



| Adding *tomorrows* every day.

April 6, 2009

The Honorable Barack Obama
President
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear President Obama,

On behalf of the Cystic Fibrosis Foundation, representing 30,000 people with cystic fibrosis (CF), we write to you to express our support for health care reform that benefits people with rare diseases. We are making remarkable strides in our fight against this life-threatening disease, but people who live with it are facing greater obstacles each year.

Cystic fibrosis is an inherited, life-threatening disease that affects the lungs and digestive systems. Just 50 years ago, people with the disease rarely lived to attend grade school. Today, thanks to medical research and new treatments fueled by the CF Foundation, the median life expectancy for people with cystic fibrosis is 37 years. While research and advanced therapies have made significant progress in improving the quality and length of life, people with cystic fibrosis depend on specialized care to stay alive and healthy.

Cystic fibrosis is a costly disease and people living with it are in need of timely access to high quality care to help confront the significant roadblocks they routinely face. While the cost of medical care for CF varies, it is significant even among patients who don't report significant hospital or prescription drug costs. The disease typically costs around \$42,000 per person per year. By comparison, the average commercially insured population costs only \$3,000 per person per year. People with the disease require longer and more frequent hospital stays and typically pay more for prescription drugs. Because of this, their medical costs are nine to thirteen times higher than the average health care consumer.

The Cystic Fibrosis Foundation has been the primary sponsor of critical research, investing more than \$660 million over the past five years in medical programs dedicated to advancing life-sustaining treatments and a cure for cystic fibrosis. In addition, the Foundation was recently honored by the National Committee for Quality Assurance (NCQA) as a leader in improving the quality of care for people living with cystic fibrosis, based on its nationwide quality improvement initiative. It is essential that people with CF have access to the therapies that emerge from research and the specialized care model that has proven so effective.

To ensure that people with cystic fibrosis receive the care they need to help them live longer and healthier lives, a reformed health care system must do the following:

- Promote and maintain a system for coordination of chronic care to enhance the quality of care and prevent gaps in care for those with chronic and life-threatening illnesses.
- Eliminate pre-existing condition exclusions that can block access to health insurance and assurance of portability of coverage, to ensure coverage and prevent economically unproductive job lock.
- Protect against out-of-pocket costs, including deductibles, co-payments, and co-insurance, that prevent access to care for chronic diseases.
- Protect against catastrophic expenses, which may require assistance to employers whose insurance plans may cover individuals with such expenses. A program to cover catastrophic expenses should also address the issue of annual and lifetime spending caps.
- Eliminate the Medicare waiting period for disabled Americans to protect against disruptions in care for those individuals.
- Develop an efficient method for coverage determinations that rapidly incorporates into the system of care those therapies that will extend and/or improve quality of life for those with CF.
- Implement a quality assessment and monitoring system that will inform decisions that will boost the quality of care.
- Ensure that Medicaid waivers do not preclude access by cystic fibrosis patients to specialty pharmacy and other services.

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 cystic fibrosis.

Sincerely,



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



Mary Dwight
Vice President, Governmental Affairs

CC: Secretary-Designate Kathleen Sebelius
Peter R. Orszag
Nancy-Ann Min DeParle