



March 22, 2023

Representative Sara Carruthers
Chair, Finance Subcommittee on Health and Human Services
77 South High Street, 11th Floor
Columbus, OH 43215

Re: Children and Youth with Special Health Needs Program Funding

Dear Chair Carruthers, Ranking Member Liston, and members of the House Finance Subcommittee on Health and Human Services:

On behalf of people living with cystic fibrosis (CF) in Ohio, we write to thank you for including funding for the Children and Youth with Special Health Needs Program (CYSCHN), formerly named the Children with Medical Handicaps (CMH) Program, and Ohio Medicaid in the SFY 2023-2024 budget. These programs play a critical role in promoting the health and well-being of Ohioans with CF by filling gaps in coverage and helping ensure access to care and treatments.

About Cystic Fibrosis

Cystic fibrosis is a life-threatening genetic disease that affects approximately 40,000 children and adults in the United States, including over 1,600 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 34.

Children and Youth with Special Health Needs (CYSHN) Program

CYSHN 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. CYSHN also provides services for people over age 21 with cystic fibrosis, including prescription medications, medical supplies, special formula, and public health nursing visits. While CYSHN 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 thank you for ensuring the SFY 2023-2024 budget preserves existing Medicaid funding, eligibility, and benefits. Over half of children and

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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.

We thank you for funding these critical programs in the SFY 2023-2024 budget. Thank you for your attention to this important issue and for all you do for people living with CF in Ohio.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', written in a cursive style.

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President of Policy and Advocacy