

Testimony of Kim Reno, M.S.W., L.I.S.W.  
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Representing patients and families of ProMedica Toledo Children's Hospital and ProMedica Toledo Hospital

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Thank you for allowing me to provide written testimony today to express concerns regarding the proposed changes to the Ohio Dept. of Health Children with Medical Handicaps (CMH) Program.

My name is Kim Reno, and I am the Social Worker for the Pierre Vauthy Cystic Fibrosis Center of Northwest Ohio caring patients and families of ProMedica Toledo Children's Hospital and ProMedica Toledo Hospital in Toledo. I have been employed with the hospital for 24 years, and have worked with adults and children with Cystic Fibrosis for 23 years.

The Cystic Fibrosis Centers in Toledo provides comprehensive care to children and adults with Cystic Fibrosis. The National Cystic Fibrosis Foundation accredits our Center and five additional Cystic Fibrosis Care Centers in the State of Ohio.

Our patients have received support from the Ohio Department of Health (ODH) Cystic Fibrosis Program since the mid 1970's. The ODH Cystic Fibrosis Program works through the Cystic Fibrosis Centers within the state to ensure and enhance the quality and availability of care for persons with CF. Coordinated comprehensive care by multi-disciplinary teams at the at the Cystic Fibrosis Treatment Centers such as our have proven to be the most cost-effective way of reducing morbidity, disability, and mortality. This is proven, as the life expectancy continues to rise for this patient population, about 50% of the patient population are 18 years or older. These individuals are capable of attending college, working and becoming productive members of society. Though the life expectancy is expanding, these patients and families will not have access to the care they receive today if the proposed changes are approved for the CMH program. Patients and families will make difficult decisions between providing food clothing and shelter or paying for life saving medications.

We have a crisis currently in the State of Ohio with the ODH Bureau for Children with Medical Handicaps Program, also known as "CMH." CMH is a wonderful program designed to help working families who have children with special health needs.

CF is a terrible disease, and the CMH program has done wonders in keeping children and adults healthy who otherwise would be medically intensive cases. CMH made a commitment to keeping these children healthy. Now the proposed changes will drastically scale back coverage and this is simply unacceptable.

For an example, under the proposed changes a family of four that has an annual income of \$55,000 will be ineligible to receive the CMH services. Realistically, a family such as this will not be able to pay for their child's health care needs due to rising out of pocket expenses and medication co-pays. Some of the families I work with are required to pay several hundred dollars out of pocket per month in order for their children to receive the life sustaining medications and treatment. Typically an individual with CF is on about 8 different medications. These patients will face huge new medical bills, in some cases thousands of dollars per month. Families will choose between paying utility or food bills versus purchasing their child's medications.

There is a recent study "Survival Comparison of Patients With Cystic Fibrosis in Canada and the United States" published in Annals of Internal Medicine. It was noted in this study there is a 10 year gap in longevity for those with CF treated in Canada vs. The United States; that is, Canadians are living longer with CF. The researchers noted for patients who have access to private health insurance in the US, the longevity was the same; for those with no insurance or Medicaid, the gap widened to 10 years. This is a dramatic example of how important access to medications and care is to the person with CF for longevity as well as to become active, productive members of society.

CMH, a program that is used to assist those persons who worked, pay for a portion of their medical expenses, under the new proposal will be unable to provide this basic service. Reducing the eligibility of the program is inhumane and will result in more people going on Medicaid rolls or incurring huge costs to Ohio's already strained system of uncompensated care.

If we cut funding for children and adults with chronic illnesses now, the state will simply be forced to pay tenfold in the future. More children and adults will become sicker from their illness; have more frequent trips to their local emergency rooms, and frequent emergent hospitalizations, which will provide fragmented care. This will lead children to reach disability status sooner and drain our system further as they will become medically complex.

Please help change the proposal that will force working families with children with special health needs to quit their jobs, sell their homes, and file for bankruptcy to receive medical care on Medicaid. Such a policy is destructive to families, to our health system, and to our economy.

The potential for more children and adults to die prematurely is a tremendous risk if interventions are not made. I am requesting your support for the CMH program, to keep it under the Ohio Department of Health and to both draw attention to state policy and to help CF families obtain the lifesaving care they require to become productive members of society.

Thank you again for this opportunity, I am confident we can and will make a difference in the lives of people with CF with your help today.

Respectfully,  
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