June 12, 2018

Dear Senator Baker and the Senate Health & Human Services Committee,

On behalf of people with cystic fibrosis (CF) living in Pennsylvania, the Cystic Fibrosis Foundation opposes HB 2138: “An Act amending the Human Services Code, in public assistance, providing for work requirements” which would create additional barriers to Medicaid eligibility and access to medically necessary benefits by adding work requirements.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 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. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. Medicaid is a crucial source of coverage for patients with serious and chronic health care needs, including almost 400 adults living with cystic fibrosis in Pennsylvania. Given the role that Medicaid plays in helping this patient population access the high-quality care and treatments they need to maintain or improve their health, we urge you to reject this proposal as it would create additional barriers to eligibility and access to medically necessary benefits.

Making work a condition of Medicaid eligibility could threaten access to care for people with CF, as their ability to work can vary over time with changes in health status. While many people with CF work full or part-time, declines in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce for significant periods of time. Patients also bear a significant treatment burden on a daily basis, amounting to hours of chest physiotherapy, delivery of nebulized treatments, administration of intravenous antibiotics, and/or other activities required to maintain or improve their health. As such, maintaining sustained employment may not be possible due to the time required to undergo necessary treatment.

The Cystic Fibrosis Foundation appreciates your attention to this important issue. As the health care landscape continues to evolve, we look forward to working with the state of Pennsylvania to improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,

Mary B. Dwight
Senior VP of Policy & Advocacy
Cystic Fibrosis Foundation

Lisa Feng, DrPH
Senior Director of Policy & Advocacy
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CC: Senate Health & Human Services Committee