CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

October 4, 2017

The Honorable Orrin G. Hatch
Chairman
Senate Finance Committee

The Honorable Ron Wyden
Ranking Member
Senate Finance Committee

The Honorable Greg Walden
Chairman
House Energy and Commerce Committee

The Honorable Frank Pallone, Jr.
Ranking Member
House Energy and Commerce Committee

Dear Chairmen Hatch and Walden and Ranking Members Wyden and Pallone,

On behalf of the approximately 30,000 people in the U.S. living with cystic fibrosis (CF)—47 percent of whom are under age 18—I write to express strong support for the Children's Health Insurance Program (CHIP) and applaud your committees for putting forth proposals for a five-year funding extension. CHIP is critical for people with this life-threatening, chronic disease and we appreciate your work to ensure the program's continued viability in the years ahead.

Cystic fibrosis, one of the most common life-threatening genetic diseases, is primarily a lung disease that makes the body produce thick, sticky mucus that clogs the lungs and leads to life-threatening infections and serious digestive complications. In the 1950s, those with CF rarely lived to attend elementary school. Now, thanks to advances in the development of treatments and access to specialized, quality care, those with cystic fibrosis are living into their 30s, 40s, and beyond.

This is largely due to groundbreaking advancements in treatments in conjunction with the development of a coordinated specialty care center network. The Cystic Fibrosis Foundation funds and accredits more than 120 care centers and 55 affiliate programs nationwide that provide treatment and care in accordance with systematically reviewed clinical practice guidelines. Many of these care centers specialize in the needs of the pediatric CF population across the country and in so doing treat many CHIP children.

Medications for cystic fibrosis must be taken regularly for the patient's entire life, and this can result in heavy cost burdens for patients and their families. According to a recent survey, half of CF patients (50 percent) pay more than $300 a month in insurance premiums and over quarter (26 percent) pay over $500. However, most patients who receive coverage through CHIP will pay lower out of pocket costs than those with commercial insurance or Medicare, which helps them maintain their treatment regimens.

Access to highly specialized care and therapies from the time of diagnosis promotes greater quality of life, has the potential to help those with cystic fibrosis live healthier lives, and may reduce the need for

hospitalizations. Without continued funding for the CHIP program, children could face gaps in coverage and lose access to this specialized, quality care.

The Cystic Fibrosis Foundation appreciates your committees for their leadership in ensuring continued funding for this important program. Specifically, we applaud the inclusion of long-term CHIP funding in the KIDS Act of 2017 and the HEALTHY KIDS Act. A five-year funding extension will provide stability to states, and ensure that children with CF have continued access to this vital program.

We thank you for your commitment to this program and recognition of the need for a long-term funding plan in order to maintain access to care. We stand ready to work with you in the weeks ahead. Thank you for your consideration.

Sincerely,

Mary B. Dwight
Senior Vice President
Policy & Advocacy