



November 14, 2014

The Honorable Harry Reid
U.S. Senate Majority Leader
S-221 U.S. Capitol Building
Washington, DC 20510

The Honorable Mitch McConnell
U.S. Senate Minority Leader
S-230 U.S. Capitol Building
Washington, DC 20510

The Honorable John A. Boehner
Speaker of the House
H-232 U.S. Capitol Building
Washington, DC 20515

The Honorable Nancy Pelosi
U.S. House Minority Leader
H-204 U.S. Capitol Building
Washington, DC 20515

Dear Majority Leader Reid, Minority Leader McConnell, Speaker Boehner and Minority Leader Pelosi,

On behalf of 30,000 U.S. patients living with cystic fibrosis (CF) and their families, I write to express strong support for the Children's Health Insurance Program (CHIP) and convey the importance of CHIP to those with this life-threatening, chronic disease. As Congress reconvenes and continues discussions on the reauthorization of this important program, **we ask that you extend funding for CHIP and ensure its 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 accredits 121 care centers and 49 affiliate programs nationally that provide treatment and care in accordance with systematically reviewed clinical practice guidelines. The vast majority of CF patients receive care through an accredited care center, which allows the CF Foundation to ensure that patients receive standardized, evidence-based treatment through a patient-centered medical home. One hundred three of these care centers specialize in the needs of the pediatric CF population across the country and in so doing treat many CHIP children.

Access to highly specialized care 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 costly hospitalizations.

National Office

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Without continued funding for the CHIP program, it is our concern that the resultant gap in coverage could result in lack of access to this specialized, quality care and greater health care costs overall. Because damage done to the body by CF is cumulative in nature, it is essential that children with CF have access to high quality, specialized care and treatment as soon as possible.

Children ages 19 and under make up 63 percent of the cystic fibrosis patient population, and 10 percent of CF patients under the age of 19 receive health benefits through CHIP programs. Programs like CHIP, which help make children's health care affordable, are essential for the health of not only the pediatric population, but also continued health into adulthood. When children with cystic fibrosis have health coverage, they are more likely to get the regular treatments they need to live long and healthy lives.

CHIP is an effective and efficient program that provides health care for children when working families cannot afford coverage. 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. In fact, 80 percent of CF patients who are enrolled in CHIP and Medicaid pay less than \$200 per month in out of pocket medical costs. Further, CF patients who participate in CHIP programs are less likely than those with commercial insurance coverage to skip treatments or delay medical care due to cost.

Since its original passage in 1997, CHIP has ensured that thousands of children with CF get the coordinated, specialized health care they need. Extending funding for CHIP through 2019 will safeguard access to care and adherence to treatment that can not only improve the quality of life for these patients but can also help them to live longer as well.

We once again urge that funding for this critical program be extended and protected. We stand ready to work with you in the months ahead.

Sincerely,

A handwritten signature in black ink, appearing to read "Robert J. Beall". The signature is fluid and cursive, with a large initial "R" and "B".

Robert J. Beall, Ph.D.
President and Chief Executive Officer