

Good morning. My name is Becky Strong, and I have pemphigus vulgaris, a rare autoimmune blistering skin disease. I've been asked to share what it's like to have a rare skin disease. I will start by asking everybody here to participate in an exercise.

Close your eyes and imagine you were the one who went to the doctor because you couldn't swallow due to the fast-growing blisters in your mouth. You can't sleep due to the weird water blisters and open areas rapidly appearing on your skin. You can't eat - even something like a cup of chicken noodle soup feels like you are chewing shards of glass. You can't shower because the water removes skin from your body, and you can't lie down or sleep due to the grueling pain. Imagine sitting on wax paper so you don't stick to your furniture. Many in our community have open blisters on the face, arms, feet, and legs, which cause people to move their children away from you when in the grocery store and cause you to be the object of glaring eyes everywhere you go.

You've been to multiple appointments with 5,6, or even ten or more specialists and still can't find a diagnosis. You are in pain and exhausted, and you fight the healthcare system and insurance company like it's your full-time job. This is what it is like to be diagnosed with a rare skin disease.

At this point in the journey, fighting for most of us with a rare skin disease starts to ramp up.

Within minutes of learning you have pemphi-*WHAT??* The doctor explains that although pemphigus is a rare skin disease with many forms, there is only 1 FDA-approved treatment for moderate to severe pemphigus vulgaris. It's crazy expensive, and the FDA-approved protocol suggests 4 infusions over a year. So, knowing your insurance will probably fight this, your doctor starts telling you he will put you on high-dose steroids. You'll need a bone density scan because you're going to be on such a high dose of prednisone. Then the doctor says, when you pick up your script, pick up calcium and vitamin D. While you'll lose bone density, it will help to slow down the amount you lose. You also go on immunosuppressive medications, usually reserved for solid organ transplants. These are serious medications, and you go for bloodwork weekly for a month or so to ensure you don't completely wipe out your immune system. Side effects are discussed, and you're told you're increasing your risk for lymphoma, osteoporosis, and even death by taking these medications. There are other treatments, but insurance will most likely approve this first. If it doesn't work, there are a couple of other medications to try, but you may need IVIg, which is also very expensive, and then there's this medication that is FDA-approved for another disease, but it's showing promise to treat this too. You'll probably have to get a 2nd mortgage to afford it, but it's showing patients can achieve remission from this. And then the doctor asks, "Is this what you want to do?"

Knowing you can't continue to live like this, you agree. You pray that the medication works and you don't wipe out your immune system, beg for the pain to stop and your skin not to come off, and hope for remission. And this is what it's like to live with a rare skin disease.

So, how does this change? This is where you come in!

Our doctors and specialists often want to put us on a particular medication, but insurance won't approve it. This causes patients undue pain, suffering, embarrassment, and other physical and mental side effects due to delays in treatment. These medications can take weeks to months to work, significantly delaying access to proper treatment that will allow healing.

Lots of us with skin disease have multiple rounds of incorrect treatments and procedures even to get a diagnosis. Multiple prescriptions, lab tests, and medical monitoring may be required to get a condition to a bearable place, and more medicines may be needed to deal with the side effects of our treatment. All this is a tremendous physical, mental and financial burden on a patient like me.

Then, we must discuss the differences between private and governmental healthcare programs, with multiple parts covering doctors, specialists, and prescriptions. The best-case scenario is confusion. For example, many people know the first four parts of Medicare. Medicare Part A covers inpatient care, lab tests, surgery, and home healthcare. Part B covers doctors and healthcare providers, outpatient care, durable medical equipment, home health care, and infusions and preventative services. Part C is a Medicare advantage that combines part A&B and provides additional prescription drug coverage, dental, vision, and hearing services, while part D is for drug coverage. But many of us need to learn what Parts E, F, G cover. Coverage isn't the same from plan to plan, and it can be difficult to determine the best plan for you. Skin diseases don't know they need to be diagnosed in late September to apply during the enrollment period for the appropriate plan for necessary treatments and medications, which can leave skin patients without the right kind of insurance plan or necessary parts to be covered for our condition. It's also crucial to mention that the most affordable plans have the highest deductibles.

Imagine being in good health, and you thought you had some bug bites in October. Then, after enrollment closed, you discovered that you had a rare autoimmune blistering disease that required rituximab and IVIG infusions. How quickly could this bankrupt a family when Rituximab averagely costs \$50 - 60,000 and IVIG \$120,000 per infusion without the right insurance coverage?

Even with insurance, our office co-pays, deductibles, and out-of-pocket limits can be extraordinary. Drugs are traded like commodities now; everybody wants to make a profit. The prices of something like clobetasol went from \$25 in 2010 to over \$150 co-pay without any new research being done.

Many health plans require step therapy before another medication can be tried. With Pemphigus, my insurance wanted me to try an immunosuppressant that required a certain enzyme for metabolism. My level was borderline, and within three days of taking this medication, I developed permanent liver damage and must see a liver specialist for the rest of my life. Then, I was able to be switched to another medication, which put me into remission.

The Safe Step Act helps to ensure patients can get the medications their doctors want them to have when they want them to have it. This bill requires health plans to establish an exception to medication step-therapy protocols in specific cases. A request for such an exception to the protocol must be granted if (1) an otherwise required treatment has been ineffective, (2) such treatment is expected to be ineffective and delaying effective treatment would lead to irreversible consequences, (3) such treatment will cause or is likely to cause an adverse reaction to the individual, (4) such treatment is expected to prevent the individual from performing daily activities or occupational responsibilities, (5) the individual is stable based on the prescription drugs already selected, or (6) there are other circumstances as determined by the Employee Benefits Security Administration.

The bill requires a group health plan to implement and make a clear process available for patients like me to request an exception to the protocol, including required information and criteria for granting an exception. The bill further specifies timelines under which plans must respond to such requests.

Doctors should be able to prescribe a treatment. A patient should be able to afford and get the prescription their doctors want them to have, and it should not depend on the size of their pocketbook. Together, our voice on the Hill will impact everyone in this room and this country. Let me remind you that you have the ability to make a difference for people like me.