# voices of main street Health Care Stories from Small Business Owners

Spring 2019









H ealth care is deeply important to people across the country. This is no less true for the millions of small business owners who now count on the Affordable Care Act (ACA) for themselves, their families, and their employees. And, with insurance markets advantaging big employers over small business, ensuring quality, affordable health care for all is a crucial part of leveling the playing field between large corporations and Main Street.

For many entrepreneurs with pre-existing conditions, the day the ACA went into effect was the day they had the freedom to strike out on their own and start their businesses. And for many others, although not perfect, the ACA did offer stable, single-digit increases in premiums from year to year and protected entrepreneurs forced to choose between sustaining a business and keeping their health care. By making health care more affordable, the ACA allowed many small business owners to invest in their companies and in their employees.

For the communities these Main Street businesses serve, the ACA and other key health care programs may mean the difference between a thriving small business sector and shuttered firms, empty storefronts, and lost jobs. Last year, it was estimated that repealing the ACA's premium tax credits and Medicaid expansion would cost 2.6 million jobs in 2019 and \$2.6 trillion in business output from 2019 to 2023.<sup>1</sup>

Despite the importance of affordable health care to the small business sector, the Trump Administration and some elected officials, from members of Congress to state attorneys general, have endeavored to undermine the ACA and Medicaid and Medicare. These attacks have included withholding of cost-sharing funds, eliminating the individual mandate, and circumventing preexisting condition rules by expanding junk plans. This year, the Trump Administration argued in court that key pre-existing condition requirements should be eliminated. Now that Brett Kavanaugh has been appointed to the US Supreme Court, he could provide the final vote to dismantle the ACA.

This attack on health care comes at a great cost to the Main Street businesses that form that backbone of our local economies and communities. New analysis shows that the steps taken by Congress and the Trump Administration to dismantle the ACA, piece by piece, have resulted in premiums that are higher than they would have been absent these actions.<sup>2</sup>

Main Street business owners feel these costs acutely and worry for their future. The health care system in the United States was grossly unequal before the ACA, favoring large corporations over small businesses and compromised by racial and gender inequity. The ACA has been a step in the right direction for Main Street. That is why thousands of small business owners have come together to protect and expand health care for themselves, their employees, and the people of all races who make up their customer base and their communities.

Here are some of the voices of Main Street.

<sup>1.</sup> Leighton Ku et al, Repealing Federal Health Reform: Economic and Employment Consequences for States The Commonwealth Fund, January 2017, https://www.commonwealthfund.org/sites/default/files/documents/\_\_\_media\_files\_publications\_issue\_brief\_2017\_jan\_ku\_aca\_repeal\_job\_loss\_1924\_ku\_repealing\_federal\_hlt\_reform\_ib.pdf

<sup>2.</sup> Emily Gee and Aditya Krishnaswamy, Estimated Increases in 2019 Premiums by Congressional District Due to ACA Sabotage, Center for American Progress, July 24, 2018,

https://www.americanprogress.org/issues//news/2018/07/24/453917/estimated-increases-2019-premiums-congressional-district-due-aca-sabotage/

### SPOTLIGHT: Susan Lyon, Lyon & Associates Creative Services, La Jolla, CA

Attacks on protections for people with pre-existing conditions are putting my business at risk and endangering my livelihood, that of my husband, as well as the livelihoods of the nine full-time, professional-level staff we employ at LYON.

My husband and I started our business 28 years ago, and it's hard to believe that our future hangs in the balance because one of us is at risk for being denied insurance because of a pre-existing condition.

My husband has Parkinson's disease, a disorder of the central nervous system that affects movement. Thanks to the protections in the ACA, he's insured, he's healthy and he is a vital part of our business. If these protections were eliminated, we'd have to make some very difficult decisions for our family and our business. My husband could be declared uninsurable.

One option would be for my husband to take disability for the next decade or so until he is eligible for Medicare. This would not only mean a significant adjustment to our earnings and a cruel blow to my husband's quality of life; it would shift a productive contributor to the private sector into reliance on state support. However, Republicans in Congress are looking to slash Medicare, Medicaid, and Social Security to finance their trillion dollar tax bill. Our ability to access these vital services also hangs in the balance.

Another possibility would be that I would have to step away from our business to find a position with insurance that would cover my husband. Even then, there are no guarantees. Would I find work? Would they cover my husband with his condition? How many hours would I have to work on the side at a Starbucks for us to make ends meet?

The implications for our business are uncertain, and they certainly aren't positive. We could lose talented employees, lured away by larger corporations with deeper pockets and access to more cost-effective large group plans. We could be forced to downsize if my husband or I have to take extended or permanent time away from the business. It's not out of the question that we might have to sell or close our firm.



Our future hangs in the balance because one of us is at risk for being denied insurance because of a pre-existing condition.

When we first started our business, we both took turns working full time jobs just to have insurance --one person would cover the other while he/she worked on the business. We were forced to do it this way because we needed access to health insurance. This, of course, impacted the trajectory of our business during its inception. The ACA changed all this, and many entrepreneurs were able to take the risk of starting their own business, without sacrificing access to quality, affordable health care.

In light of the attacks on the underpinnings of the ACA—especially attacks on stipulations protecting people like my husband with pre-existing conditions and with a new appointment to the Supreme Court by President Trump threatening the law, lawmakers must do everything in their power to safeguard insurance for small business owners who need it, especially if they want to see at thriving Main Street.

### SPOTLIGHT: ReShonda Young, Popcorn Heaven, Waterloo, IA

Regular check-ups have helped ensure my potentially lifethreatening condition is kept in check. I shudder to think what would happen if we went back to the days when the care you need the most is the hardest to get covered by insurance companies.

I started fighting for the ACA in 2009, when I was actually running my dad's small businesses. We had been searching for insurance for years, and preexisting conditions were the biggest stumbling block. The failed system that was in place made it unaffordable for us to provide health insurance for our employees. The policies we were shown also denied health benefits for several of our employees due to pre-existing medical conditions.

Even with plans that charged very high rates (and this was close to 10 years ago)—\$1,100 for a family and \$700 for an individual—they planned to exclude any coverage for specific health issues and employees. My brother, who was an employee at the time, has high blood pressure, and any coverage for that would have been excluded. An employee who was stocky, but probably in better health that anyone else at the firm, would have been denied any coverage at all, since he did not fit within the insurance company's healthy height/weight categories. And our employee with a genetic condition that required his esophagus to be regularly stretched would almost certainly have been excluded from coverage.

Knowing that most of our employees had no health insurance in place, and had no way of paying for it on their own, was a huge concern for us. We knew that an illness or an accident could put our employees in a situation where they had to choose between getting the medical care that they need, and paying their rent/mortgage, putting food on the table or keeping the heating on during cold lowa winters. Those aren't choices anyone should have to make.

After passage of the ACA, we were able to put a plan place for our employees that did not exclude their preexisting conditions. When I opened Popcorn Heaven in 2014, I was grateful to have an affordable health insurance option for my employees.

This issue is now personal for me as well. One year ago I was diagnosed with blood clots in my legs. Regular check-up's have helped ensure this potentially life-threatening condition is kept in check. I shudder to think what would happen if we went back to the days when the care you need the most is the hardest to get covered by insurance companies.

To go back to where we started from doesn't make any sense. Our Members of Congress, and especially Representative Rod Blum, need to start making some smart decisions, and undermining access to lifesaving health care to give trillions of dollars in tax cuts to their wealthy donors is NOT one. It is putting us into a tailspin.

ReShonda Young is the owner of a gourmet popcorn franchise called Popcorn Heaven. Popcorn Heaven is headquartered in Waterloo, IA with locations in Des Moines, IA; Kansas City, MO; Peoria, IL; Charlotte, NC and soon in Waldorf, MD.

### SPOTLIGHT: Chris Petersen, Family Farmer, Clear Lake, IA

I've been an independent family farmer for most of my life, raising crops, livestock and local foods in rural lowa. I'm gravely concerned with Congress' latest health care game-playing. We farmers are looking at, once again, being priced out of health insurance.

Nearly two decades back I had health coverage through an outside job and was diagnosed with a nickel-sized hernia. It was a minor inconvenience and I did not have surgery. As time went by, farming was looking up and I was able to quit the job, farm full time and afford private insurance. We were approved for a policy, even with my hernia and my wife's lifelong heart murmur—which we disclosed during the application process. Each month we religiously paid the \$700 premium.

After about a year, I decided I needed to take care of the hernia and was pre-approved for the surgery. After the surgery, the bills started coming. After months of talking to our agent and mountains of correspondence the insurance company denied the claim, citing a pre-existing condition and dropped me, but kept my wife on.

Then my wife had pre-approved heart tests for the second time. The insurance company denied the claim she was dropped from the policy. The company's stated reason: discrepancies between medical records and insurance forms. Paperwork filled out nearly two years earlier by their agent listing my wife, Kristi, as one inch taller and a dozen pounds lighter than on the day of her tests.

So, for 14 years, we made \$200 monthly installments for medical care that we had already paid thousands in premium costs to cover. Since we were marked as uninsurable, we had to purchase coverage through a safety net program that cost \$1,300 a month, with a \$2,500 deductible. I also became diabetic during this time, but was forced to skip three out of four annual diabetes and blood pressure checks because it cost too much.

Then came the ACA. Kristi and I were able to purchase quality, affordable health care that did not exclude our pre-existing conditions through the ACA marketplace. But now, with Republicans' underhanded sabotage



## Kristi and I were able to purchase quality, affordable health care that did not exclude our pre-existing conditions through the ACA marketplace.

of the ACA we are getting eaten at both ends. And Trump's nominee to the Supreme Court may be the final nail in the coffin for the ACA.

Kristi and I will likely be forced to drop all insurance next month. Premiums have increased so much from sabotage efforts at both the federal and state levels that we can no longer afford our plan, which now costs \$42,500 per year. As farmers, our income is sporadic. We are in our early 60s and we are just hoping to make it to 65 and Medicare. Hopefully Republicans don't decimate Medicare before then.

### SPOTLIGHT: Jenny Newman-Arruda, TL6 the Gallery, New Bedford, MA



In 2008, my business partner and I opened up TL6 the Gallery for local artists and designers. Our gallery and other new local businesses have helped revitalize New Bedford.

I'm proud of my business and want to expand it. Instead, I'm afraid I may have to close up shop. My fear isn't because of anything I'm doing as an entrepreneur. It's because the Trump Administration is still trying to take away people's health care.

In addition to operating my gallery, I'm also one of the 2.9 million Massachusetts residents with a preexisting condition. Three years ago, I was diagnosed with a rare genetic condition, Ehlers-Danlos Syndrome (EDS) that affects my body's collagen and requires expensive medication and consistent care.

Collagen is in all parts of our bodies: skin, eyes, the heart. My diagnosis explained the joint pain and eye problems I'd been having. It also meant I could get treatment for a heart condition that had been misdiagnosed as anxiety.

There's no cure for EDS, but thanks to the Affordable Care Act and the Massachusetts Health Connector, I have the health care coverage I need. This keeps me out of the ER and keeps our gallery open.

The gallery is a passion for me. It also meets my financial, health care, and childcare needs better than any job I could find. I've worked out a delicate balance considering my health situation.

There are 130 million people in the U.S. with preexisting conditions who are in a similar situation. We're people of all walks of life, races, and religions who are managing a delicate balance and need politicians to There's no cure for EDS, but thanks to the Affordable Care Act and the Massachusetts Health Connector, I have the health care coverage I need. This keeps me out of the ER and keeps our gallery open.

have our backs instead of putting the interests of big corporations and super-rich donors first.

Before the ACA, health insurers often rejected people with health conditions, or they jacked up our premiums. Massachusetts was ahead of the rest of the country and took steps to stop insurers from discriminating this way. Then, with the ACA, the rest of the country caught up. Now these health care protections are in jeopardy.

That doesn't mean my coverage under the ACA is perfect. It isn't. I still have to work part-time on top of running my business so I can pay for all the health care I need.

But the ACA provides a baseline of protection for small business owners like me, and I'd suffer a lot without it.

I know we need to make sure the rules support small businesses and communities. We need to stop the Trump Administration from chipping away at our health care. And we need to keep moving forward and make health care affordable for every person in our country, no matter our health condition, our race, or our income.

I know how much we can accomplish by working together. I've seen it in my own community—retailers like me in New Bedford who sweep the sidewalks, shovel the snow, and anchor our downtown.

In speaking up now, I'm not just fighting for my life. I'm fighting for everything I own and love. Everything is at risk if I lose my insurance.

### SPOTLIGHT: Jonathan Werbel, Fairhaven Yachts, Fairhaven, MA

Having two pre-existing conditions makes me an insurance pariah. Before the ACA, I was completely uninsurable. I would start a job, begin getting health insurance, and then the insurance would be rescinded.

The only thing I really care about is boats. I grew up on boats. My grandfather was in the fruit importing business. He had a boat called The Banana Queen that brought him so much luck in business, he named his second boat the Banana Queen 2. My mother went into labor with me while on the Queen 2, so the family story is that I was on a boat when I decided to be born.

Eventually, I ended up at New York Maritime Academy. When I got out, I really only had two choices. I was more Popeye than GI Joe, so I went into the merchant marines. Getting a job was easy. Getting health insurance was a different story.

When I was 12, I was diagnosed with osteoid osteoma—a type of bone cancer. When I first heard the news, I remember Dr. Marco telling me it had something serious to do with my leg and I needed emergency surgery. The surgery was a success. But it left me with a serious staph infection causing medical complications well into my 20s.

Having two pre-existing conditions made me an insurance pariah.

Before insurance companies were banned from some of their worst practices, I was completely uninsurable. I would start a job, begin getting health insurance, and then the insurance would be rescinded.

For people who have the privilege of always being healthy, rescission is when an insurance company cancels your health insurance because you are too expensive to insure. This usually happens after you've been paying for the insurance a few months. There is no refund. Yes, that's right, insurance companies would find any way they could to drop you.



Or worse. Once the company i worked for found out how expensive I was to insure and they left me high and dry and just replaced me with a cheaper-toinsure employee.

It wasn't until we passed health care protections that I was finally able to get consistent guaranteed insurance. The ACA made rescission illegal, except in the case of fraud.

The thing is, not getting sick is mostly luck.

With health care you have to frontload your luck; regular check-ups, constant attention, and listening to the doctor. It is the frontloading of my health that keeps my medical bills down and makes it cheaper for the insurance company overall.

News flash, even people with pre-existing conditions have ambition and own businesses. Just because someone was sick once, doesn't mean you should be excluded from the safety that health insurance provides. Instead, small entrepreneurs like me have become a scapegoat for costs being too high and are demonized by Washington.

My business only pays a modest living, but I offer a needed dockside service. Independent businesses like mine are essential to the maritime industry that New Bedford functions around.

The Trump Administration claims to be pro-business, but what they really mean is only if you are rich enough. If you are self-employed, don't have perfect health, or don't make enough money to play golf in Florida, they aren't on your side. Brett Kavanaugh's confirmation was another example of them gaming the system in their own interest.

### SPOTLIGHT: Jonathan Fulford, Artisan Builders, Swanville, ME



After graduating high school, I started a small farm with my brother in Monroe. After having my first child, I started a building company, and I have spent the last 30 years raising a family and building a business and building houses.

For most of my working career I did not have health insurance, and I was fortunate enough to get health insurance when the Affordable Care Act was enacted. A couple years later I was diagnosed with prostate cancer. I would not have been able to afford the treatments and surgery I needed if I had not had that insurance.

I am cancer now free, but I need to get regular checkups to ensure that my cancer does not come back. As a cancer survivor, I have a pre-existing condition. If it were not for the ACA and its protection of people with pre-existing conditions, I would not be able to afford the treatments necessary if my cancer does come back.

When Senator Collins voted to confirm Brett Kavanaugh, she voted to go back to the days when we discriminated against people with pre-existing conditions. She voted to discriminate against cancer If it were not for the ACA and its protection of people with pre-existing conditions, I would not be able to afford the treatments necessary if my cancer does come back.

survivors like me, who, after surviving a battle, would be virtually uninsurable.

Here in America we have some of the world's most incredible doctors and medical advancements, but without health insurance millions of Americans don't have access to life-saving health care. There should not be some people who don't survive an illness just because they cannot afford health insurance. Thanks to the Affordable Care Act, I can stop worrying about cancer and can focus on growing my business and taking care of my family.

### SPOTLIGHT: John Costin, Veneer Services Unlimited & New Pioneer, Sanford, ME

I started Veneer Services Unlimited over 25 years ago and we are now located in Sanford, Maine. We employ three workers in a mill in Sanford and manufacture high-quality custom veneer work for the custom woodworking industry. My wife Rachel and I also own New Pioneer, an old mill in Sanford that we have revitalized into a hub for craftsmen in southern Maine.

My wife is alive today because of the Affordable Care Act. Before the ACA we struggled to patch together health care coverage for our family and employees. At various times as our business was growing, sometimes we had coverage through her other job as a social worker, other times we had bare-bones policies we paid for on our own. Five years ago when the ACA was enacted, we were relieved to purchase a good policy through the health care exchange.

When Rachel began experiencing low-level symptoms, she went to the doctor and followed through with recommended testing. If we'd been on a bare-bones policy with a high deductible she would likely not have taken either step. We found out that she had a tumor on her parathyroid. This condition is called the 'silent killer' because it is often not detected until it's too late. So having good insurance is key to my family. We now are a family with a pre-existing condition.

I have been advocating for affordable, quality health care even before the Affordable Care Act. The ACA has taken critical steps to lower costs and bring affordable, good quality health coverage within reach for small businesses. I was proud that Senator Collins introduced a bill to stabilize the Affordable Care Act, which the Trump Administration is doing its best to dismantle piece by piece. But with her vote for Brett Kavanaugh—who President Trump nominated in part due to his extreme hostility toward the ACA—she undermined her past efforts and has left thousands of Maine businesses in the lurch.

Today my family is covered under Rachel's employer's plan, but the cost is really steep. And if coverage for pre-existing conditions is stripped away, our family and so many others will lose our health care. My son turns 26 soon. He's in graduate school, and being able to cover him up to this point has been critically



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important to his future. I don't ever want to see him have to put his health on the line because he can't access affordable care.

Provisions of the ACA—from rate review to guaranteed coverage for pre-existing conditions—have made a real difference for me and my employees. Thanks to the Affordable Care Act, Mainers no longer have to worry about spending their lifetime or retirement savings, or losing their home in order to pay for health insurance. It's allowed us to expand our business and feel more secure. Small business owners know that we can't afford to go back to the nightmare scenario that health care was for us before reform.

### SPOTLIGHT: Dave "Stretch" Tuemmler, Stretch Studio, Portland, ME

### To date, I've had nine surgeries and 55 radiation treatments. That's impossibly expensive care to receive in our county. But because of the ACA, there's a chance my legacy will not be bankruptcy.

I have been seriously ill for over three years. All the appointments, hospital stays, long drives to visit specialists and excruciating procedures come with idle time – in waiting rooms, on exam tables, hooked up to machines. It's given me time to really consider what it means to leave our world and community better for our kids. I think a lot about my son, Kasch, who suffers from a stomach disease called gastroparesis.

I've had time to think about these things because I am still alive. I am still alive because of Obamacare.

Myxofibrosarcoma is a rare cancer that forms in connective tissue. It attacked my elbow, then my lungs, and then my lymphatic system. I've compared receiving my diagnosis to a car wreck because of the way it turned my life on its head – but living with this disease has been more like a car wreck that happens over and over again every day.

To date, I've had nine surgeries and 55 radiation treatments. That's impossibly expensive care to receive in our county. But because of the Affordable Care Act, there's a chance my legacy will not be bankruptcy.

I am a small-business owner by trade, a photographer. Like 21 million other Americans, I gained access to better health care through the ACA marketplace. If the vicious attacks on our health care continue, people from all walks of life will suffer. Some may even die.

My son is an adult now, and there's one thing I know I can still do for him: I can still fight for his right to health coverage.

I've already been alive over three times longer than is usually expected for people with my diagnosis. I simply don't have the time to wait for Sen. Susan Collins to keep her promise to work across party lines



to improve health care for anyone – not for me, not for you and not for our children.

And still, I have hope. The recent shake-up in the U.S. House of Representatives has breathed new life into our Congress. It's showing signs of progress and momentum on health care.

These leaders are moving the conversation from saving the ACA to further protecting the 133 million of us who have pre-existing conditions. Maybe they will reduce premiums and out-of-pocket costs for all of us. Instead of turning back the clock, they're working to strengthen the ACA and move toward universal health care that protects everyone, whether we run a Fortune 500 company or a small business. No matter our income or where we were born, and no matter whether we're white, black or brown, we all deserve access to health care.

I hope our Congress will hear the cries of people like me who are willing to fight for our future while fighting cancer. I want a future where someone who is sick doesn't have to think twice about getting the care they need. And where entrepreneurs – even those with pre-existing conditions – have the safety net necessary to take a risk and start their businesses.

On the really tough days, I think about being back in my studio – without the cancer. I dream about being able to move through my workday with my sole focus being delivering the best to my clients. I hope to see the day where I don't have to worry about health care – not the cost, not the quality, not its future.

### SPOTLIGHT: Elizabeth Spehar, Snooty Fox Tea Shop, Duluth, MN



The amount of money I would have had to pay if I was uninsurable would have been astronomical and would have likely put me out of business.

When someone starts a small business, especially a restaurant business, they don't expect to make a profit—or even pay themselves—for a while, years in many cases. For me, having a pre-existing condition adds to the risk of financial security. Luckily for me, I had access to high quality affordable health care through MNSURE.

I was born with osteogenesis imperfecta, a genetic bone disease that makes my bones break easily. Growing up, my parents worked in the public sector so we always had really good health care. Without that, I might not be alive today. I simply cannot be without health care—at any cost. When I started my small business in 2013, I knew I wouldn't be making much money for myself right away but I knew I needed health insurance.

In February of 2013 Governor Mark Dayton signed HF9, a bill that expanded access to Medicaid under the ACA to 35,000 newly eligible Minnesotans. It reduced the uninsured rate in the state by 39%; because of that, I qualified for state health insurance through MNSURE. I have to worry about a lot of things for my business, but health care is not one of them. It gives me piece of mind that if I need insurance, I have it.

Since starting the business four years ago, I have had five surgeries. Without high-quality health care, my condition would have been devastating to me and my business. The amount of money I would have had to pay if I was uninsurable would have been astronomical and would have likely put me out of business.

Next month, we celebrate our fourth anniversary, and I am proud to how far we've come. Over the past four years, we have expanded the business tremendously. We have two employees who are paid living wages and have benefits, we are a safe and welcoming community space and are active in our city and business community.

There are so many people in our community who are just like me who have innovative ideas, have a dream of starting a business, but also need health care, and are held back from it. Whose ideas aren't coming to light because they are so bogged down by how they will pay for their medication or treatment? What would our economy look like if more people like me, who has a vision for a new business, and want to bring something new to their community were able to do it?

As a small business owner with a pre-existing condition, I am urging all our lawmakers to continue to build from the protections in the ACA and not take us back to the day when taking on the risk of starting a new small business was out of reach for any innovators with a pre-existing condition.

### SPOTLIGHT: Joel Vikre, Vikre Distillery, Duluth, MN

In October 2017, our lives changed forever when our boy Vidar was born at Children's Hospital in Minneapolis. He was born with several heart defects. In spite of successful surgical repair, Vidar developed heart failure and had to be placed on life support. This began a three month stay in the hospital, three months away from our home and our business, and a deeper dive into the American health care system than we could ever have imagined.

As small business owners, my wife and I provide health insurance to our nine full time employees and their families, including ourselves. It is a major expense for us as a small employer, but it was there when we most needed it. Blue Cross Blue Shield has so far paid well over two million dollars for Vidar's care. We have paid our out of pocket maximum for 2017 and 2018. Our friends and family held a social media campaign to help us raise that \$13,400. But insurance has covered the rest.

Vidar is now a happy healthy little guy with the biggest smile you've ever seen. He still requires medications, and he's fed through a stomach tube due to surgical damage to the nerves that control swallowing, but all indications are that he will recover completely and be able to live a normal life. This is the way health care is supposed to work: covering expenses of the most specialized heroic care possible.

But we also experienced the downsides to US medicine. When we came home from the hospital Vidar was on 12 medications, delivered every three hours around the clock. One of the most critical medications was required by the insurance company to be filled by a specialty compounding pharmacy, which would suspend the medication in liquid to be delivered through his stomach tube. Though the insurance company would cover the \$5,000 medication, they wouldn't cover the \$5 liquid it had to be suspended in; due to some truly mind-bending rules, neither the pharmacy nor the insurance company could bill us for that \$5. We spent countless hours over the course of 47 days on the phone with the insurance company, the pharmacy, and Vidar's doctors, but none of them could resolve this catch-22 of uncoordinated systems and regulations. In the end, we resolved the problem by buying an alternative drug out of pocket Because of [our son's] heart history, the health care system will always be a significant part of Vidar's life. If we continue on our current course.



that part of his life will always be a fight... We owe it to Vidar to work to ensure the protections in the ACA are preserved—especially for those with pre-existing conditions.

and compounding it in our own kitchen. Without that, Vidar would have ended up back in the hospital. Our experience exemplifies the downside of the US health care system. It is an adversarial system where the providers and the insurance companies are competing to make money, not collaborating to improve health.

Because of his heart history, the health care system will always be a significant part of Vidar's life. If we continue on our current course, that part of his life will always be a fight. Health insurance premiums and copays will eat up a huge part of his salary. He'll be on the phone and at the keyboard trying to get bills covered and prescriptions refilled. He'll have to be his own advocate, navigating a fractured system that is designed for profit, not for human health.

We owe it to Vidar to work to ensure the protections in the ACA are preserved—especially for those with pre-existing conditions. But we can do better than that. Whether or not you believe health care is a human right, we can all agree that health is a public good. We already spend more than enough as a nation to get a much better system. But it will take us as citizens standing up and saying that health matters more than profit, and demanding Medicare for all.

### SPOTLIGHT: Kelly Conklin, Foley-Waite, LLC, Kenilworth, NJ



My wife, Kit, and I first started Foley-Waite, an architectural woodworking company, 40 years ago, in 1978. She was on one end of a sheet of plywood and I was on the other. And it's grown since then to a 16-person company.

Just before the Affordable Care Act we were looking at double-digit year-over-year increases in our insurance premiums. And in the last year before the ACA passed they raised our rates 126 percent. We were getting older, and my wife has a chronic illness, Discoid Lupus. After a couple of big claims, the insurance company just wanted to dump us.

After the ACA was enacted, our rates stabilized. Our premiums rose just between five to seven percent annually. If it weren't for the ACA's protections for preexisting conditions Kit would most likely have been labeled uninsurable. And we wouldn't have had any insurance coverage when she had her first stroke two years ago.

Kit and I recently reached the Medicare eligibility age. Earlier this year, she had her second stroke, and the surgery that followed was covered under Medicare. But if we had to pay the medical bills on our own, it would have brought us to financial ruin.

But Medicare, Medicaid, and protections for preexisting conditions are all under assault. After President Trump was elected, his Administration and Congress began attacking these critical programs. Earlier this year, my wife had her second stroke, thankfully, the surgery that followed was covered under Medicare. But if we had to pay the medical bills on our own, it would have brought us to financial ruin.

In 2017, Foley-Waite got hit with a 26 percent premium increase. The vacancy on the Supreme Court could lead to the end of protections for preexisting conditions all together. It's clear to me that we are headed back to where we were pre-ACA.

As a responsible business owner, I have to be pragmatic and figure out what we can afford. We are really already at the threshold. I am likely going to have to stop providing health insurance to my employees and they will have to go out and find coverage in a collapsing individual market with skyrocketing premiums. What the country does next is critically important.

### SPOTLIGHT: Matt McColm, Suzie Health Solutions, Wenatchee, WA



If insurers were free to deny me coverage because of my diabetes, I'd have to close the doors to my business. It's as simple as that. I'd have to abandon what I've built over the last seven years.

As a small business owner, an insurance broker, and a health insurance consumer with a pre-existing disease, I'm extremely concerned with the concerted effort to undermine many common-sense protections in the Affordable Care Act, especially the latest attempt from state attorneys general that takes aim at people with pre-existing conditions.

I'm a diabetic. Under the old rules—before the ACA mandated protections for people with pre-existing conditions—I'd be virtually uninsurable. Without these protections, at best my rates would skyrocket. At worst, I wouldn't be able to find health insurance.

When the ACA came into effect, I immediately signed up for insurance on the exchange. This was a practical decision—the VA coverage I am eligible for only covers 80 percent of costs with no cap on my out of pocket expenses. That means that in the event of a serious illness, I could go into a great deal of debt. My father had cancer and I need to be prepared. I can barely survive \$7,000 in medical expenses, but I could never survive \$70,000. My entire family is receiving health care through our state exchange. At this point, I don't know how we would manage without it.

If insurers were free to deny me coverage because of my diabetes, it would be personally devastating health care cost would be insurmountable. Additionally, it would mean that I have to close the doors to my business. I'd have to abandon what I've built over the last seven years and find a job that could insure me to pay for my testing strips and other medical needs, which aren't covered by the VA.

I wouldn't be selling this business and reaping enormous profits. I'd be closing it down. Small brokerage firms like mine are virtually unsellable. I've seen others try to transfer their brokerage businesses, and it just doesn't work. Anybody who has been in this business for more than a month knows that it can change faster in a week than other businesses ever will.

And while losing insurance and closing my business would be a serious setback for my family, given the services I provide—insurance brokerage from birth to death at no cost to the vast majority of my clients—the repercussions would be felt by dozens, if not hundreds of families in Central Washington, many of them low-income families with precious few insurance options. In rural areas in particular a repeal will strain the local providers with a possibility of one collapsing.

If sabotage plans are successful, I believe many more people than currently estimated will lose insurance because of their pre-existing conditions. Many new diagnoses have been made as a result of millions of people getting better care. Simply put, the ranks of those with pre-existing conditions is rising and will continue to rise.

Current developments such as the recent lawsuit brought by the states attacking the ACA and supported by the Trump Administration, as well as a new conservative Supreme Court Justice, mean that every measure possible should be taken to ensure millions of people—many small business owners such as myself—aren't needlessly and cruelly thrown off their health insurance plans.

### SPOTLIGHT: Amber Halbert Childress, High Ridge Roofing & Construction Springfield, OR



I needed a life-saving procedure. Had I not been properly insured because of the ACA, I would have most likely lost my business due to liens, medical bankruptcy or continued medical issues hindering my ability to keep a traditional job.

Fulfillment in my career was an intangible dream I never thought I would achieve. For years, I was clocking in and out of a job I didn't enjoy for the sole purpose of providing health benefits for myself and my children, and it was beginning to wear me down and take away the joy in my life. After the Affordable Care Act was signed into law I able to take a chance and become a small business owner without fear of financial ruin due to a medical catastrophe. The security of having medical benefits for my family and me gave me the opportunity to become the business woman I had always dreamed of.

Women entrepreneurs and women entrepreneurs of color are one of the fastest-growing demographics in small business and contribute greatly to our economy. According to the National Association of Women Business Owners, in 2014, 7.8 million firms in American owned by women grew to 9.1 million firms across the country by 2016. Women owned businesses have the buying power of over \$1.5 trillion per year in sales receipts.

Having the ACA has given many small business owners and women entrepreneurs a safety net of financial security to maintain their businesses, pay employees living wages and provide health care to all parties. According to the US Census in 2015 women owned businesses had more than 7.9 million employees and paid \$217 billion in salaries.

If the ACA is repealed, millions of newly insured small business owners, employees and self employed

entrepreneurs could lose their health care. If those businesses fail because of medical bankruptcy, sudden illness and loss of work would make our local economies suffer.

In September of 2016 I needed a life-saving procedure. Had I not been properly insured because of the ACA, I would have most likely lost my business due to liens, medical bankruptcy or continued medical issues hindering my ability to keep a traditional job.

Then, in July of 2018, I almost died from pulmonary embolisms, I had blood clots on both sides of my lungs. Fortunately, I can now afford insurance, and I'm recovering. That said, I'm paying \$1,472/month for my insurance, and last year I paid \$32,000 out of pocket for my premiums and care my family needed which, if we had a universal health care system, is money that could go to train a young adult part time in a much-needed construction trade—something we can't afford to do with these health care bills.

We are the small business that fuels our economy, but not if we can't hire more employees because we're crippled by extreme premium costs

I am so grateful to the elected officials who have fought hard for our basic human right to be healthy, see a doctor, have quality insurance, and live without fear of financial ruin so we can better our communities by stimulating our local economies and achieving our dreams of being small business owners.

### SPOTLIGHT: Kaci Aslamov, Herringbone Books, Redmond, OR

I'm living cancer-free in large part because of the care I received through the Affordable Care Act. My business, an independent bookstore in central Oregon, didn't collapse under the weight of medical expenses thanks to the comprehensive coverage my husband and I have been able to secure on the exchange.

Two years ago, I found a patch of skin that concerned me. After a visit to my primary care physician and then to a specialist, doctors told me they had found basal cell carcinoma, a type of skin cancer. Thankfully, treatment was covered by my insurance and I had the surgery I needed to remove the cancerous cells. It was a harrowing experience, but I survived. I have my health, my business and, importantly, my health insurance, which still covers me in the event any more cancerous skin cells are found.

Should Congress and those trying to undermine the ACA in the courts get their way, people like me will go back to being uninsurable. Imagine being a cancer survivor and not being able to find health insurance. Who would wish that on their worst enemy, let alone subject thousands, perhaps millions, of innocent people to a fate like that?

Needless to say, going without insurance isn't an option for me. And because my husband is selfemployed as well, should protections for cancer survivors like me be stripped away and insurance companies given the go-ahead to deny me coverage because of my health history, I'll have to find another way to get the insurance I can't live without.

In all likelihood, that would mean closing my bookstore and looking for work with health benefits. I'd lose the dream I've worked for, and Redmond would likely lose a local business. It would be one less bookstore for Amazon and Barnes & Noble to help run out of town. And while I'd like to think I'd find a great job here in Redmond, there's no guarantee that I will. I may have to commute thirty miles every day to Bend to find work that could support our family.

We should be coming together to improve the ACA so it works better for small business owners like me, our employees and our neighbors. We shouldn't be trying to kick the legs out from under it. Congress hasn't found a way to repeal the law yet, but they're



My business didn't collapse under the weight of medical expenses thanks to the comprehensive coverage my husband and I have been able to secure on the exchange.

close to successfully using the courts to undermine our fundamental right to basic health care.

Now with Judge Kavanaugh on the Supreme Court, our right to health care may very well be trampled upon in order help insurance companies to maximize profits at the expense of the lives of millions of people like me.

Giving insurance companies such a free hand invites a public health disaster. And given what a central role health care provides in creating a stable economy, it will also likely lead to financial upheaval in communities like Redmond all across the country. It certainly won't help the small business economy my bookstore supports and thrives in. In fact, it will give another leg up to corporations like Amazon and other giant booksellers who use every advantage they already have to knock us little guys out of the market.

It doesn't take much imagination to envision a better way. But at this juncture, what we need is the courage of our representatives to reject those that would choose insurance companies over people. My business, my livelihood and my health depend upon it.

### SPOTLIGHT: Mike Simmons, Fluent Business Solutions, Lancaster, PA

After going through prostate cancer in the mid-2000s, I was declared uninsurable because of my preexisting condition. Since I wasn't able to find coverage in the individual or small group markets, after operating my business for nearly 20 years, I was forced to close. I had to accept a low-level management position, just to obtain group health insurance through my employer.

Once the Affordable Care Act was implemented, I immediately resigned and went back into entrepreneurship with my wife. We haven't looked back. Since then, our business has grown exponentially and our economic security has improved. In additional to ourselves, we've created three quality jobs and are contributing to Lancaster's economy.

However, right now the ACA is under assault, and as a result, my rates have gone up considerably. I am still happy to have insurance, but I have gone from paying \$719 for a gold plan for my wife and me in 2016, to now paying \$1,584 for a bronze plan with a lot more out-of-pocket expenses. That's a 120 percent increase —for a lower quality plan.

This is a direct result of the Republican sabotage of the ACA. The repeal of the individual mandate, the elimination of cost-sharing reduction payments, and the expansion of junk and short-term health plans all contributed to the destabilization of the market. And then President Trump's Department of Justice went to court to get rid of the ACA's protections for people with preexisting conditions, like me. And now, the new Supreme Court vacancy puts the entire ACA at risk. These are insidious attempts to reduce the availability of affordable, quality health insurance.

Simply put, without the ACA, I wouldn't have been able to purchase quality health insurance, and couldn't have went back into entrepreneurship. The Affordable Care Act is vital to my family and our economic future, and the economic future of those who rely on me, including my employees and their families.



I was declared uninsurable because of my preexisting condition. Since I wasn't able to find coverage in the individual or small group markets, after operating my business for nearly 20 years, I was forced to close. Once the Affordable Care Act was implemented, I immediately resigned and went back into entrepreneurship with my wife.

### SPOTLIGHT: Michael Row, Penn Book Center, Philadelphia, PA

When I first set out on an entrepreneurial path I was ill-prepared for the evaporation of financial and health security that would come upon entering the individual insurance market. I wanted to sell books, but instead found myself sunk into the dystopian world of the individual insurance market before the Affordable Care Act, where consumers were forced to commit to a plan without any guarantee that our rates would hold or the coverage would meet our needs.

Back then, insurance companies could require "exclusions" in policies that eliminated coverage for certain health concerns. In my case, all treatments for back issues were excluded because of a back surgery I'd had five years earlier, one they labeled a pre-existing condition and a risk they didn't want to take. Fortunately, I didn't have any major back issues while I was on this threadbare plan. If I had, paying for the treatment I would have needed might have bankrupted us, forced us to close our business and lay off our employees.

When the ACA passed it was a godsend for me and my family. I no longer had to worry that any twinge in my back might lead to financial ruin because I knew I could get the treatment I would have been denied under the old rules. Instead of yearly premium increases, our rates went were slashed. In the first year after the ACA came into effect, our premiums were cut in half, going from \$2,000 to \$1,000 per month. Under our new plan, coverage for the care we needed was expanded. We no longer had to forgo testing and other preventative care that was previously out of reach because of the high out-of-pocket expenses we paid with our old bare-bones plan.

The ACA meant savings for our household and a higher quality of life, but it also meant putting our family's business on more solid footing. The quality insurance we now had under the ACA eliminated the risk that an unexpected medical situation would turn into a financial catastrophe and threaten our ability to keep our doors open. It's removed a serious source of insecurity and allowed us to focus on growing our business.

And because the ACA has allowed our employees access to quality insurance we can't afford to provide at our size, it's helped us attract and retain the



# All treatments for back issues were excluded because of a back surgery I had five years earlier, one they labeled a pre-existing condition and a risk they didn't want to take.

talented team that powers our business. In doing so it's helped level the playing field for us as we strive to make sure that independent bookstores can thrive and support our neighbors in the era of online book giants that answer to shareholders not communities.

The full frontal attack on the ACA portends not only a disaster for public health, but a cynical undermining of small businesses, the people who run them and those that are employed by them. Across the country, thousands of shops like mine will close because some want insurance companies to be able to pick and choose who deserves coverage for what.

Judge Kavanaugh's confirmation was not an intellectual endeavor, and it wasn't a victory for conservatism. It's very likely the onset of the dismantling of a basic pillar of society and our economy and the undermining of our basic right to health care. For millions of people like me with what insurance companies call pre-existing conditions, it's a return to the dystopia of life without the protection of affordable, quality health care.

Michael Row is co-owner with his wife, Ashley Montague, of Penn Book Center in Philadelphia, PA, an independent bookseller established in 1962. Michael and Ashley bought the business from its founders in 2005. Main Street business owners have a big stake in protecting and expanding health care for every person in the United States. They have a personal stake in knowing their health, as well as their freedom and success as businesspeople, will not be impeded by the high cost of care or insurance company discrimination against people with pre-existing conditions.

They have a stake in terms of their business bottom line. They believe the small business sector is best served by a health care system that levels the playing field between large and small employers and takes health care costs out of the competitive equation.

Finally, Main Street business owners have a stake as participants in local economies and communities. They know their prosperity depends on the wellbeing of their neighbors and people of all races and backgrounds across the country.

