



May 29, 2020

Governor Gretchen Whitmer
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Electronically sent to gretchen.whitmer@michigan.gov
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Dear Governor Whitmer,

On behalf of those living with cystic fibrosis (CF) in Michigan, we thank you for all that you and the State of Michigan are doing to ensure the health and safety of state residents in the midst of the COVID-19 pandemic. While we understand that these are unprecedented times, we ask for your continued support of adequate funding for Medicaid and the Children's Special Health Care Services (CSHCS) Program.

Cystic Fibrosis is a life-threatening genetic disease that affects approximately 1,150 people in Michigan and 30,000 people in the United States. CF causes the body to produce thick, sticky mucus that clogs that lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. In order to stay healthy, people with CF must be able to get their care at accredited care centers where clinicians use evidence-based guidelines to deliver multi-disciplinary, coordinated care centered on patients' unique needs.

As you begin negotiations for the 2020-2021 biennial budget, we urge you to support allocating \$228.4 million per fiscal year for the Children's Special Health Care Services Program, 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 important treatments and services such as medications and doctor's visits when there are gaps left by other forms of insurance. According to a survey conducted by George Washington University, 45 percent of people with CF spend \$5,000 or more annually in out-of-pocket costs for copayments, coinsurance, and non-covered services, demonstrating the importance of funding programs like CSHCS to ensure that people with CF have access to the care and treatments they need.

Medicaid is also a crucial source of coverage for patients with serious and chronic health care needs, including CF, and we urge you to reject any proposed reductions to eligibility or benefits. Over half of children and nearly 40 percent of adults living with CF in Michigan 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. For many with CF, Medicaid fills coverage gaps in private insurance that leave patients with unsustainable out-of-pocket costs.

We understand that Michigan is facing budget constraints as it works to mitigate the effects of the COVID-19 pandemic but we are concerned that reductions in CSHCS program funding could potentially disrupt access to care for people with CF, at a time when they need it most. Similarly, cuts to Medicaid

will further stress hospitals and providers already in a weakened financial state. Reductions in provider reimbursement, in particular, will have a lasting effect on CF care centers as they are often housed within academic medical centers, which see a disproportionate number of low-income patients. These institutions rely on Medicaid for a large portion of their revenue and are already in financially precarious positions due to reduced volume in elective procedures. We have heard reports of care centers having to furlough or lay off staff and fear that additional cuts to provider reimbursement could further exacerbate these issues and result in more centers losing critical staff.

We thank you for keeping the needs of people with CF in mind when forming the FY 2020-21 budget. By protecting funding for Medicaid and the Children's Special Health Care Services Program, you will help ensure people living with CF in Michigan who rely on these programs can get the care they need. We appreciate your partnership and hope you will consider the CF Foundation a resource throughout the budget process and beyond.

Sincerely,

Mary B. Dwight

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