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**DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
**OFFICE OF DIRECTOR**

**ACTION REFERRAL**

TO <i>Giese / Williams</i>	DATE <i>2-7-13</i>
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DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>000242</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR  <i>CC: Mr. Keek cleared 3/21/13, letter attached</i>	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>2/21/13</i>
	<input type="checkbox"/> FOIA DATE DUE _____
	<input checked="" type="checkbox"/> Necessary Action

APPROVALS (Only when prepared for director's signature)	APPROVE	* DISAPPROVE (Note reason for disapproval and return to preparer.)	COMMENT
1. <i>Val Williams</i>	<i>3-13-13</i>		
2. <i>BB Giese</i>	<i>3-21-13</i>		
3.			
4.			



**CYSTIC FIBROSIS  
FOUNDATION**  
ADDING TOMORROWS

February 1st, 2013

The Honorable Anthony Keck  
Department of Health & Human Services  
1801 Main Street  
Columbia SC 29201-8206

**RECEIVED**

FEB 07 2013

Department of Health & Human Services  
OFFICE OF THE DIRECTOR

Dear Director Keck,

On behalf of people in State who are living with cystic fibrosis (CF), we write to express the urgent need for reliable access to high-quality care to maintain good health status. We also offer the experience, knowledge and background of the Cystic Fibrosis Foundation as you undertake the difficult work of developing the state's plan for health care funding and operations in the upcoming term. We ask that, as you make difficult budget recommendations, you protect Medicaid and other key health care programs that people living in the state with cystic fibrosis rely on to stay healthy.

Cystic fibrosis is a genetic disease that affects 30,000 children and adults in the United States and 70,000 people worldwide. CF is caused by a defective gene that makes the body produce thick, sticky mucus that clogs the lungs and leads to life-threatening infections. In addition to its serious impact on the lungs, CF also affects the digestive system and compromises the nutritional status of many with the disease. When the CF Foundation was established in 1955, people with the disease rarely lived to attend grade school. Today, thanks to medical research that has yielded new treatments, people are living into their 30s, 40s and beyond.

Specialty care programs are critical for people with CF, especially for young adults with the disease. Nationwide statistics show that people with CF ages 18-30 are sicker and have greater difficulty obtaining care than any other age group. While the median age of survival has grown dramatically in recent decades, fifty percent of young adults with the disease still die before the age of 26. Because the cost of care for the disease is so high (patients typically have medical costs of approximately \$80,000 per year for adults, 15 times greater than the medical costs of the average person) it is vital that programs that make care affordable continue to operate, thus preventing families from unnecessary reliance on and helping to control state costs.

So that people with the disease retain access to the care and coverage that they need to live longer, healthier lives, the CF Foundation urges you to consider the following policies in the coming year:

*Protect Vital CF Care Programs in the FY2014 Budget*

Maintain funding for key public programs that people with cystic fibrosis rely on for their care. They help people living with the disease to better afford the increasingly costly co-pays and co-insurance rates for their prescription medications and in-patient and out-patient care. As a result, adequate funding to sustain it is a primary concern for people with cystic fibrosis in the state. We strongly urge that these programs be allowed to continue to provide the same level of services for its families.

NATIONAL OFFICE

6931 ARLINGTON ROAD  
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BETHESDA, MD 20814

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T: 301.951.4422  
F: 301.951.6378

W: WWW.CFF.ORG  
E: INFO@CFF.ORG

*Ensure Access to High Quality Specialized Care*

People with CF must be able to get coverage for their prescriptions and receive specialized care from providers at an accredited cystic fibrosis care center. The clinicians at CF care centers are experts in the evidence-based, peer-reviewed clinical practice guidelines that form the standard of care for people with this rare disease. The state should take all necessary steps to ensure that people with CF have the option of receiving the high quality specialized care available in the state's accredited care centers. This can be accomplished in four ways:

1. Expanding Medicaid to 138 percent of the federal poverty level to allow for better coverage for people with the disease. Greater than 1 in 2 children and greater than 1 in 3 adults with cystic fibrosis rely on Medicaid or a similar public insurance plan for their health care. People with CF who need Medicaid to afford their care must have access to comprehensive and continuous coverage for high quality specialized care; an important component of cystic fibrosis treatment.
2. Providing pharmaceutical benefits for specialized medications like the ones that form the core of cystic fibrosis treatment must remain accessible. Barriers to these orphan drugs, such as high co-payments, excessive co-insurance rates and unnecessary prior authorization requirements, should not become overly burdensome for those who need the treatments to stay healthy.
3. Developing Health Insurance Marketplaces that will ensure that those with CF who are insured through health insurance exchanges have adequate coverage for cystic fibrosis care, including access to CFF-accredited care centers, cystic fibrosis medications and cystic fibrosis specialty care physicians.
4. Ensuring that easily navigable exceptions are available, both within the qualified plans selected to participate in the Health Insurance Marketplace and Medicaid managed care plans, if these plans do not have benefits appropriate for people with cystic fibrosis. This is particularly important to ensure that people with cystic fibrosis have access to the high quality specialty care delivered at accredited care centers.

The CF Foundation stands ready to assist you and your administration as you complete development of the upcoming budget. We thank you in advance for your consideration of our needs and look forward to working with you as we continue to add tomorrows for people with cystic fibrosis.

Sincerely,



Robert J. Beall, PhD  
President and Chief Executive Officer



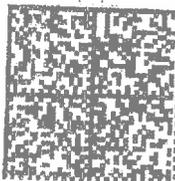
Mary B. Dwight  
Vice President of Government Affairs



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The Honorable Anthony Keck  
Director

Department of Health & Human Services  
1801 Main Street  
Columbia SC 29201-8206



Hasler

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02/04/2013

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FEB 07 2013

Department of Health & Human Services  
OFFICE OF THE DIRECTOR

29201240501





March 21, 2013

Robert J. Beall, PhD  
President and Chief Executive Officer  
Cystic Fibrosis Foundation  
6931 Arlington Road  
Bethesda, Maryland 20814

Dear Dr. Beall:

Thank you for your letter advocating for the citizens of South Carolina with Cystic Fibroses. We appreciate the opportunity to be of assistance.

Governor Nikki Haley has decided not to accept the Expansion of Medicaid for South Carolina under the Patient Protection and Affordable Care Act (ACA). The South Carolina Department of Health and Human Services (SCDHHS) will continue to focus our efforts on three strategic pillars; payment reforms, clinical integration, and targeting hotspots and disparities which we believe can have a positive impact for our beneficiaries. To achieve payment reform, the department has implemented incentives and withholds for Managed Care Organizations, payer-provider partnerships, and value based insurance design. Clinical integration is being achieved by focusing on patient centered medical homes, dual eligible care coordination and telemedicine/monitoring. Hotspots and disparities are being addressed by the birth outcomes initiative, foster care coordination, and the Health Access Right Time (HeART) program.

For the State of South Carolina, more South Carolinians will be enrolled with Medicaid due to President Obama's mandate that all citizens have medical insurance beginning January 1, 2014. Individuals with Cystic Fibroses, as well as other recipients, will continue to receive their current level of care. The Department continues to work on improving value in the health system that affects all citizens in the state, and to set performance expectations for health systems to improve value. All of these activities will benefit the constituents that your organization serves.

Thank you for your continued support and if you have any additional questions please feel free to call Valeria Williams, Program Director at 803-898-3477.

Sincerely,

Melanie "BZ" Giese, RN  
Deputy Director

MG/ajr

DEPARTMENT OF HEALTH AND HUMAN SERVICES  
OFFICE OF DIRECTOR

**ACTION REFERRAL**

TO <i>Giese</i>	DATE <i>2-7-13</i>
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February 1st, 2013

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President and Chief Executive Officer



Mary B. Dwight  
Vice President of Government Affairs



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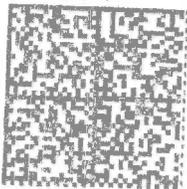
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