

My name is Rebecca Wood. Most people on Capitol Hill know me as “Charlie’s Mom”. Charlie and I are grateful to appear before the committee at the Pathways to Universal Coverage hearing and provide an oral statement. In my five minute oral statement, I try to give a brief summary of the last seven years of my life:

This is my daughter, Charlie. She loves the color pink, princesses, bubbles, the outdoors, the band Dispatch, and Speaker Pelosi.

Charlie is the reason I joined the healthcare fight in January of 2017. Prior to that, I had never been to Capitol Hill nor had an interest in politics. But, after all we had been through, I was not going to let bad policy steal her chance at a typical and independent adulthood.

Her story begins in May of 2012. Due to severe preeclampsia, she was delivered via emergency c section ten hours into her twenty sixth week of gestation. She weighed one pound twelve ounces and was the size of my hand.

My NICU bedside vigil began because I did not want her to die alone. It’s the bravest I’ve ever been.

When Charlie was three months old, she was well enough to come home. Issues from her premature birth appeared one after another. Each one required treatments and therapies.

Her birth is a preexisting condition and she would have exceeded a lifetime cap before she came home for the first time. Even with private insurance through my husband’s employer, she relied on a medicaid waiver for much of her care.

There were specialists, medications, injections, physical therapists, occupational therapists, speech therapists, specialty formula, formula thickeners, orthotics, eye glasses, therapeutic equipment, attendant care, and, later, a feeding tube. Charlie was in diapers years longer than most kids and needed adaptive cups, silverware, and plates. The costs added up quickly.

Co pays, deductibles, automatic denials, and exclusions drained our savings and financially devastated us over time. In addition, I had to, and have to, make impossible choices.

Do I pay for her therapy or my overpriced asthma medication? Choices like these really aren’t impossible. I choose to pay for hers and go without mine.

One day, I needed an expensive dental procedure. Unfortunately, it was at the same time a therapy payment was due. Charlie’s speech was emerging. I was afraid we would miss a window of opportunity in her development if we cut her therapy. I chose to make her therapy payment and put off my dental procedure. The decision cost me dearly.

Due to the delay, an infection spread throughout my mouth and jaw. I went to the emergency department because the swelling in my mouth obstructed my airway. After a course of IV antibiotics, I was discharged. The next day, I had all of my teeth pulled, the infection drained, and parts of my jaw scraped away in a six hour procedure under local anesthesia. I could not afford to have it done under general anesthesia. I sobbed the entire ride home afterwards.

I don't know what the worst part is. The excruciating pain I live with every day, how I worry whether I'm drooling when I smile, how eating is awkward and challenging, or how I love jazz but will never play the trumpet again.

Currently, I can only afford to seek medical care when I happen to be volunteering at a free clinic or when I'm afraid an ailment will kill me. Forget wellness, self care, or preventative care -- I'm simply trying not to die.

While I juggle needs and problem solve, Charlie did and does her part too. She survived a brutal beginning in which every breath was strenuous and touch was agony. She willed uncooperative muscles to move, pushed her sensory threshold to the limit, gagged down food in feeding therapy, endured countless therapy sessions, and visited a multitude of doctors.

Charlie never quit.

At the age of one, she was able to sit independently. At twenty months, with the assistance of orthotics, she took her first steps. Last September, she learned to eat and her feeding tube was removed. Currently, she is hard at work on speech and fine motor issues.

Charlie celebrated her 7th birthday last month.

Today, when people see Charlie, they call her a miracle. They say she is amazing. Or, they tell me we are blessed.

But, there is nothing special about Charlie. She is merely an example of what is possible when kids get the healthcare they need.

I'm lucky she survived. I'm fortunate she thrived. But, it shouldn't have cost me nearly everything.

Her name is Charlie. I joined the ACA and Medicaid fights for her. However, I joined the Medicare For All fight for me. I have to believe all of this happened for a reason.

But my brief oral remarks are an oversimplification of our story. Five minutes is simply not enough time to convey the full health care nightmare we endured over the last seven years.

First, I left out how crucial services like Early Intervention (EI) vary across geographic regions and it costs patients in poorer areas more. For example, the EI program in northern Virginia had a dietitian on staff. Therefore, the out of pocket cost to parents for services was minimal.

A year after Charlie's birth, we moved from northern Virginia to northwestern Virginia. There, EI had one occupational therapist covering five counties and no dietitian. The cost for the dietitian services that Charlie needed had to come entirely out of pocket. Additionally, services available to children in those counties were restricted due to limited resources. As a result, many families had to go without the services that would have helped their child develop.

Second, I lacked the time to dive into automatic denials with my oral statement. I still haven't figured out why I have to fight private insurers constantly for the coverage I pay for with rising premiums.

In one example, Charlie's formula, which at the time was over 80% of her nutritional intake, was a nightmare to get covered. Coverage for the formula was initially denied. When I called to contest the denial, the private insurer misdirected me multiple times. I was told it was covered under her drug policy. Later, I was told it was covered by her secondary insurance. This was also incorrect.

Through my own research, I discovered there was coverage for medical food (what formula is called when children are no longer infants) provided under the Durable Medical Equipment portion of my child's private insurer's policy. Either private coverage is so confusing that insurers don't understand their own policies or they are knowingly being disingenuous and misleading. Regardless of the answer, it is highly disturbing and put Charlie's health at risk.

I pointed out to the private insurer that there was coverage provided for the formula under the DME portion of their plan. In response, the insurer asked for a letter of Medical Necessity from the prescribing doctor. The doctor provided one. Yet, coverage was denied again.

I inquired why it was denied. The private insurer said the letter was insufficient but would not disclose the details that needed to be included in the letter. In response, the doctor provided yet a second letter of Medical Necessity. But, coverage for the formula was denied again. Finally, the doctor provided a third letter. Here is that letter:

Date: July 15, 2014

TO: Anthem

From: Dr. Stephen Borowitz

RE: Request for coverage /reimbursement for Peptamen Junior with fiber as a medical necessity.

I am requesting insurance coverage and reimbursement on behalf of my patient, Charlie Allene Wood, DOB 05/29/2012. I have prescribed Peptamen Junior with fiber oral formula, Manufactured by Nestle HealthCare Nutrition Inc, for the dietary management of Failure to Thrive, placing her in the 5th percentile of her age group. Charlie also has delayed gastric emptying, swallowing /mastication problems, oral motor dysfunction, cerebral palsy, and is developmentally delayed.

After an evaluation by our speech pathologist in on June 5th, 2014 it was determined that Charlie takes majority of her calories by bottle or cup with minimal solid food intake. She shows no complete aversion or strong refusal of foods but takes only a few bites of foods offered. Charlie shows frequent food holding of un-masticated food. A previous trial of limited liquid intake to encourage solid food intake was not successful as Charlie lost weight. In this evaluation, Charlie showed only tongue mastication, without any true "munching or chewing" of solids suggesting that she may not be able to comfortably handle higher textured solids yet.

Charlie is doing well maintaining her weight and progressing slow and steady up the growth curve consuming her Peptamen Junior with fiber orally. If oral supplements fail than a tube may need to be placed. But at this time, I see no need to put her through a surgical procedure to place a G tube for supplemental feeds. If the G tube is contraindicated, then TPN would need to be considered, since she would not be getting any nutritional support by mouth or tube feedings.

Per my order our registered dietitian evaluated Charlie's diet history. At the present time only about 20% of Charlie's diet comes from solid food.

Peptamen Junior with Fiber formula is a nutritionally complete elemental formula with the nutritional support that Charlie needs. It is intended for the nutritional management of those patients with impaired GI function and or a requirement for early enteral feeding to maintain a healthy weight as a child grows and develops. It can be given as an oral supplement since as demonstrated during her speech/feeding assessment Charlie does not require tube feedings.

My hope is that you would consider covering the monthly cost of the Peptimen Jr with fiber. Since liquid formula provides 80% of her nutrition, her growth will certainly be affected if she is unable to receive it on monthly basis.

I have included additional medical information that might be needed for your evaluation for medical necessity to provide formula to be taken orally.

Thank you for taking the time to review this request. Please contact me should you require any additional information.

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After the third letter was submitted, coverage was finally approved. The process took two months. In the meantime, because my child had to eat, I had to find a way to get Charlie her formula that cost \$28 a day. Furthermore, the automatic denial cost the provider time that could be better spent providing care to patients.

Third, my oral statement leaves out how underfunded the Medicaid Waiver system is in Virginia (where we lived up until a month ago). When we applied, there was a ten year waiting list for the waiver Charlie qualified for. But, because we needed services immediately, she received a different waiver that provided lesser coverage.

In later years, the waiting list was changed to a priority based method. Charlie would never receive the waiver (and services) she qualified for because she was not considered high priority on the waiting list. Not having the correct waiver directly contributed to the financial burden on my family brought on by the healthcare system.

Fourth, my oral statement fails to mention how, in desperation, I drove all over Virginia, for years, to get Charlie the services she needed. Her specialists were in Charlottesville. We were able to get a partial therapy scholarship for weekly services in Upperville. I found somewhat affordable speech therapy in Harrisonburg twice a week. And, Winchester provided a reasonably priced dietitian. I drove to those places because that was the only way I could get her services she needed in a way that I could afford.

Fifth, my oral statement highlights the massive co-pays we experienced but I would like to elaborate on how challenging they were for us to afford. When Charlie was young, she had eight specialists. She saw about half of them once a month and the other half about every two months. Our specialist co-pays were \$40 per an appointment. Our therapist co-pays (she had three a week) were \$40 a session. The costs added up quickly, and placed a major strain on our family finances. Those expenses leave out exclusions, the things (like adaptive equipment) insurance didn't cover at all. Charlie needed the equipment and so we dug deep to find the money to afford them.

Sixth, my oral statement leaves out the details of the additional toll this has unnecessarily taken on my body. For example, I still can't afford to treat my asthma as well as I should. I'm priced out by the cost of the specialist co-pay in addition to the high monthly co-pays of several medications. Therefore, my asthma remains poorly controlled and only treated when it presents an emergency. That means I regularly wake up in the middle of the night air hungry and gasping for breath, I get pneumonia about once a year, and I frequently have a hacking cough.

Also, my oral surgery is not just a cosmetic issue. It's a quality of life issue. There is significant nerve and tissue damage which causes constant pain. Eating is difficult. I constantly worry about drooling or slurring my words.

Furthermore, a few years ago, I was diagnosed with an autoimmune condition. Again, I can't afford the specialist co-pays and maintenance medication. I can only afford to get treatment when I have significant flares. This means my daily life often consists of functioning through symptoms of minor flares which includes vomiting (even when I'm out in public), pushing through the exhaustion of anemia, and masking joint pain with ibuprofen.

Because of our broken healthcare system, I'm going to die before I should because I can't afford to take care of myself AND pay for Charlie's care. My goal is to live long enough to see that she is in a place where she can take care of herself. I used to dream of getting a master's degree, of rewarding careers, or of owning a home. Now, I just want to survive long enough to see my child become an independent adult.

Finally, my oral testimony fails to point out that it's cheaper to provide healthcare than it is to pay for a lifetime of unnecessary disability. The services Charlie received while she was young will make it possible for her to be an independent adult.

At the age of two, this was the list of Charlie's diagnoses:

- Development Delay
- Failure to Thrive
- Feeding Disorder of Childhood
- Sensory Processing Disorder
- Cerebral Palsy
- Swallowing/Mastication Problems
- Delayed Gastric Emptying

Later, Childhood Apraxia of Speech was added.

Upon reviewing these things, one would expect Charlie to be a significantly disabled child. Instead, she is the kid that ran all over Capitol Hill during the last two and a half years. If her trajectory continues, she will be a typical adult.

I appear before the committee to simply state: It shouldn't have been this hard. It shouldn't have cost us so much. I shouldn't have had to spend the last seven years fighting the healthcare system to get my child what she needs.

It is seven years later and we are finally starting over with nothing.

My story is one of profound policy failure.

My family had a good income and were fully insured. If this can happen to us, what chance do those with fewer resources have?

Every other industrialized nation in the world recognizes healthcare is a human right. It's time the United States of America does as well.