

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO <i>Grise</i>	DATE <i>2-7-12</i>
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DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>101305</i>	<input type="checkbox"/> I Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>cc: Mr. Hoek</i>	<input type="checkbox"/> I Prepare reply for appropriate signature DATE DUE _____
	<input type="checkbox"/> I 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.			
2.			
3.			
4.			



...adding tomorrows every day.

RECEIVED

January 30, 2012

FEB 03 2012

Department of Health & Human Services
OFFICE OF THE DIRECTOR

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

Dear Director Keck;

On behalf of people in South Carolina living with cystic fibrosis (CF), we urge you to support strong funding for health care and Medicaid in the 2013 budget. Families and individuals with cystic fibrosis (CF) rely on these vital programs to afford the medical care that they need to survive.

Cystic fibrosis is a genetic disease that affects 30,000 children and adults in the United States and 70,000 people worldwide. It is primarily a lung disease caused by a defective gene that makes the body produce thick, sticky mucus that clogs the lungs and leads to life-threatening infections. When the CF Foundation was established in 1955, people with cystic fibrosis rarely lived to attend grade school. Today, thanks to medical research and new treatments, people are living into their 30s, 40s and beyond. 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.

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 around \$76,000 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.

We recognize that economic considerations are forcing all states to make tough choices and that the "easy" cuts have already been made. Nevertheless, we urge you to remember that access to appropriate health care makes the critical difference in improving the longevity and quality of life for people with CF as well as the economic health of the state.

We thank you for your help in preserving the funding for these critical programs and look forward to working with you as we continue to add tomorrows for people with cystic fibrosis.

Sincerely,

Handwritten signature of Robert J. Beall in black ink.

Handwritten signature of Mary B. Dwight in black ink.

Robert J. Beall, PhD
President and Chief Executive Officer
National Office

Mary B. Dwight
Vice President of Government Affairs

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