



May 6, 2021

Senator Stephen A. Huffman, Chair
Senator Niraj Antani, Vice Chair
Senator Nickie L. Antonio, Ranking Member
Senate Health Committee

Re: Funding for the Children with Medical Handicaps (CMH) Program and Medicaid

Dear Chair Huffman, Vice Chair Antani, Ranking Member Antonio and Members of the Senate Health Committee:

On behalf of people living with cystic fibrosis (CF) in Ohio, we write to support Governor DeWine's proposal to preserve funding for the Children with Medical Handicaps (CMH) Program and Ohio Medicaid in the SFY 22-23 budget. These programs play a critical role in promoting the health and well-being of Ohioans with CF, especially during the ongoing COVID-19 pandemic, and we urge you to retain this funding as you consider HB 110.

About Cystic Fibrosis

Cystic fibrosis is a life-threatening genetic disease that affects approximately 30,000 children and adults in the United States, including nearly 1,550 Ohioans. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Because cystic fibrosis is a complex, multi-system condition and requires specialized treatment and medications, most people with CF receive care at one of the more than 130 accredited CF care centers in the United States, including 13 in Ohio, where clinicians use evidence-based guidelines to deliver multi-disciplinary care. While great strides have been made in the treatment of the disease, the lives of young people with cystic fibrosis are still cut far too short; half of young adults with the disease still die before age 30.

Children with Medical Handicaps (CMH) Program

CMH is a state program run by the Ohio Department of Health (ODH) that serves as a safety net for children with special health care needs who meet medical and financial eligibility requirements. The program fills gaps in coverage related to the child's special health condition and acts as a payer of last resort to help families access the services their child needs. CMH also provides services for people over age 21 with cystic fibrosis, including prescription medications, medical supplies, special formula, and public health nursing visits. **While CMH is a resource for some patients enrolled in Medicaid, it also helps privately insured CF families with their out-of-pocket costs, allowing them to maintain their commercial insurance and sometimes diverting them from public coverage.**

Ohio Medicaid

Medicaid is also a crucial source of coverage for people with CF, and we urge you to ensure the SFY 22-23 budget preserves existing Medicaid funding, eligibility, and benefits. Over half of children and a third of adults living with CF in Ohio depend on the program for some or all of their health care needs.

Medicaid plays an important role in helping people with cystic fibrosis afford the specialized care and

treatments they need to stay healthy and, for many with CF, it fills coverage gaps in private insurance that would otherwise leave patients with unsustainable out-of-pocket costs.

Additionally, preserving Medicaid funding will help protect the financial viability of hospitals and providers that may be in a weakened financial state due to the pandemic. CF care centers are often housed within academic medical centers, which serve a disproportionate number of low-income patients. These medical centers rely on Medicaid reimbursement for a large portion of their revenue and many have been in financially precarious positions due to reduced volume in certain procedures during the COVID-19 pandemic. Some CF care centers were forced to furlough or lay off staff during this time and cuts to provider reimbursement could further exacerbate these issues and result in centers losing critical staff.

Medicaid and the CMH Program remain more important than ever in helping those with CF access the care and treatments they need, especially during these uncertain times. Please retain Governor DeWine’s request to fund Medicaid, the Medically Handicapped Children line item, and the Targeted Health Services – Over 21 line item in the SFY 22-23 budget. Thank you for your attention to this important issue.

Sincerely,

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President of Policy and Advocacy
Cystic Fibrosis Foundation
Bethesda, MD

Elliot Dasenbrook, MD, MHS
Director, Adult CF Care Center
Cleveland Clinic Cystic Fibrosis Program
Cleveland, OH

Nathan Kraynack, MD
Co-Director, Adult CF Care Center
Cleveland Clinic Cystic Fibrosis Program
Cleveland, OH

Titus Sheers, MD, MBA, FACP
Director, Adult CF Care Center
Children’s Hospital Medical Center of Akron
Akron, OH

Greg Omlor, MD, FAAP, FAASM
Director, Pediatric CF Care Center
Akron Children’s Hospital
Akron, OH

M. Veronica Indihar, MD
Director, Adult CF Care Center
University of Cincinnati Medical Center
Cincinnati, OH

Alpa Patel, MD
Director, Adult CF Care Center
Nationwide Children’s Hospital
Columbus, OH

Kimberly McBennett, MD, PhD, FACP
Director, Adult CF Care Center
Rainbow Babies and Children’s Hospital
Cleveland, OH

Cc: Senate Health Committee Members

Appendix: CF Community Testimony on Importance of CMH

The Hoffman Family, Marion County

Meet the Hoffman family from Marion County, who rely upon the safety net provided by the Children with Medical Handicaps (CMH) program of the Ohio Department of Health. The Hoffmans rely upon employer-sponsored private health insurance to care for their two young adult daughters who are living with cystic fibrosis, but that is not nearly enough. Mr. Hoffman shares, "Our own experience has shown to us that we cannot walk this journey alone. Dealing with children who have complex medical conditions is costly, complicated, and constant. Even with excellent insurance coverage, there are still gaps in coverage, expensive high deductible plans, and numerous co-pays. We estimate that our out-of-pocket expenses for our daughters' healthcare, which is not covered by private insurance, exceeds \$10,000.00 annually and doesn't begin to stop there. Not everything that is medically necessary is always covered, and it depends on who is determining medical necessity. We know that we cannot do it alone, and we have come to rely upon the help and benefits of CMH. CMH meets families where they are and provides a level of care coordination that understands the context of their family and the communities in which we live. CMH walks with patients and families coming behind private and public insurance to take away some of the worry and frustration so that parents can concentrate on caring for their children, remain working to make ends meet, and receive the medically necessary care our daughters need to live longer and stronger lives."

Patrick Kilbane, Darke County

My name is Patrick Kilbane and I am a young father to Kilian Bridget Kilbane. Kilian is 6 years old and is in Kindergarten at Arcanum-Bulter Local Schools. Kilian has cystic fibrosis and has been linked up with CMH since her diagnosis was discovered by the newborn blood screen that the State of Ohio put into law. Kilian's medication and medical appointments are very costly. Her one medication she takes monthly is almost \$5,000 per month billed to our insurance. CMH has helped us cover the cost of this medication. Without their assistance the first week of January in any given year would be extremely difficult to get the proper funding needed for her medication and maintain funding needed for her medical appointments, such as going to Nationwide Children's hospital to be seen by her pulmonary team and other specialists.

We are currently working with our CMH team to get a range of specialists covered by the program due to the nature of her medical needs. It has been extremely eye opening to see how much her medical care cost and what is needed to keep her healthy. We strive to keep her healthy and avoid hospitalizations. COVID 19 has been a big barrier to keeping her safe; however, we have been blessed by CMH, which helped provide medical masks to keep her safe. Kilian is going to school and that is only possible due to her staying healthy. She gets to be with her typical classmates and develop the appropriate relationships with her friends to develop the social skills needed. CMH is the foundation of medical support, funding, and resources that Kilian needs to be healthy and successful in school.