Cystic Fibrosis Foundation
...adding tomorrows every day.

July 12, 2007

The Honorable John D. Dingell
Chairman
Energy & Commerce Committee
United States House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Joe Barton
Ranking Member
Energy & Commerce Committee
United States House of Representatives
2322A Rayburn House Office Building
Washington, DC 20515

Dear Chairman Dingell & Congressman Barton,

On behalf of the Cystic Fibrosis Foundation, representing 30,000 people with cystic fibrosis (CF), I write to express our support for language in the State Children's Health Insurance Program reauthorization legislation to ensure children with CF who are covered by the program have timely access to high quality care that reflects the current standards of care recommended by experts in CF care and research.

We are making remarkable strides in our fight against this life-threatening disease. The predicted age of survival for children with cystic fibrosis has doubled in the last two decades. Today, people with CF are living to a predicted median survival age of 37 years old. This significant improvement in life expectancy for those with CF is attributed to the fact that there are now more CF therapies than ever before, earlier interventions in CF patients to help them maintain their health, quality care, and strict adherence by patients and providers to the defined standard of care.

At the Cystic Fibrosis Foundation, we aggressively fund a drug discovery and development pipeline in an effort to produce effective therapies, and ultimately a cure. Equally important to this research, is ensuring that people with CF have access to new treatments as soon as they become available. Access to care and adherence to treatment can not only improve the quality of life for patients but can also help them to live longer as well. Without timely decision making by SCHIP programs about the inclusion of CF therapies, patients may be adversely affected. Early intervention is essential not only to longevity but to containment of health care costs.

While the cost of medical care for CF varies, it is significant even among otherwise healthy patients. The median survival rate for patients with CF is also substantially lower for those without health insurance than those who have it. Low-income CF children have far poorer medical outcomes as well. The risk of death is almost four times higher for poor children with CF and they are more likely to experience the symptoms of the disease at an early age. Without health care coverage, life expectancy for children with CF is suggested to decline dramatically.

In order to ensure that children with CF enrolled in SCHIP have access to effective therapies as soon as they become available, we ask that you support language in the SCHIP reauthorization bill to create a federally sanctioned CF Clinical Practice Guidelines Committee to establish best practices for the treatment of this disease; to encourage SCHIP coverage boards to look to the Committee for recommendations to cover all health care services that are medically necessary and appropriate for the treatment of CF in a timely manner; and to request the Government Accountability Office to issue an annual report to Congress that evaluates to what extent state SCHIP programs provide coverage for the care standards established by the Committee.

We look forward to working with you as we continue our mission to find a cure and control for this life-threatening genetic "orphan" disease, and as we continue to build hope and add tomorrows every day for those with CF.

Sincerely,

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

Mary Dwight
Vice President, Governmental Affairs

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