

**Testimony of Randi Wolfe “WRITTEN ONLY”
Mother of Ryder Wolfe with Cystic Fibrosis
HB49 as Introduced by the Governor
House Finance- Health and Human Services Subcommittee
March 23, 2017**

To Whom It May Concern:

My name is Randi Wolfe. My husband, Ben, and I were ecstatic to learn that we would be having our first-born, a son, in 2013. We had been married for 10 years and felt confident we were going to be able to provide a good life for our children. We both had steady jobs, and I had great benefits through my employer at the time. We had paid off our home and both of our vehicles. We didn't have the newest and best of everything, but we knew we could provide our family a nice life filled with love.

Our son, Ryder, was born in August of 2013 and we were overjoyed. During my pregnancy, we had learned that my husband and I were both carriers of Cystic Fibrosis. This came to a surprise, as there is no history in either side of our family history of this disease. It was in the back of our minds throughout the pregnancy, and we periodically checked in with a high-risk doctor just to keep an eye on the baby. Everything appeared so good, that we were actually released from his care before I delivered. When our son was born, he seemed healthy. His lungs sounded good. We were on Cloud 9 and thought we had beat the slim chance our child would be born with a devastating disease.

Within two weeks of Ryder's birth, a different picture was coming into view. Signs that I would now recognize right away as being a problem, I attributed to my sweet baby "just being a newborn". He lost weight. His bowel movements were frequent, and didn't look quite right. He was spitting up large amounts of what he ate. But he was such a delight and we were so happy to finally enjoy our child, that we were somewhat ignorant of our new reality; not just the new reality of having a newborn, but having a newborn with a disease for which there is no cure.

We had anxiously been awaiting the results of his newborn screening to confirm that Ryder was okay. But when I had a message from my pediatrician to call her back right away, and upon calling was asked how quickly I could come to her office, at a time my husband could come as well, I knew right away we were not going to be told Ryder was ok. Upon arriving she informed us Ryder has Cystic Fibrosis. CF is a genetic disease that primarily affects the digestive, respiratory, and reproductive systems. Our doctor was kind and informative, and had already set up an appointment for us at Akron Children's Hospital later that week to meet our new care team that we would be meeting with frequently, and for the rest of Ryder's life. You can imagine this news was a lot to take. On top of having a newborn, now we had a *sick* newborn; a son whose future wasn't as bright and cheery as it had been when we woke up that morning. His life, and ours, was changed forever at that point.

After a whirlwind, few weeks and months, Ben and I decided it would be best to quit my job to stay home and care for Ryder. We were told we would be in Akron once a week for at least the first few months. While we have a wonderful support system of family and friends living near us, it was not a burden we wanted to place on anyone else, and more importantly, we wanted to be on top of his care and treatments ourselves as his parents. A simple cold can lead to hospitalization for CF'ers, so we weren't comfortable placing him in daycare with the germs he would be exposed to in that environment. We lost my income,

and my good benefits. My husband was able to pick up insurance at his job – at the cost of over \$600 a month, on top of a \$10,000 deductible. That was a devastating blow. Daily medications are required to live with Cystic Fibrosis. This is not a \$4 bottle of Penicillin you pick up at your local grocery store pharmacy. We are talking hundreds of dollars a month, even *with* insurance, for the bare minimum of scripts – the one required to enable him to digest food. *He needs pills to eat.* It's a scary thing to have your child dependent a pill that costs you so much money.

A lot was thrown at us in a very short amount of time. One of the positives was learning about BCMH through our hospital social worker. Though it was a lengthy process, with various delays along the way, we were eventually approved and reimbursed for the thousands of dollars we had paid out of pocket for prescriptions. And that was just within the first six months of Ryder's life. It has been a saving grace for our family. As an infant Ryder needed fortified bottles (bottles made with more formula than normal) to have the weight gain he needed to stay healthy. Because of digestive problems with CF, there were days – even as a toddler – we were going through 8+ diapers a day. Now that Ryder is eating solid foods we make sure to have a good variety of healthy food on hand that will give him the extra vitamins he needs, as well as the extra fat and calories he needs in his diet. My point here is, not including all of the “medical” costs that come with living with CF, there are costs above and beyond which impact our family financially. Without BCMH, I'm scared to think what our financial picture looks like.

Despite having CF, Ryder has been incredibly healthy. He has had two hospitalizations; the main one was for one week, in the fall of 2015. He had home IV's for 2 weeks after that. Our insurance covered most of these costs, but figuring in food at the hospital, gas back and forth, extra doctor visits, it was a weight off our shoulders knowing BCMH was there to cover the rest of his medical costs. The other costs had been a blow to our budget as they were. This summer, Ryder cultured a very dangerous bacteria in his lungs. It is hard to treat in those with CF. To eradicate it, he took 28 days of nebulized medicine. My 3-year-old sat hooked up to various machines for an hour a day to keep his lungs healthy; an hour a day so he could breathe. When our doctor called with the lab results one of the questions was, “How's your insurance?” Her reason for asking? The medicine required to fight this bacteria costs \$8000 - \$10,000 a month. Luckily, we *do* have good insurance, which authorized the medication. She also told me with BCMH as our back-up we shouldn't have to pay anything out of pocket. So while I'm dealing with thoughts of “how do I keep my kid healthy while letting him be a kid?” and even worse things like “disease progression”, I do have one relief - knowing I can give my son what he needs without having to take out a mortgage my house. No one should have to think of such things. We were lucky in the fact that Ryder only had to run one month of this medication before the bacteria he had cultured was gone. It is not likely to be his last bout taking it in his life, but there are patients who have to take this medication every other month for *years* to try and treat this one symptom of CF. We have been extremely lucky our son's health has been so great up to this point, for the obvious reason of, he's an active, ornery 3-year-old boy. We are also grateful because we have had very little medical care necessary (in CF terms), as well as the associated costs, compared to other diseases and others who deal with CF. This can change on a dime and it is scary to think of what could happen to our family without BCMH in place.

Our family has made a lot of sacrifices due to Ryder's diagnosis. We have cut and trimmed the budget more times than I can count. We live a very modest life. My husband has since changed jobs and our insurance situation has improved. However, I cannot express how grateful we are, on a daily basis, knowing we have BCMH to help cover what insurance does not. We are not looking for a handout. We just need a little help. As it is now, we are just barely over the Medicaid requirements. And truthfully, I am glad we don't need Medicaid. Even if we were *under* the requirements I don't feel we need it because *we have good insurance*. We don't need help with everything. *We just need a little help*. And that is what BCMH has provided for us. From the bottom of our hearts, *thank you* for having this program in place. It may not look like much in the big picture of BCMH but it has truly been a saving grace for our family.

We are asking that you keep BCMH in place as a stand-alone State program and not part of Medicaid. I do not trust that the same level of assistance will be available to us through Medicaid. I have heard over and over again about how difficult Medicaid is to deal with, and the hoops one has to jump through to get things approved. My son does not have time to jump through hoops when he is sick or in need of medication. He needs it now. We do not want to have a nurse come to our home who is not familiar with the precise protocol that the hospital enforces, as directed through the CF Foundation, on the best ways care should be administered to keep a child with CF healthy. As it is now, we are able to use a home nurse affiliated with our children's hospital, who follows this important protocol. With Medicaid, that is not likely to be the case, and I am not comfortable with a nurse in my home who does not follow this protocol. So, in the end, I would choose to pay out of pocket instead of having a nurse come that Medicaid will cover. This defeats the purpose of the program if we can't use it to benefit our child's health. The way the program is run now has been wonderful and the thought of it being combined with Medicaid does not make sense. They are two very different things in my opinion.

I would also like to commend the Columbiana County Board of Health, and the nurses who have been available to answer questions and assist us along the way as needed. It is comforting knowing they are just around the corner if we need them. We have met our nurse Kayla in person. It makes handling questions and concerns so much easier when there is a personal connection. She is kind and professional and she, along with the other nurses in the department, does a great job representing families of children with disabilities in Columbiana County.

Thank you for listening to our story. I am asking that you will keep this wonderful program in place *as-is*, that is so crucial to our family's finances and to our son's overall health. Families like ours have problems to deal with that I wouldn't wish upon my worst enemy. Please do not take away the bit of peace we have knowing we are not on our own.

Sincerely,

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