

Statement of Vernal Branch
Steering and Policy Committee Hearing
January 18, 2011

I would first like to thank Chairman Miller, Chairwoman DeLauro, Leader Pelosi, Democratic Leadership and Committee Members for this opportunity to share my story. My name is Vernal Branch and I'm proud to say I'm a 15-year breast cancer survivor.

I was diagnosed in 1995 and was fortunate to have good health insurance coverage through my husband's employer. That same year I underwent a mastectomy and began Tamoxifen. Shortly after treatment, I began my work as an advocate for the National Breast Cancer Coalition and for health care reform.

Since 1995, I have been without a reoccurrence of the disease.

That sounds like a great story, doesn't it? A story with the best outcome you could hope to hear when learning a family member or friend is faced with breast cancer. Well, as with most aspects of life, it was not that simple.

In 2000, my husband, Calvin, lost his job and, in turn, health insurance coverage for our family. He decided to open his own consulting business and elected to continue health coverage through COBRA. We remained covered for 18 months, the maximum time allowed for this type of insurance. Calvin and I then began shopping around for a new insurance plan. Once we found one that seemed to be a good fit, we applied. Calvin and my only son of three, still at home at the time, were approved and covered immediately. Coverage for me, on the other hand, was delayed. I was then asked to submit my health records. I supplied the information, but did not hear back for two months. I tried to find out what the hold-up was, but did not get a straight answer. A total of four months went by until I found out definitively -- I was denied insurance.

When I asked the insurance representative point-blank if I was denied coverage due to my breast cancer diagnosis years ago, I was met with heavy silence. The best they could offer me was a recommendation to find an employer who would offer me health coverage.

I lived without insurance for three years. During that time, I broke my foot twice and had to visit the emergency room each time. Any time I had a cold, or needed treatment for a common ailment, I had to visit a walk-in clinic. All of these expenses had to be paid for out-of-pocket. At one point, while uninsured, I had a screening mammogram. The technician found a suspicious mass and recommended a biopsy to be sure cancer had not returned. The mass thankfully turned out to be scar tissue, but the fact remained, I had to pay full price, out-of-pocket, for this costly screening and surgery - which turned out to be a false alarm. I wish I could explain to you what it is like to live every day with the knowledge that your breast cancer could come back. And to couple that fear with the reality of being uninsured is devastating.

After three years without coverage, my family and I moved from California to Virginia. We wanted to start over and look for new opportunities near where my husband Calvin and I both grew up and had family support. Calvin and I were then able to find work and health coverage through his employer. But, for three years, I never knew if there would be a reoccurrence and I would not be able to afford the care I needed. I lived in fear that if cancer returned I would not have insurance to help pay for treatment to enable me to

beat the disease again and continue living as the healthy breast cancer survivor I have been for the past 15 years.

For years as a Field Coordinator, Team Leader and advocate for the National Breast Cancer Coalition I fought for health care reform and last year, I proudly celebrated the passage of the Patient Protection and Affordable Care Act. For me, this law represents protection from the uncertainty and fear that came with being denied health insurance coverage because of my past disease. It represents freedom for my husband and me to make important choices about our lives and careers without the specter of a preexisting condition hanging over our heads. And, it means that no other breast cancer survivor will be forced to walk in my shoes. Removing these protections would bring a halt to this progress, and mean a huge step backwards for us all.

Testimony of Lori Bresnan
Steering and Policy Committee Hearing
January 18, 2011

I want to thank Chairman Miller, Chairwoman DeLauro, Leader Pelosi, Democratic Leadership and Committee Members for this opportunity to testify. My name is Lori Bresnan and I am here today from St. Louis, Missouri.

My 22 year old son is a full time college student, works part time and is also a Celiac patient with extensive food allergies that often come with Celiac disease. His condition requires periodic testing and leaves him vulnerable to more serious complications and conditions.

Prior to new consumer protections, he could not have stayed on our family's health insurance past this coming June, when he turns 23. We were quite concerned about the options that we had at that time which were for him to go uninsured, hoping for the best, or to pay huge insurance premiums, if he were able to find coverage at all.

We now have the right to keep him on our insurance until age 26, giving him time to finish college and get a full-time job. This law also assures that when that time comes, he will have insurance options available to him, even with his preexisting condition.

Repealing important new consumer rights means not only that my son won't be allowed to stay on our insurance policy until age 26 but that he won't see the day when pre-existing conditions don't dictate your ability to get health insurance and insurers can't charge you astronomical prices for health conditions you have no control over.

Many students find themselves in this exact position. Well-educated youth often have not completed their education by age 23. This legislation is very helpful to support building our country's intellectual capital necessary to move us forward in the global economy.

Allowing us to keep him on our insurance until 26 came at the perfect time. By 26 we hope he will have graduated and has a job. We are thrilled we have the option to keep him on our insurance in this interim when families so often struggle to keep their kids covered or are left worrying about the health of an uninsured child.

Thank you.

Testimony of Edward Burke
Democratic Steering and Policy Committee Hearing
January 18, 2011

Good Afternoon, my name is Edward Burke, and I am a 52 year old factor VIII severe hemophiliac. Hemophilia is a bleeding disorder that can be inherited or from spontaneous gene mutation.

I would first like to thank the Democratic Steering and Policy Committee, in particular Chairman Miller, Chairwoman DeLauro, Leader Pelosi, Democratic Leadership and Committee Members, as well as Families USA and the National Hemophilia Association for the tremendous work that they do bringing stories such as mine to light. I am grateful for this opportunity to share with you some real facts about the efforts to repeal the efforts to take away my protections and freedoms.

Let me emphasize this point. I oppose the patient's rights repeal legislation being considered in the House of Representatives this week. Simply put, I will lose the freedom to keep my job if efforts to repeal my protections are successful.

I grew up in the suburbs of Philadelphia, PA with an older and a younger brother who both also had hemophilia. In the 1960's when we were boys the only treatment for an internal bleeding episode was an infusion, accompanied by a few nights stay in the hospital. When the medical bills arrived, the folks at Blue Cross and Blue Shield would routinely inform my parents that my brothers and I have a pre-existing condition and therefore the insurer would not cover any medical costs. This denial seems audacious given that both my parents worked full time jobs specifically to receive ample income and adequate health benefits for their children. Even as my parents paid their monthly premiums for a family of five, the insurance company kept their money without providing any assistance with the mounting medical bills. To me, and the millions of Americans with a chronic disease, this was blatant discrimination. But our new protections ended this practice – protecting individuals with pre-existing conditions and providing families with the security they deserve.

There are approximately 125 million individuals in the United States who have a chronic disease, disability, or functional limitation –these Americans account for three quarters of the nation's health spending. Nearly all Medicare spending and more than 80 percent of Medicaid spending is attributable to chronic disease.

I bring those statistics to your attention for the following reasons. In the mid 1970's a medical breakthrough in hemophilia treatment was discovered.

Hemophiliacs, such as myself, could receive an infusion of the very protein our bodies do not make, and we could control our bleeding episodes. Unfortunately, this new medicine was, and still is, very expensive. For me at 6'4" and 250 lbs, I

infuse 3000 units three times a week at approximately a \$1.00 per unit. That is \$18,000 per week. So just the factor I need costs me one million dollars annually. This has been highly problematic due to health insurance industry's creation of lifetime caps.

On average most Americans through their employer have had a two million dollar cap on insurance claims, and a healthy American with no chronic disease would have been able to get by for a longtime without reaching this cap. But for someone like me, this can be devastating. Once you had reached your lifetime cap you would be forced to pay the rest of your health care out-of-pocket, or to change jobs, sometimes even careers in order to have health benefits and a new cap. In the end lifetime caps forced you to make tough, life-altering decisions for you and your family – often forcing the individual on to a Federal or State insurance program that other tax payers pay for. However, our new patients' rights prohibit insurance companies from having such caps, and even removed annual limits so that any insured American can receive all of the care they need without fear – leaving them to focus instead on living as healthy and full a life as possible.

When elected officials are voting to repeal patients' rights legislation, they are, in reality, forcing Americans like myself, a working, tax paying citizen, back into a world where health insurance coverage is constantly an issue and life saving care is often out of reach – just so the health insurance industry can continue its multi-million dollar for profit industry. That my fellow Americans is really what is about to occur here in the halls of Congress.

I stand here and ask our Representatives to not play politics with our lives. Oppose the patients' rights repeal legislation!

Thank you for this opportunity, and God Bless this wonderful country I love.

Edward M. Burke

Testimony of Dr. Odette Cohen, Son Light Pediatrics and New Jersey Main Street Alliance, before the Democratic Steering and Policy Committee – January 18, 2011

Good afternoon. My name is Odette Cohen. I am the owner of Son Light Pediatrics in Willingboro, New Jersey and a member of the New Jersey Main Street Alliance.

I want to thank Chairman Miller, Chairwoman DeLauro, Leader Pelosi, and the members of the Steering and Policy Committee for inviting me to testify today.

Small businesses are the backbone of our economy. In New Jersey, we account for 98.5 percent of the state's employers, and another 590,000 New Jersey residents are self-employed. On behalf of New Jersey's small businesses, I want to thank you for the work you've done to enact legislation to make health care work better for us.

As a small business owner, I oppose efforts to roll back the protections and benefits of the health care law. Both my business and my patients stand to lose important benefits if the law is repealed or watered down.

Experience with Health Care

When I began my medical practice 21 years ago, I couldn't afford to offer health coverage to my employees. As a result, I couldn't compete for the most qualified applicants, and lost many to larger businesses that offered better benefits.

Now that I do offer health insurance, I dread renewal time every year. In 2009, my premium increased 33 percent. This past year I was quoted a 50 percent increase – 50 percent! I had to switch to an inferior plan with a much higher copayment.

Waiting for that renewal quote every year, it feels like you're on a ship that's sinking. Well, that's where the new health law comes in - throwing a lifeline to small businesses like mine by protecting us from unreasonable rate hikes.

Small Business Tax Credits

My business is one of an estimated 144,000 businesses in New Jersey that could benefit from the new health care tax credits. The money I'll receive in the credit this year will allow me the flexibility to relieve employees of their portion of rate increases and provide coverage for an additional employee.

As these credits and other incentives expand over the next four years, I look forward to hiring another provider and support staff. Repealing these credits would prevent me from expanding my practice and creating jobs in my community.

State Insurance Exchanges

I am also looking forward to the new state insurance exchange set to be up and running by 2014. Through the exchange, my business will be able to pool together with thousands of other small businesses across the state to access higher quality coverage at a lower cost, finally putting us on a level playing field with the insurance companies. A vote to scrap these exchanges is a vote endorsing the discrimination and lack of bargaining power small businesses face in today's insurance markets.

Value for Premiums and Minimum Medical Loss Ratios

As a physician, I am keenly aware that health care consumers aren't getting fair value for their premium dollars. Insurers use premiums to pay for many things that are not health care – things like executive bonuses, lobbying activities, and expensive political advertising. But now, thanks to the health law, small businesses and other consumers can count on having a basic level of value for our premium dollars. And if insurance companies don't meet the minimum standard, we'll get a rebate starting next year. I say it's about time!

Consumer Protections

Small business owners and our employees should have the right to the same protections as everyone else. But that's not how things worked before the new law was passed – I know this from personal experience.

In 2008, two of my first cousins were diagnosed with cancer at approximately the same time. The first, a young woman of 25, worked for a large company and had access to good coverage through her job. Today, she's alive and doing well.

My other cousin worked for a small family business that simply couldn't afford health insurance. Uninsured, he didn't seek the care he needed early on. When his pain became unbearable, he went to the ER where he was diagnosed with end stage metastatic cancer. He died two months later at 35 years old.

The choice to work for a small business versus a large company should not be a life or death decision here in America – but it was for my cousin. The new health care law changes that, giving small businesses and our employees the basic security and protections we deserve.

Conclusion

These lifelines – the new tax credits, stronger rate review, new consumer protections, and the insurance exchanges – these all help give small businesses a fighting chance to access quality, affordable health care.

As a small business owner and a physician, I believe we must continue to advance policies aimed at providing quality health care for everyone, at putting health care decisions back into the hands of physicians and their patients, and at rewarding quality care.

We must not step back into the broken health system of the past. I urge you to stand with us, Main Street's small businesses, and oppose any effort to roll back the benefits of the new health care law. Thank you.

Written Testimony of Alexander Lataille

January 18, 2011

Chairman Miller, Chairwoman DeLauro, Leader Pelosi, Democratic Leadership and Committee Members: thank you for having me here today. My name is Alexander Lataille. This past May I graduated from Lyndon State College with two Bachelor degrees, one in Atmospheric Science, the second in Social Science. Even before graduating I was looking for a job but as you can imagine the economy has made it harder for companies to hire new people. However, by graduation day I had believed that I had secured a great prospect working with a private company contracted with the Federal Aviation Administration. Nevertheless due to budget issues, timing, and other factors out of my control the date for employment has been progressively pushed back. Although I could likely find a temporary job, I chose instead to go back to work for a professor at the University of Rhode Island that I've previously interned with. Much of his own funding has been lost and he is no longer able to pay me as he had in the past so I am unpaid. I am currently volunteering there as a Research Assistant working with weather balloons, ozone monitoring, and data processing- honing skills and gaining experience that will be expand my career opportunities as a Atmospheric Scientist. The research assistant position, like many such jobs, does not offer health care benefits, but under the new law I was able to stay covered by going back on my mother's plan after graduation.

In my current situation, if I lost my protections under the law I would be faced with a choice, either pay my student loans or get health insurance. Actually, the truth is that I would have little choice in the matter; I would need to pay down my loans first and go uninsured. Yet I know how important having health insurance is, even for a healthy young person like myself. If perhaps I get cancer, or get hurt in a car accident, what happens to me? My parents can't afford to bankroll such catastrophic health care costs. I could decide to get a temporary job and use that income to buy private health insurance. But to do this I would have to leave my position at the University, where I am currently gaining a wealth of experience, education, and career mobility. No doubt many future job opportunities will arise because of my experience interning right now. If I were not able to stay on my parent's plan, I would need to make a sacrifice, either my career future or my health. That's a choice no one should have to make. With this new law, I can stay on my parents' insurance plan up to 26, and feel safe as I navigate my career choices and this economy.

Again, thank you for your time, and this opportunity to speak on behalf of young Americans. While my political views on different issues often fall across a wide range on the political spectrum, this issue isn't partisan to me. I believe that allowing young people to stay on their parent's insurance gives us

a new and real freedom to work toward a career goal without going uncovered. I want to also say thank you to Young Invincibles for giving me this chance to stand up for something I believe in and make my voice, and the voices of other young Americans, heard on this critical issue.

Testimony of Stacie Ritter
Democratic Steering and Policy Committee
January 18, 2011

I want to thank Chairman Miller, Chairwoman DeLauro, Leader Pelosi, the Democratic Leadership and Committee Members for this opportunity to testify about how important the our new health care rights and freedoms are to me, my husband Ben, and our family.

Our twin daughters Hannah and Madeline are childhood cancer survivors. At the age of 4 they were diagnosed with leukemia. Long and difficult treatments, including stem cell transplants, saved their lives, but at great cost to our family. My husband had good insurance at work but had to take family leave to care for our family. The premiums and co-pays under COBRA were so high we wound up with \$30,000 in medical debt, which forced us to file for bankruptcy in 2003.

Madeline and Hannah survived, but the glands controlling their growth were damaged by the treatment. Their doctor, the author of a textbook in pediatrics and one of the leading pediatric endocrinologists in the country, recommended that the twins receive daily growth-hormone injections. But my husband's company had switched to CIGNA for health insurance, and CIGNA refused to cover the hormone shots, calling them experimental. We were lucky that Eli Lilly was willing to give us their growth hormone drug free. CIGNA only relented after when I became a involved in the fight for health care reform and spoke publicly about their failure to provide the care my kids needed. So now we are paying CIGNA \$140 for a 3 month supply of the medication.

In the fall of 2008, I read part of Barack Obama's health care proposal to my then ten year old daughters, especially the part about cancer patients and research. One began to cry and said, "Mom, Barak Obama really understands. He is really going to help us".

Our new health care rights and freedoms really address what people like us need. Our lives would have been much easier had we had them when my kids first became sick.

If we had these protections when my husband took family leave, we would have been able to buy affordable insurance through an Insurance Exchange. Had these protections been in effect when CIGNA denied Madeline and Hannah human growth hormone, we would have been able to appeal that decision. And, most likely, we would have won that appeal.

These rights and protections came too late to help us deal with those problems. But we're grateful to know that other families won't suffer as we did when Hannah and Madeline got sick.

But there are other rights and protections that will help our girls in the future. And it is now critical that we work against efforts to them.

Clinical trials are a cornerstone of cancer research and they often are important for people who have to deal with a recurrence of cancer. We hope Congress will oppose efforts to repeal prohibitions against insurance companies limiting or denying coverage to individuals participating in clinical trials.

One of our biggest fears for our children has been that they would not be able to receive affordable insurance or find insurance that covers pre-existing conditions. We must ensure that Hannah and Madeline, and millions of survivors of cancer and other diseases, do not lose their rights to this critical protection and the freedom it provides.

Early detection and treatment is vital to recovery from childhood cancers and other diseases. And it is also important for children who have suffered from cancer. Hannah and Madeline, and millions of children like them, will always need access to regular checkups and preventative care to catch any recurrence early. Until now it has cost us over \$500 in co-pays for annual cancer survivorship follow ups. We must all oppose efforts to repeal a law that requires health insurance plans to provide these services without copayments, deductibles, or coinsurance.

Cancer treatment is very expensive. Today cancer survivors can reach an annual cap on benefits before they leave the hospital. The elimination of annual and lifetime caps on insurance coverage is a protection against one very common road to bankruptcy. Taking away this protection means so many will struggle as we did.

As we look to the future, our new rights and protections give us the assurance that neither their history as cancer survivors nor any possible financial problems they have in the future will keep Hannah and Madeline from having good health insurance. I can't begin to tell you what that means to a mother who has seen her children fight to survive a deadly disease.

I remain convinced that if Americans could just hear my story and understand why these rights and protections are so important to millions of their fellow citizens, they would oppose patients' rights repeal legislation. My children now have protections from insurance discrimination based on their pre-existing cancer condition. They will never have to fear the rescission of their insurance policy if they get sick. They can look forward to lower health insurance costs and preventative care. No one who understands how important these and other provisions are to so many of us could endorse legislation that repeals these important patients' rights.

So I'm proud to be here to once again tell our story. It is important that more become people aware of how critical these new rights and protections are to so many of us. And I would like to thank all of you who helped protect my children from predatory insurance practices and who fought for this legislation in order to secure their future health.

Nothing is more important in the promotion of strong family values, than the protection of the health of our children.

Thank you.

Statement of Claudette Therriault
Steering and Policy Committee Meeting
January 18, 2011

Thank you Chairman Miller, Chairwoman DeLauro, Leader Pelosi and Committee Members for this opportunity to testify. My name is Claudette Therriault and I'm from Sabattus, Maine.

My husband Richard and I are now both on Medicare. A major new protection for seniors just started this month. Medicare now pays for preventive services with no out-of-pocket cost to us. We made a decision last year to put off preventive care, waiting until this year to make appointments for my mammogram and both of our colonoscopies. The last time Richard had an endoscopy and I had a mammogram, we were left with co-pays we could not afford. I was diagnosed with pre-cancerous cells in my breasts and must have a mammogram yearly. I've also had polyps in the past and need to have a colonoscopy every 3 years. It's been five years.

Richard takes a number of brand-name medications for diabetes, chronic pain and gastric problems. He enrolled in Medicare in May 2010 and in June he was already in the doughnut hole. His insulin alone was \$993 for a 25 day supply. After three months paying 100 percent of his bills, he reached the maximum and the plan started paying 95 percent of his costs. But by then we'd spent \$4,550 out-of-pocket.

We didn't foresee this and it was devastating. That money was equal to 4 house payments. We had to choose between defaulting on our loan or my husband's health! Fortunately, a local charity loaned us money and I'm now volunteering for them in order to repay the loan.

But changes made are starting to end the donut hole so families like ours aren't forced to choose between staying healthy and paying the mortgage. This year seniors can get a 50% reduction on the cost of name brand drugs in the donut hole. This assistance could have saved us thousands last year alone.

In the past week, I've heard from other seniors in our community. Don, who finally retired last year and in the fall, he hit the donut hole. Now, he works two jobs so he can afford his medications. Larry and Rita are retiring at the end of this year. Both are ill, one with cancer and the other with rheumatoid arthritis. They are counting on the donut hole closing so they can survive. Pauline, who is 61, had never heard of the Donut Hole. She and her husband expect to retire in 4 years. As I explained it to her, I saw the disappointment in her face. Her remark was "If this is repealed, we can't retire." I posted on Facebook that I was going to DC to speak against the repeal of these new consumer protections. The response and support from my Facebook friends was tremendous! Jeannine, a former high school classmate is 66 and has spent her life as a single woman

caring for special needs foster children and adopted most of them. She still has a young child at home. Early last year, she lost her family home to foreclosure and is now struggling to continue working to support her child and pay for her donut hole expenses and is looking forward to preventive care at no charge. She too has been putting off preventive care.

These are our stories and the stories of countless others who will need to choose between the medical care they need or keeping a roof over their heads if these new life saving protections are repealed.