



April 18, 2022

Representative Mary Whiteford, Chair
Representative Felicia Brabec, Minority Vice Chair
House DHHS Subcommittee on Appropriations

Senator Rick Outman, Chair
Senator Sylvia Santana, Minority Vice Chair
Senate DHHS Subcommittee on Appropriations

Dear Senate and House DHHS Subcommittee on Appropriations Leadership,

On behalf of the nearly 1,200 Michiganders living with cystic fibrosis (CF), we write to ask for your support of adequate funding for the Children's Special Health Care Services (CSHCS) Program and Medicaid in the upcoming state budget. These programs are critical safety nets for a large proportion of the CF community in Michigan and play an important role in ensuring consistent access to needed care.

About Cystic Fibrosis

Cystic fibrosis is a rare genetic disease that affects more than 30,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications.

While significant advances in care are helping people with cystic fibrosis live longer, healthier lives, the cost of care presents a barrier to access for many people with the disease. Many people with CF depend on multiple forms of insurance and nearly three-quarters rely on some form of financial assistance. Still, 45 percent of respondents to a 2019 George Washington University survey of more than 1,800 people living with CF and their families reported delaying or forgoing care due to cost concerns, which can put patients at increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

Children's Special Health Care Services (CSHCS) Program

As you form the FY 2023 budget, we ask that you support the Michigan Department of Health and Human Services' (MDHHS) request for \$290.2 million per fiscal year to CSHCS, a state-run program that helps people with CF afford the high cost of their care. CSHCS acts as a payer of last resort by reimbursing families for needed treatments and services such as medications and doctors' visits when there are gaps left by other forms of insurance. While the proposed funding level represents a decrease from the current appropriation, it is our understanding that it is based on caseload projections and will not affect the program's eligibility or covered services in any way. We worry that reductions in program funding beyond that level, however, could disrupt access to care for people with CF and have negative consequences on their health.

Michigan Medicaid

Medicaid is also a crucial source of coverage for people with CF, and we urge you to ensure the budget preserves existing funding, eligibility, and benefits. Over half of children and nearly one in three adults living with CF in Michigan depend on Medicaid for some or all of their health care needs. The program plays an important role in helping people with cystic fibrosis afford the specialized care and treatment they need to manage the disease and, for many with CF, it fills coverage gaps in private insurance that would otherwise leave patients with unsustainable out-of-pocket costs.

Adequate funding for Medicaid and the Children's Special Health Care Services Program will facilitate access to needed care and promote the health and wellbeing of Michiganders who rely on them, including those with cystic fibrosis. Thank you for keeping in mind the needs of people with CF when forming the FY 2023 budget.

Sincerely,

Mary B. Dwight

Chief Policy and Advocacy Officer
Senior Vice President of Policy and Advocacy
Cystic Fibrosis Foundation

Amy Filbrun, MD

Associate Director, Pediatric CF Care Center
University of Michigan Health
Ann Arbor, MI

Dana G. Kissner, MAT, MD, MS

Co-Director, Adult CF Care Center
Wayne State University Harper University Hospital
Detroit, MI

Ryan Thomas, MD

Director, Pediatric CF Care Center
Michigan State University
Lansing, MI

Thomas Sisson, MD

Co-Director, Adult CF Care Center
University of Michigan Health
Ann Arbor, MI

Zubin Mukadam, MD

Director, Adult CF Care Center
Wayne State University Harper University Hospital
Detroit, MI

Samya Nasr, MD, CPI, ATSF

Director, Pediatric CF Care Center
University of Michigan Health
Ann Arbor, MI

Shijing Jia, MD

Co-Director, Adult CF Care Center
University of Michigan Health System
Ann Arbor, MI

Stephen J. Fitch, MD, FCCP, FAASM

Director, Adult CF Care Center
Helen DeVos Children's Hospital
Grand Rapids, MI

Ibrahim Abdulhamid, MD

Director, Pediatric CF Care Center
Children's Hospital of Michigan
Detroit, MI

John N. Schuen, MD

Director, Pediatric CF Care Center
Helen DeVos Children's Hospital
Grand Rapids, MI

Marc R. McClelland, MD

Associate Director, Adult CF Care Center
Helen DeVos Children's Hospital
Grand Rapids, MI