

Testimony of Tonya Gomez - An Adult Cystic Fibrosis Patient from Fulton County, Ohio

To the Senate Finance and Financial Institutions Committee

Regarding the Ohio Department of Health Bureau for Children with Medical Handicaps Adult Cystic Fibrosis line item 440-507

April 10, 2019

My name is Tonya Gomez and I was born with Cystic Fibrosis (CF). When I was born, the life expectancy of CF was age 14. I am proud to say that I am a 46 year old female working as a Registered Dietitian, having graduated from the Ohio State University. I am married and a proud mother of a 17 year old son. I have been working as a dietitian for the past 19 years. With the disease, comes many side effects, medications, and procedures required to survive. I developed diabetes at age 22, and along with that, came more medication therapy. After 31 years of Cystic Fibrosis, I was in need of a double lung transplant. There are anti-rejection medications that are required to survive. I also have osteoporosis, avascular necrosis in my left knee, and other conditions as a result of Cystic Fibrosis. CF patients, including those with transplants and other co-morbidities are far more susceptible to illnesses that a healthy person might otherwise be able to fight off. This is a deadly disease and without proper care, chances of survival decrease drastically.

For a Cystic Fibrosis patient with a double lung transplant and diabetes, these expenses do not come cheap. They come with many co-pays for medications, physician visits, and all the deductibles and co-insurances that come with those physician visits, routine lab work, and any other needed care, depending on the severity of your illness at any given time. These co-pays, co-insurance, and deductibles can be thousands of dollars per year for many, including myself.

I have been fortunate enough to be on the BCMH program for over 30 years. This benefit allowed me the opportunity to receive the appropriate health care to be where I am today. I have had my share of hospitalizations, surgeries, medications, and so on. In recent years, the level of coverage has declined drastically and now I only receive medication assistance. This is a big deal due to all of the medications required for survival, with just CF alone. Most CF patients have developed diabetes or intestinal issues, may require feeding tubes, hospitalizations, and so on. These come with a price tag, and that price tag is never cheap. Without BCMH, I would be paying quite a bit of money each month for my medications. Even with insurance and a good job, it still takes a toll on finances.

Prior to graduating from The Ohio State University, I worked on and off due to side effects of Cystic Fibrosis. At that time, I received BCMH with all the benefits of hospitalizations, lab work, medications, and more. This allowed me to stay as healthy as possible by receiving the best medical care and medications needed to thrive. I do receive health insurance through my employer, which is very helpful. However, working full-time as a CF patient with diabetes, osteoporosis, digestive issues, and being a double lung transplant recipient with lowered immunity has taken its toll on my body, physically and mentally. I feel as if this is what I need to continue to do regardless because losing health insurance is not an option for me. If BCMH brought all the benefits back to patients, I wouldn't feel like I need to "kill myself" just to "stay alive". How much sense does that even make? In CF patients, I am the minority. Most patients are not fortunate to have a decent insurance plan, let alone work at all, or for

as long as I have. What choice do I have at this time? If I stop working, I won't be able to afford a health plan and BCMH would not cover my critical medical needs.

I am asking you as a CF patient, mother, tax payer, and more to please consider adding all of the benefits back to the BCMH program. It is crucial to the survival of cystic fibrosis patients throughout the state. If the house is willing to provide Cystic Fibrosis patients, children and adults, with the funding needed for healthcare, that would take a great burden off the individual who is trying everything in their power to lead a normal life or provide a normal life for their child. Of course, there is nothing normal about the life of a CF patient!

Thank you very much for your time and allowing my voice to be heard.

Sincerely,

Tonya Gomez

Fulton County, OH