

**Proposals to Achieve Universal Health Care Coverage**  
**Tuesday, December 10, 2019 10AM**  
**Subcommittee on Health of the Committee on Energy and Commerce**  
**Room 2322 – Rayburn House Office Building**

**STATEMENT OF PETER MORLEY – DISABLED PATIENT AND PATIENT ADVOCATE**

Thank you, Chairwoman Eshoo, Ranking Member Burgess and Members of the Committee, I am honored to be here to speak with you today regarding Proposals to Achieve Universal Health Care Coverage.

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 12 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 12 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 would 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 how essential it is to protect our care. I also realize that due to my advancing diagnoses I am thankful and appreciative for every day.

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 U.S. 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.

In the last two years, I have traveled to DC twenty-seven 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 only three of the thousands of stories

people have shared with me who have benefited from the ACA. They have given their permission and consent to share their own personal stories of how the Affordable Care Act has helped them:

**PATIENT STORIES:**

**Ben Jackson, Natick, MA, father to Emma Jackson:** "Emma Jackson is a 17-year-old girl who has spent almost half of the last 5 years hospitalized. Without Medicaid, we would be bankrupted by hospital costs alone, and that does not take into account durable medical equipment, outpatient services, or medications. In addition, Emma would be forced to live only in States who choose to offer robust Medicaid programs. She would be denied the fundamental freedom of choosing where to live. She is about to become an adult, and her entire financial future will be ruined the day she turns 18 if she lost access to Medicaid."

**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 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.”

**Mina R. Schultz, Washington, D.C.:** “When I was 25, I was finishing my graduate program at the University of Missouri and preparing to enter the Peace Corps. I had student insurance, but it would end upon graduation, and I would have about 9 months without coverage before my Peace Corps service began. I didn’t give it much thought; I was young, healthy, didn’t go to the doctor much. I would just go without coverage for a few months, no problem. My parents foresaw the gap in coverage and told me about a new law that would allow me to stay on their coverage until I turned 26. I said, sure, sign me up. It didn’t really matter to me, but why not? So, I joined their plan. The pain started in April 2011, about a month before graduation. I wrapped my knee, iced it, and took a break from running for a while so it would heal. I walked the stage with a wrapped knee and a limp. After graduation I was planning on taking a temporary job in rural Montana, to pay the bills until my Peace Corps service started. I was still having pain, and not wanting to end up in the middle of nowhere Montana with a torn ligament, I scheduled an MRI. I will never forget the MRI techs telling me, “You’ll be glad you came in.” I was sure I had torn something. I was on my parents’ insurance at the time. I will never forget the phone call, when the doctor said, “Ms. Schultz, it appears you have a tumor.” I called my mom and asked her to come home from work. I cried for days because I was scared to die. The tumor was osteosarcoma, an aggressive bone cancer usually found in children and adolescents. I endured 5 surgeries, including a

total knee replacement, and 9 rounds of chemotherapy (each involving 3 doses of chemo, so 27 doses all together) over the course of a year. Most of my treatment was inpatient, though I also received at-home physical therapy and IV services. Just one of my post-chemo injections cost thousands of dollars. My knee surgery cost almost as much as my mother's house. In January 2012, my port, through which I received my chemotherapy, became infected. During this time, I regained consciousness for a bit and realized my mother was present in my hospital room. She was there because the doctors didn't think I was going to make it. But I did. I beat it. And because I had taken that insurance, most of my treatment was covered, and my family avoided bankruptcy. I would not have qualified for charity care. I don't know how we would have afforded my lifesaving treatment had I chosen to forgo coverage because I was 25 and thought I was healthy. I think about it every day. Today I depend on medical services to keep up my good health so that I can work and advocate. I'm proud to have just finished my second Master's, this time in Public Health. I have four chronic conditions that I must control and monitor with medications and lab work. I also need yearly scans to make sure my cancer doesn't come back and that my extensive knee hardware is functioning. Without these services, I could die. I depend on many of the 10 essential health benefits, as well as the pre-existing conditions protections provided to me by the Affordable Care Act. The ACA not only saved my life, it keeps me alive. I could not afford my health care without access to insurance. Please protect my care so I can continue to work and contribute to my community."

### **My Personal Story of Advocacy:**

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 one of his staffers. I shared my story about my healthcare 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 twenty-eighth trip, since July 2017. I have held over 350 meetings. 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 the December 14, 2018 Federal Ruling in the Texas v. United States case that declared the entire ACA unconstitutional, 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!

President Trump's desire to repeal and replace the Affordable Care Act (AKA "Obamacare") 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 -- horrifies me. From his campaign to the inauguration, I have witnessed 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 of 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.)

I lay awake at night worried about the more than 130 million Americans with pre-existing conditions who would lose their protections if the Texas v. United States court case ruling is upheld. Losing access to healthcare means different things to everyone. For many people I know with Lupus that are protect by the Affordable Care Act, it would mean losing access to continuity of care, not affording prescriptions, and infusions that are keeping them alive.

Due to the chronic fatigue that Lupus causes and my other diagnoses, 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.

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.

I’m here today to ask you, on my twenty-eighth trip to DC, to not only protect the Affordable Care Act, but to enhance it. I believe it’s an opportunity for us all to work together to build on its foundation as a pathway to Universal Coverage.

As a patient, I have often found myself holding my breath and worrying about such things as *Texas v. United States*, which would strike down and reverse the health care and protections of millions of Americans. I believe I speak for all patients when I say we need a life of focusing our energy on our health without the stress of inability to access or our current protections being ripped away from me. Thank you for allowing me the opportunity to testify, for making my voice heard, and for hearing the voices of the thousands of others I have advocated for in the last two-and-a-half years throughout Congress.