

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO <i>Singleton</i>	DATE <i>3-27-14</i>
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DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER 000336	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>* Attached is last years response.</i> <i>* Extend until 4/15/14, per Cynthia on 4/4/14</i>	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>4-15-14</i>
	<input type="checkbox"/> FOIA DATE DUE _____
	<input 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>Cleared 7-14-14, letter attached.</i>			
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Any response
needed?

RECEIVED

MAR 10 2014

Department of Health & Human Services
OFFICE OF THE DIRECTOR

February 28, 2014

Director Tony Keck
Medicaid Director
South Carolina Department of Health & Human Services
1801 Main Street PO Box 8206
Columbia, SC 29201

File NON-Log
PLS - Thx!

Dear Director Keck,

On behalf of people in South Carolina living with cystic fibrosis (CF), we urge you to protect Medicaid, Children with Special Health Care Needs programs, and other state health care programs as your state continues budget negotiations. These programs promote access to the high quality, specialized care and treatments that people with cystic fibrosis rely on for optimal health. We also offer the expertise and support of the Cystic Fibrosis Foundation as you undertake the challenge of developing the state's priorities for health care funding and operations in the upcoming term.

Cystic fibrosis is a life-threatening genetic disease that affects 30,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to serious, life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. For this reason, it is vitally important that all people with CF are able to access appropriate CF treatments and care by cystic fibrosis experts at accredited care centers.

In order to help people with the disease retain access to the care and coverage needed 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 FY 2015 Budget

Although real progress has been made, the lives of young people with cystic fibrosis are still cut far too short; half of young adults with this disease still die before age 26. Nationwide statistics show that while 98% of people with CF have some type of health insurance coverage, nearly a quarter of CF patients delay necessary medical care or skip prescribed treatments due to cost concerns. This number rises to one in three patients among low-income households.

For people with cystic fibrosis, adequate coverage is not a luxury, it is a necessity. Without access to expert CF care and treatments, the risk of lung exacerbations, costly hospitalizations, irreversible lung damage, and decreased quality of life increases dramatically. Medicaid, Children with Special Health Needs and other state health care programs help people living with cystic fibrosis better afford increasing out-of-pocket costs for lifesaving treatments and care. Often, these programs serve to bridge coverage gaps left by other types of health care insurance. We strongly urge that you provide the same level of funding, or better, for these crucial health care programs.

National Office

6931 Arlington Road, Suite 200, Bethesda, Maryland 20814
301.951.4422 800.FIGHT.CF Fax: 301.951.6378
www.cff.org email: info@cff.org

Ensure Access to High Quality, Specialized Care

Maintaining lung function and nutritional status as well as preventing lung infections and treating them when such prevention fails requires access to a number of different therapies delivered according to evidence-based standards of care. Availability of FDA-approved treatments and high quality CF care is critical to management of this disease and the achievement of the best possible health status.

It is vital that people with CF are able to access all FDA-approved treatments and receive 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 ability to receive the high quality, specialized care available in at accredited CF care centers.

The specialized medications that form the core of cystic fibrosis treatment must remain accessible to CF patients. Barriers to these orphan drugs, such as high co-payments, excessive co-insurance rates and exceedingly burdensome prior authorization requirements, should not hinder a patient's ability to receive a treatment given a clear medical need.

The CF Foundation stands ready to assist you as you prepare for the upcoming fiscal year. Thank you for considering the needs of people with cystic fibrosis, we look forward to working with you to continue to *add tomorrows* for all people living with this disease.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a large initial "M" and "D".

Mary B. Dwight
Vice President for Government Affairs

✓

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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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>
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1. <i>Val Williams</i>	<i>3-13-13</i>		
2. <i>BB Grew</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

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
SUITE 200
BETHESDA, MD 20814

T: 800.FIGHT.CF
T: 301.951.4422
F: 301.951.6378

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

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FEB 07 2013

Department of Health & Human Services
OFFICE OF THE DIRECTOR

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

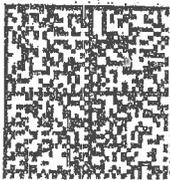


NATIONAL OFFICE
6931 ARLINGTON ROAD, SUITE 200
BETHESDA, MD 20814

The Honorable Anthony Keck

Director

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



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\$00.460

02/04/2013

Mailed From 20814
US POSTAGE

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FEB 07 2013

Department of Health & Human Services
OFFICE OF THE DIRECTOR

29201 29201





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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DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>100-242</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
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**CYSTIC FIBROSIS
FOUNDATION**
ADDING TOMORROWS

February 1st, 2013

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

Dear Director Keck,

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FEB 07 2013

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Ensure Access to High Quality Specialized Care

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Sincerely,



Robert J. Beall, PhD
President and Chief Executive Officer



Mary B. Dwight
Vice President of Government Affairs

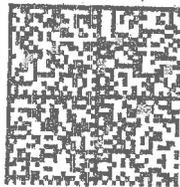


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The Honorable Anthony Keck

Director

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



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02/04/2013

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Department of Health & Human Services
OFFICE OF THE DIRECTOR

29201290901



Response to lrg letter
000336 7/14/14



Nikki Haley GOVERNOR
Anthony Keck DIRECTOR
P.O. Box 8206 > Columbia, SC 29202
www.scdhhs.gov

July 14, 2014

Ms. Mary B. Dwight, VP of Government Affairs
Cystic Fibrosis Foundation
6931 Arlington Road, Suite 200
Bethesda, Maryland 20814

Dear Ms. Dwight:

This correspondence serves as a response to the letter submitted to the Department by the Cystic Fibrosis Foundation requesting the Department's specific consideration for the needs of individuals with cystic fibrosis during its state fiscal year (SFY) 2014-15 budgeting process.

Thank you for writing on behalf of South Carolinians living with Cystic Fibrosis and other special health care needs. We commend you and your Organization's for the work you do in support of individuals with such a life-threatening disease.

In SFY 2013-14, the Medicaid program paid more than \$9.4 million in medical claims for approximately 2,200 individuals with a diagnosis of cystic fibrosis. The SFY 2014-15 Executive Budget places a major emphasis on protecting South Carolina's most vulnerable citizens by stabilizing the Medicaid program's finances and striving to make progress in reducing waiting lists for the waiver programs that serve disabled and special needs communities.

The SFY 2014-15 Executive Budget builds on key tenets of the Department's mission—to *purchase the most health for our citizens in need at the least possible cost to the taxpayer*. This approach ensures careful consideration of the needs of our population and allows us the opportunity to improve the existing coordinated care system with enhancements that we believe will work most successfully in South Carolina. Furthermore, it creates alignment with the administration's priorities from the very beginning—creating jobs and improving the business climate in South Carolina, providing a better education for our children, making our state a safer place to live and work, finding ways to develop our infrastructure without raising taxes, and protecting the most vulnerable members of our society.

Thank you again for your dedication and making it a great day in South Carolina. For questions related to financial matters, please contact Adriana Day by phone at (803) 898-0336 or by email at Adriana.Day@scdhhs.gov. For questions related to Health Programs, please contact Deirdra Singleton by phone at (803) 898-2647 or by email at singled@scdhhs.gov. For Pharmacy and Quality questions, please contact Bryan Amick by phone at (803) 898-0212 or by email at bryan.amick@scdhhs.gov. For questions regarding Health Services / Medicaid Managed Care policies, please contact me by phone at (803) 898-2018 or by email at pattnat@scdhhs.gov. For operational questions related to Health Services / Managed Care, please contact Stephen Boucher by phone at (803) 898-2938 or by email at boucher@scdhhs.gov.

Sincerely,



Nathaniel J. Patterson
Program Director, Health Services

cc: **Deirdra T. Singleton, Deputy Director**
Adriana Day, Chief Financial Officer
Donna Parker, Accounting/Fiscal Manager
Bryan Amick, Program Director
Stephen Boucher, Operations Director
Jeff Saxon, Program Manager
Valeria Williams, Program Director
Amanda Williams, Program Manager
Kevin Bonds, Program Manager
Evan Gessner, Assistant General Counsel
Cynthia Gore, Executive Assistant
Courtney Sanders, Administrative Assistant

To Note 4/9/14

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

RECEIVED
April 1, 2014
MAR 31 2013

Department of Health & Human Services
Office of Health Programs

ACTION REFERRAL

TO <i>Singleton/Patterson/William</i>	DATE <i>3-27-14</i>
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Sincerely,

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Mary B. Dwight
Vice President for Government Affairs

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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



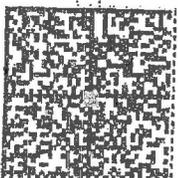
Mary B. Dwight
Vice President of Government Affairs



NATIONAL OFFICE
6931 ARLINGTON ROAD, SUITE 200
BETHESDA, MD 20814

The Honorable Anthony Keck
Director

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



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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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DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>101-242</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>cc: Mr. Keek</i>	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>2/21/13</i>
	<input type="checkbox"/> FOIA DATE DUE _____
	<input 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.			



**CYSTIC FIBROSIS
FOUNDATION**
ADDING TOMORROWS

February 1st, 2013

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

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.

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Department of Health & Human Services
OFFICE OF THE DIRECTOR

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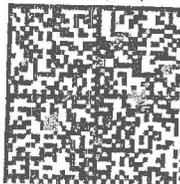


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