including 4 spinal surgeries (3 of which are failed spinal fusions; the last one caused irreversible nerve damage); I was subsequently diagnosed through an incidental finding with kidney cancer in 2011 and lost part of my right kidney, but I fought my way into remission in 2016; I have had 2 neurosurgeries for benign pituitary tumors; 2 carpal tunnel surgeries; and one surgery to remove a malignant melanoma.

In addition, I have had diagnoses over the last 11 years that have catapulted me well-above 10 pre-existing conditions including but not limited to: Spinal Fusion Failure; Chronic Neuropathic Pain; Degenerative Disc Disease in both my cervical and lumbar spine; Renal Cell Carcinoma; BPH; Osteoporosis; Angiomyolipoma on my left kidney; Fibromyalgia; Sjogren’s Syndrome; Raynaud's Phenomenon; Small Fiber Neuropathy; Nodular Regenerative Hyperplasia (non-cirrhotic Liver Disease) w/Portal Hypertension and Obliterative Portal Venopathy; and Adhesive Arachnoiditis (which there is no cure or successful treatment, and I am progressively losing the function of my right leg as it becomes paralyzed).

In 2013, I was diagnosed with what has become my primary health concern to-date: Lupus, which is an autoimmune disease when activated, creates autoantibodies that attack not only an invading infection, but will turn and continue to destroy healthy cells and organs, thus causing inflammation known as a Lupus flare. Therefore, I must be checked frequently by my rheumatologist. Lupus has a multitude of side-effects, but for me, the most challenging is the chronic fatigue that I fight every day. It is a struggle and challenge to get out of bed every single day.

I take 25 different medications daily, 38 yearly, and receive 12 lifesaving infusions yearly for my Lupus. Without access to insurance, I could not afford to pay for these medications and would lose access to my team of doctors. As a result, my disease would progress, and I could die.

Despite all my health challenges, I have flourished by the continuity of care provided to me by the 17 doctors I see on a monthly, quarterly, semi-annual and annual basis. Depending on the week, I spend about 60-70% of my waking moments in doctors' offices. And as someone who has faced my own mortality on more than one occasion, I am grateful to be here. I know how first-hand essential it is to protect our care. I also realize that due to my advancing diagnoses I am thankful and appreciative for every day.

Observing President Trump's desire to repeal and replace the Affordable Care Act (AKA "Obamacare" as President Trump refers to it) and all the protections that it comprises -- such as barring discrimination against those with pre-existing conditions and allowing children to continue to be covered under their parents' plan through age 26 -- horrified me. From his campaign to the inauguration, I watched the unrelenting attacks on the ACA in ways that are tantamount to writing prescriptions with purposeful, harmful side-effects, including but not limited to: an Executive Order on day one allowing dismantling of the ACA 'to the maximum extent permitted by law.'"; shortening Open Enrollment; slashing ACA advertising and navigator budgets; not enforcing and then repealing the individual mandate; withholding cost-sharing reduction (CSR) subsidy payments to insurers, thereby threatening the stability of the individual insurance marketplace; HHS stopping staff in its regional offices from participating in insurance enrollment events; allowing employers to opt-out of covering contraception based on moral or religious objections and potentially affecting 62 million women; allowing states to implement Medicaid work requirements, which have resulted in a loss (as of this date) almost 17,000 people having access to care in Arkansas; proposing rules to expand the use of short-term “junk” insurance plans as an alternative to plans under the ACA, exposing consumers to coverage gaps and higher costs; The Department of Justice (DOJ) filing a legal brief declining to defend the constitutionality of the ACA in a suit brought by 20 states; and the Labor Department issuing rules to increase enrollment in association health plans (AHPs) that lack ACA coverage requirements. (These rules would also allow insurers to charge higher rates for older people or based on gender or occupation.)

In December 2016, shortly after President Trump’s election, I joined Twitter and created the handle @morethanmySLE with the goal of fostering awareness of men who have Lupus. My account gave me visibility that led me to work with my US Congresswoman, Carolyn Maloney to advocate for healthcare that is accessible and affordable to people with Lupus and other chronic illnesses.

I want you to know that I was a very private person prior to the 2016 election, but once President Trump was elected, I realized I could no longer keep quiet. I had to in good conscience do something to promote healthcare advocacy and empowerment. I recognized that meant I had to share the very personal details of my own story on social media. There are people in my life that were not aware I had kidney cancer or Lupus and have found out through Twitter -- that’s how guarded I was. But listening to President Trump’s campaign rhetoric for 18 months caused me incredible stress and motivated me to speak my truth.

Before the ACA guaranteed health insurance coverage to those with pre-existing conditions, many people like myself with Lupus and my multitude of diagnoses could be denied health insurance policies by many providers. The ACA defined what benefits insurers would be required to include in order to enroll consumers in “health insurance” products (including Medicare and Medicaid). It’s important to understand what it was supposed to do. Before the ACA was passed, each insurance company had different restrictions as to what services it would cover, at what premium cost, and from what providers. Someone at the company would then review each claim and decide what to pay. Standardization of options was intended to reduce non-medical administrative costs and make insurance more affordable. I think we can all agree that the ACA is not perfect and could greatly benefit from being enhanced. We need to return to the intent to cover 10 “essential health benefits,” including preventive (wellness exams, colonoscopies, mammograms, chronic disease management, etc.); doctor visits, surgery, and hospital stays; outpatient care; maternity (including pregnancy and newborn care); mental health (including substance abuse); lab services; prescription drugs; emergency services; pediatric (including children’s dental and vision care); and rehabilitative care. And most importantly improve accessible and affordability for everyone, which includes lowering premiums, deductibles and drug costs.

In the last two years, I have traveled to DC fourteen times to advocate not only for myself, but for thousands of people who have reached out to me through Twitter and my website, morethanmySLE.com. These are two of the thousands of stories people have shared with me who have benefited from the ACA. They both wanted to testify and have given their permission and consent to share their own personal story of how the Affordable Health Care Act has helped them:

PATIENT STORIES:

Gloria Palencar, Sykesville, MD: “The ACA saved my life 4 years ago when I became very ill. I went to the ER in excruciating pain and the moment I stated I didn't have health insurance I was no doubt placed at the bottom of the priority list. After going to a public clinic, they advised me to apply for the ACA and only qualified for Medicaid. I had gallbladder surgery and recovered. A year later I visited the ER 5 times in 7 days because the ER doctors kept discharging me without a diagnosis for the severe gastrointestinal symptoms. Thanks to having ACA health insurance, I was eventually diagnosed and properly treated. My children still have a mother thanks to the ACA.

The pre-existing conditions coverage under the ACA is keeping my younger sister alive after years of weekly chemotherapy for what now appears an incurable rare condition. I plead with you to work to ensure American citizens like my sister will not lose their health insurance due to a pre-existing condition. A few weeks ago, the ACA saved my premature grand nephew's life. He received all the medical care he needed while his parents couldn't work.”

Stephanie Snow, Rochester, MN: “I was paying $1400 a month for insurance before ACA. Every year it went up $100 a month or more. I was in my early 50’s. The ACA lowered it to $650 a month the first year, $870 a month second year. The third year it went to $1350, so I went to MN Sure exchange, and it went down to $260 a month. It has saved me money, I do have a higher deductible, but I also started an HSA to help pay that. The ACA is great, and I wish they would fix it for everyone and keep it.”

I was inspired to make that first trip to Washington, D.C., on July 27, 2017 the day of the Vote-a-Rama in the Senate for the “Skinny Repeal”. Mostly because I felt helpless sitting at home waiting for the outcome, which seemed likely to be that the ACA was doomed. I also happened to watch then Energy and Commerce Subcommittee on Health Ranking Member, Gene Green on July 25, 2017 on C-SPAN use his one-minute on the floor to say, “recently we learned the Trump Administration has diverted taxpayer funds allocated for the enrollment of the Affordable Care Act. Activities to create a social media video's content claiming the Affordable Care Act is failing, a deliberate act of sabotage. Instead of making sure that Americans remain healthy and improve the risk pools the HHS is peddling misleading online propaganda to discourage enrollment in health insurance.” This was happening at a time when the Kaiser Family Foundation published reports that the ACA markets had stabilized, and polling showed over 50% of the American people were in support of the ACA. The Congressman went on to say: “The President has repeatedly declared that he would let the ACA fail just to score political points. It’s unbelievable that a sitting President would wish catastrophic harm on his own people but unfortunately that’s what is happening. Colleagues, the ACA is not failing on its own, it’s being actively sabotaged by the President and our Republican Congress. The administration has repeatedly wavered in its responsibility to administer cost-sharing reduction payments, relaxed enforcement of the insurance mandate, and refused to help state governments shore-up their own healthcare exchanges. The majority and the Trump Administration should quit playing politics with our healthcare system.”

I was outraged by Congressman Green’s recitation of the facts, and I was even more aghast that there wasn’t a collective gasp from the House. What I heard the Congressman say sounded criminal, illegal, and extremely personal to me. So, I booked a 3:25am Amtrak train for the morning of 7/27/17 and with two meetings set before I arrived, I walked in and out of every Senate office I could and spoke with anyone who would listen, Democrat and Republican alike. The very last office I visited was Senator McCain's office at around 5:15pm. I'd gone to his office twice before that day, and his staffers kept telling me to come back so I did. I knew how important his vote was. On the train ride down, I kept thinking if anyone would listen, it would be him. On the third try, is when I spoke with his Legislative Assistant. I shared my story about my health care fight and told her I had Lupus and she burst into tears. She shared with me her story, about her best friend who also had Lupus. I had seen some emotional responses that day, but I hadn't seen one like this. I paused and asked, 'Are you okay?' She said, 'I'm sorry. My best friend worked here in D.C. and she suffers from Lupus as well and had to move to a climate more conducive to her Lupus. And you sharing your story just reminds me of her and her struggle.' I asked how her friend was doing and she said she doesn't have the same resources she had here in D.C.

I gave her some info about a hotline number that could help her friend so she could have access to care and therapy wherever she was. The assistant was so grateful. She said, 'I'm here to listen to you. You're not here to listen to me.' And I told her it works both ways. The entire exchange was very symbiotic. There was a lot of empathy. I asked her to please ask Senator McCain to reconsider and vote 'no.' I begged her and told her there were so many people who would suffer.

Ultimately, I felt a calling on that day. I had felt that magnetic pull to D.C. I'd never been here in this city before that day, but I knew it was where I needed to be. On my way home I got dinner at Union Station. Strangers were talking to me out of the blue, everybody was on edge because of the vote. I'd spent the day sharing my story with anyone who would listen. I wanted to feel like I did everything in my power to stop the repeal. I gave 150% that day. I had a mission, and I felt I had done all I could. I woke up in the morning and somehow managed to get out of bed with my body ravaged by the energy I expended and the chronic fatigue from my Lupus had been triggered. I fully expected to turn on the TV and learn that the ACA had been repealed.

Instead, I saw an image of John McCain giving the vote a thumb's down and I couldn't believe what I was looking at. People began sharing their stories with me and asking me to represent them in D.C. This is my fifteenth trip, since July 2017. You are my 227th meeting, I have fifteen more office visits planned for this trip after this hearing. I have met with Representatives and Senators' staff of both parties to share these healthcare journeys: because healthcare is a bipartisan issue. In fact, I spent January 8, 2018 in the House for sixteen meetings and met with mostly Republican offices.

People have told me because of all these healthcare repeal and sabotage efforts, that they feel alone, scared, and afraid, when they should be focusing their energy on their own well-being. The truth is, we all know someone who has been helped by the ACA. I know firsthand that your health can change in an instant. That is why I fight for my life for those who will be left vulnerable if they lose their healthcare. I will continue to use my voice and encourage people to call their state and federal policy makers, because being proactive is empowering. No one should ever have to worry about having their healthcare taken away from them, simply because they became ill!

I lay awake at night worried about the more than 130 million Americans with pre-existing conditions who would lose their protections if the ACA is declared unconstitutional. Losing access to healthcare means different things to everyone. For me, it would mean not affording prescriptions, and infusions that are keeping me alive.

Due to the chronic fatigue that Lupus causes and my other diagnoses, I realize that I put my own health at great risk to travel and share these stories with you. I frequently schedule mass meetings because I never know if this will be the last time, I will be healthy enough to travel here. But having the opportunity to speak to legislators where there might be one who will listen to me and could change their mind, is the reason I keep coming back here. It energizes me and has given me a new sense of purpose in my life.

I'm here today to ask you to protect the Affordable Care Act, and to hold the Trump Administration accountable for trying to sabotage health insurance for millions of Americans. Thank you for allowing me the opportunity to testify.