DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF DIRECTOR

ACTION REFERRAL

TO	DATE
Jacobs	10-17-08

DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER 000214	[ ] Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR Cleared 10/24/08, letter attached ✓	[X] Prepare reply for appropriate signature DATE DUE 10-28-08
	[ ] FOIA DATE DUE _____
	[ ] 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.			

JIM DeMINT
SOUTH CAROLINA

CHAIRMAN, SENATE STEERING COMMITTEE

340 RUSSELL SENATE OFFICE BUILDING
WASHINGTON, DC 20510
(202) 224-6121
demint.senate.gov

United States Senate

COMMITTEES:
COMMERCE, SCIENCE AND TRANSPORTATION

ENERGY AND NATURAL RESOURCES

FOREIGN RELATIONS

JOINT ECONOMIC

OFFICE OF SENATOR JIM DEMINT
1901 MAIN STREET, SUITE 1475
COLUMBIA, SC 29201
PHONE: (803)771-6112 FAX: (803) 771-6455

FACSIMILLE TRANSMITTAL SHEET

TO:

Ms. Emma Forkner – Director

COMPANY: South Carolina Department of Health and Human Services	**DATE:** October 17, 2008
FAX NUMBER: 803-255-8235	**NO. OF PAGES, INCLUDING COVER:** 12
PHONE NUMBER: 803-898-2500	**SENDER'S PHONE NUMBER:** (803) 771-6112
RE: Mrs. Allison Shipman and Mr. Grayson Shipman	**SENDER'S FAX NUMBER:** (803) 771-6455

☐ LUKE BYARS	☐ KELLY LONG	☐ RYAN DAWKINS
☐ IAN HEADLEY	☐ JEAN MOORE	☐ KATI YOUMANS
☒ CANDICE BOATWRIGHT	☐ TIM LOLLIS	☐

NOTES/COMMENTS:

Hello Ms. Forkner.

Please review the following correspondence by Ms. Allison Shipman regarding her son, Grayson Shipman's, TEFRA application. Please let me know if I can be of additional assistance. I look forward to your response.

Sincerely,

Candice

Candice Boatwright
803-771-6112
Candice_Boatwright@demint.senate.gov

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JOINT ECONOMIC

October 17, 2008

RECEIVED
OCT 17 2008
Department of Health & Human Services
OFFICE OF THE DIRECTOR

Ms. Emma Forkner
Director
South Carolina Department of Health and Human Services
PO Box 8206
Columbia, SC 29202-8206

Dear Friend,

I am writing on behalf of my constituent, Mrs. Allison Shipman, about her request for assistance regarding her son, Grayson Shipman's application for TEFRA. Enclosed is a copy of her letter for your review.

I would greatly appreciate your addressing the questions and concerns mentioned in Mrs. Shipmans' correspondence, with respect to governing rules and regulations. I have assured Allison that I would write to emphasize my interest in her case and to help obtain a reply from your office.

Thank you for your help. Please feel free to call Candice of my staff at 803-771-6112 if you have any questions or need additional information. I look forward to your prompt reply to our Columbia office.

Sincerely,

Jim DeMint
United States Senator

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October 3, 2008

Allison W. Shipman

204 Alton Pl.

Columbia, SC 29210

Senator Jim DeMint
1901 Main Street
Suite 1475
Columbia, SC 29201

Dear Senator Demint:

My name is Allison Shipman. I am the parent of a four year old born with Cystic Fibrosis. We applied for TEFRA when he was diagnosed at 3 months old and was denied. In August of 2007, he had to get a feeding tube to help him put on needed weight. We re-applied for TEFRA in January 2008, and again denied in August 2008. We are appealing this decision and have a hearing set for October 13, 2008.

The reason for his denial was for failure to meet disability requirements. We feel he meets the disability requirements for having digestive and pulmonary disorders associated with having Cystic Fibrosis. We currently pay out of our own pocket close to $20,000 a year for our rising insurance premiums, our high deductible, and any extra medical expenses not covered.

Any help you can give would be greatly appreciated.

Thank you so much,

Allison Shipman

Allison Shipman

Appeal Summary

Petitioner: Allison Shipman for Grayson Shipman
Medicaid ID # 0780276935
Payment Category: 57 TEFRA Medicaid

On March 13, 2008 a TEFRA Medicaid application for Grayson Shipman was received in the Division of Central Eligibility Processing. The application was reviewed for completeness.

The Level of Care Assessment Form was sent to Community Long Term Care for evaluation on March 26, 2008. On April 30, 2008 the decision was received stating that Grayson did meet level of care for Skilled Nursing Facility.

On May 13, 2008 the Disability Decision Referral was sent to the Department of Vocational Rehabilitation. On August 18, 2008 the decision was received stating that Grayson did not meet the disability criteria.

Grayson was determined financially eligible for TEFRA Medicaid. He has neither income nor resources. The application met all other non-financial criteria such as a child under age 19, furnished Social Security numbers, SC residency, US citizenship, assigned rights to medical support and not an inmate of a public institution.

The TEFRA Coordinator subsequently denied the Medicaid application on August 20, 2008, because the disability criteria was not met. The denial notice was mailed to Allison W. Shipman on August 21, 2008. Medicaid Manual Sections 101.13.04, 101.08.02, 101.09.03, 101.09.04, 102.06, and 305.01of the Medicaid Policy Manual support our decision.

Prepared by:
Monica Williams, TEFRA Coordinator
Division of Central Eligibility Processing
September 2, 2008

Grayson Shipman was diagnosed with cystic fibrosis at 3 months. He was first diagnosed with "failure to thrive", and eventually tested positive for CF through genetic testing. Cystic fibrosis is an inherited chronic disease that affects the lungs and digestive system. A defective gene and its protein product cause the body to produce unusually thick, sticky mucus that: clogs the lungs and leads to life-threatening lung infections; and obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food.

Dr. Daniel Brown of Pediatric Pulmonary Associates was the first to diagnose him. Due to his frequent problems with his digestive system, he was also referred to Dr. Abernath, a pediatric Gastroenterologist who placed him on a special diet and meds such as Zantac and later Reglan to help with his reflux. He has continued to have challenges in this area and has since seen Dr. Via Goei, a pediatric Gastroenterologist from MCG Children's Medical Center. Due to the continuing complications and lack of gaining weight, he had to get a gastrostomy button for supplementary night feedings.

Below is a summary of illnesses as they pertain to Social Security's Childhood Listing of Impairments:

105.00 Digestive System

A. What kinds of disorders do we consider in the digestive system?

Disorders of the digestive system include gastrointestinal hemorrhage, hepatic (liver) dysfunction, inflammatory bowel disease, short bowel syndrome, and malnutrition. They may also lead to complications, such as obstruction, or be accompanied by manifestations in other body systems. Congenital abnormalities involving the organs of the gastrointestinal system may interfere with the ability to maintain adequate nutrition, growth, and development.

Grayson's disability (blocked pancreas and GERD due to CF) is expected to last his lifetime. He is currently almost 5 years old and due to poor nutrition and weight gain, he had to get a gastrostomy button to supplement his feeding. His surgeon, Walter Pipin, stated, he "will need his gastrostomy indefinitely and possibly his entire life." He has had 3 surgeries due to complications with his g-button. With the g-button, his weight has to be carefully monitored to his body will be able to fight off infections and for his BMI to be on target. He continues to struggle with his weight staying on par with his height growth. He is also on Polyethylene Glycol to help with his bloating and cramping of his stomach due to the CF. Each meal he takes a Pediasure with added calories such as Scandishake mix, chocolate syrup, canola oil, and a probiotic to help with the bacteria in his stomach prescribed by Dr. Goei and his Dietian, Kristen Middleton of MCG Children's Hospital. He has also been on several meds due to his GERD (Zantac, Reglan, and presently Prevacid). Due to the CF related bloatedness and pain; he is unable to be hooked up the tube feedings on some nights. He is also unable to take the feedings during the day due to feeling

anxiety associated with it. He recently began to complain of chest pain and is seeing a new pediatric gastroenterologist at MCG Oct. 21 to try to figure out what is going on with these new problems.

B. What documentation do we need?

We need a record of your medical evidence, including clinical and laboratory findings. The documentation should include appropriate medically acceptable imaging studies and reports of endoscopy, operations, and pathology, as appropriate to each listing, to document the severity and duration of your digestive disorder. We may also need assessments of your growth and development. Medically acceptable imaging includes, but is not limited to, x-ray imaging, sonography, computerized axial tomography (CAT scan), magnetic resonance imaging (MRI), and radionuclide scans. Appropriate means that the technique used is the proper one to support the evaluation and diagnosis of the disorder. The findings required by these listings must occur within the period we are considering in connection with your application or continuing disability review.

Grayson's diagnosis of CF was confirmed with the blood work conducted on him when he was three months old.

Also, documents of his multiple g-button surgeries and complications due to digestive issues associated with CF.

C. How do we consider the effects of treatment?

1. Digestive disorders frequently respond to medical or surgical treatment; therefore, we generally consider the severity and duration of these disorders within the context of the prescribed treatment.

As stated above, due to his inability to take in enough calories for his growth and to fight infections, a g-tube was needed. He will need his g-tube indefinitely due to the severity his "failure to thrive."

2. We assess the effects of treatment, including medication, therapy, surgery, or any other form of treatment you receive, by determining if there are improvements in the symptoms, signs, and laboratory findings of your digestive disorder. We also assess any side effects of your treatment that may further limit your functioning.

3. To assess the effects of your treatment, we may need information about:

a. The treatment you have been prescribed (for example, the type of medication or therapy, or your use of parenteral (intravenous) nutrition or supplemental enteral nutrition via a gastrostomy);

He currently takes two cans of "Carnation Very High Calorie" ready-made drink nightly. They each have 560 calories per can. This seems to work well, except when his stomach is hurting, or he has a sinus infection and coughs so hard at times at night, he throws up his formula. So, to prevent that, we don't hook him up when he is sick or in pain.

4. Because the effects of treatment may be temporary or long-term, in most cases we need information about the impact of your treatment, including its expected duration and side effects, over a sufficient period of time to help us assess its outcome. When adverse effects of treatment contribute to the severity of your impairment(s), we will consider the duration or expected duration of the treatment when we assess the duration of your impairment(s).

The night feedings seem to be improving Grayson's weight gain. The only side effects are the frequent tissue granulation episodes and when the g-button falls out on its own and must quickly be replaced or re-inserted.

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5. If you need parenteral (intravenous) nutrition or supplemental enteral nutrition via a gastrostomy to avoid debilitating complications of a digestive disorder, this treatment will not, in itself, indicate that you have marked and severe functional limitations. The exceptions are 105.07, short bowel syndrome, and 105.10, for children who have not attained age 3 and who require supplemental daily enteral feedings via a gastrostomy (see 105.00F and 105.00H).

As an infant, Grayson was a strong candidate for the g-button. He had the surgery at age 3.

G. How do we evaluate malnutrition in children?

1. Many types of digestive disorders can result in malnutrition and growth retardation. To meet the malnutrition criteria in 105.08A, we need documentation of a digestive disorder with associated chronic nutritional deficiency despite prescribed treatment.

See growth charts.

2. We evaluate the growth retardation criteria in 105.08B by using the most recent growth charts by the Centers for Disease Control and Prevention (CDC).

b. If you are a child age 2 or older, we use BMI-for-age measurements to assess whether your impairment meets the requirement of 105.08B2. BMI is the ratio of your weight to the square of your height. BMI-for-age is plotted on the CDC's gender-specific growth charts.

See growth charts.

H. How do we evaluate the need for supplemental daily enteral feeding via a gastrostomy?

1. General. Infants and young children may have anatomical, neurological, or developmental disorders that interfere with their ability to feed by mouth, resulting in inadequate caloric intake to meet their growth needs. These disorders frequently result in the medical necessity to supplement caloric intake and to bypass the anatomical feeding route of mouth-throat- esophagus into the stomach.

Grayson's lack of appetite and inability to feed enough by mouth made it medically necessary to get a g-tube. His surgeon, Walter Pipkin stated he was "nutritionally at-risk" without it.

2. Children who have not attained age 3 and who require supplemental daily enteral nutrition via a feeding gastrostomy meet 105.10 regardless of the medical reason for the gastrostomy. Thereafter, we evaluate growth impairment under 100.02, malnutrition under 105.08, or other medical or developmental disorder(s) (including the disorder(s) that necessitated gastrostomy placement) under the appropriate listing(s).

He received the tube at age three.

103.00 Respiratory System

A. Introduction. The listings in this section describe impairments resulting from respiratory disorders based on symptoms, physical signs, laboratory test abnormalities, and response to a regimen of treatment prescribed by a treating source. Respiratory disorders, along with any associated impairment(s) must be established by medical evidence. Evidence must be provided in sufficient detail to permit an independent reviewer to evaluate the severity of the impairment. Reasonable efforts should be made to ensure evaluation by a program physician specializing in childhood respiratory impairments or a qualified pediatrician.

> **Two methods are acceptable: the "Procedure for the Quantitative Iontophoretic Sweat Test for Cystic Fibrosis" published by the Cystic Fibrosis Foundation and contained in, "A Test for Concentration of Electrolytes in Sweat in Cystic Fibrosis of the Pancreas Utilizing Pilocarpine Iontophoresis," Gibson, L.E., and Cooke, R.E., Pediatrics, Vol. 23:545, 1959; or the "Wescor Macroduct System." To establish the diagnosis of cystic fibrosis, the sweat sodium or chloride content must be analyzed quantitatively using an acceptable laboratory technique.**

Another diagnostic test is the "CF gene mutation analysis" for homozygosity of the cystic fibrosis gene.

Grayson was diagnosed with CF using the CF gene mutation analysis. He had the Delta F508 and G21+1 GT

The pulmonary manifestations of this disorder should be evaluated under 103.04. The nonpulmonary aspects of cystic fibrosis should be evaluated under the listings for digestive system (105.00) or growth impairments (100.00). Because cystic fibrosis may involve the respiratory and digestive body systems, as well as impact on a child's growth and development, the combined effects of this involvement must be considered in case adjudication.

All apply in Grayson's case (digestive issues/lung issues/growth issues)

Medically acceptable imaging includes, but is not limited to, x-ray imaging, computerized axial tomography (CAT scan) or magnetic resonance imaging (MRI), with or without contrast material, myelography, and radionuclear bone scans. "Appropriate" means that the technique used is the proper one to support the evaluation and diagnosis of the impairment.

103.04 Cystic fibrosis. With:

A. An FEV1 equal to or less than the appropriate value specified in Table III corresponding to the child's height without shoes. (In cases of marked spinal deformity, see. 103.00B.);

or

B. For children in whom pulmonary function testing cannot be performed, the presence of two of the following:

Persistent pulmonary infection accompanied by superimposed, recurrent, symptomatic episodes of increased bacterial infection occurring at least once every 6 months and requiring intravenous or nebulization antimicrobial treatment;

Grayson has tested positive for Pseudomonas consistently since 04/05. He is treated with CIPRO for 42 days for the PA and is on TOBI 28 days on and 28 days off.

Grayson has tested positive for Stenotrophomonas consistently since 06/05. He is treated with SEPTRA each time.

These are bacteria that slowly eat away at your lung tissue. Having these bacteria also means he will have an increased likelihood of having serious lung infections throughout his life. He has to be on heavy antibiotics each time he tests positive for it and an inhaled med he does every other month that costs over $3,000. In addition, to help keep the mucous off his lungs, he does daily breathing treatments with a vest that vibrates rapidly on his chest for 30 minutes twice a day and inhaled meds that open his lungs and help him cough up the mucous twice a day. He is also on allergy meds since he has frequent sinus infections due to the mucous buildup in his nasal cavity

E. Growth impairment as described under the criteria in 100.00.

Reason for g-tube.

Daily Functional Limitations

Grayson requires more care than a typical healthy four-year old. We let him sleep as long as he can since sleep helps him fight off infections. Once he wakes up, his day begins with eating his special breakfast of pediasure with scandishake, olive oil, and chocolate syrup for the needed added calories. During his meal, he takes 3 capsules of pancreatic enzymes that must be opened up and given with fruit juice to ensure his body will absorb the needed nutrients and calories. He is also given a probiotic once a day. He has to take enzymes with any snack. After breakfast, he is hooked up to his vest, which vibrates his chest to loosen the mucous. The machine is paused every 5 minutes to allow him to cough up the mucous. He does this for 30 minutes twice day unless he is sick, we increase it to 45 minutes a day or three times a day. During this treatment, he also has 2 inhaled meds (Mucomist and Albuterol) that he breathes with a nebulizer. He also inhales (Advair) twice a day to help with his wheezing. Every other month he has an additional breathing treatment (Tobramycin) that takes 30 minutes twice a day. Due to his stomach cramping and digestive issues often times his breathing treatments are interrupted for him to run to the bathroom. After his treatments, he takes a special vitamin for persons with CF, and a Prevacid. For lunch he takes 3 enzymes with his meals. Our evenings consist of all of his breathing treatments, enzymes with dinner and then a bath. He also takes another Prevacid, allergy meds, and a decongestant if needed. One is orally (Claritin) and one is in his nose (Nasonex). Before he goes to bed, he takes three more enzymes to get him ready for his night feedings. Each night, we hook him up to a feeding tube since his weight has been a challenge since his birth. He was in the 10% for his weight and BMI since last August and he needs to be in the 50%. The feeding pump feeds him for several hours throughout the night. Due to stomach cramping he wakes up often in the night crying and has to be disconnected prematurely. Because his needs cannot be met in a standard day-care setting, it is necessary for one parent to not work and care for him at home. This further increases the financial burden caused by his illness.

The cost of caring for him is significantly more than that of a typical healthy four year old. In addition to visiting his general pediatrician for routine well check up and sick visits, he is seen every three months by his pediatric pulmonary specialist and soon a new pediatric gastroenterologist at his CF clinic visit along with a social worker, child psychologist, respiratory therapist, and dietitian. He also has to get his g-button replaced by his pediatric surgeon every three months (if not before). Along with this visits he also needs items not covered by insurance such as: syringes for meds, special formulas for his day and night feedings (Pedisure & Carnation Very High Calorie formula), Scandishake for extra calories, replacement nebulizers, over the counter Claritin for allergies, flu shots for adults in household, probiotics (Culturell), Gycolax (constipation), and lots of hand sanitizer and disinfectant sprays to keep him safe from germ exposure. His CF specialists are all

located in Augusta, GA. This makes the traveling expenses an additional financial challenge and finding childcare for our other two children.

Below is an itemization of recurring monthly medical expenses related to his illness (Note: the expenses listed below are the minimum amount each month and do not include unexpected doctor visits, extra formula/calories and other extraordinary expenses):

We have to pay a $4,000 deductible before our insurance pays for anything. In 2008, we met that January 4. After we meet the deductible we still have these expenses:

Item	Cost per Month	Our Part
Claritin	$11.00	$11.00
Scanidshake	$22.50	$22.50
Carnation VHC	$38.00	$38.00
Syringes	$8.40	$8.40
Polyethylene Glycol	$33.00	$33.00
Pediasure	$204.00	$204.00
Culturelle	$18.00	$18.00
Nebulizer equipment	$2.50	$2.50
Adult flu shots	$7.50	$7.50
	$344.90	$344.90

$4,000 deductible + yearly expenses ($4,138.80) =$8,138.80

Rising health premiums are the biggest cost. From about $250/month four years ago to $1000/month now. We can't switch providers because of his CF and our premiums continue to rise.

Leg #0214

State of South Carolina
Department of Health and Human Services

Mark Sanford
Governor

Emma Forkner
Director

October 24, 2008

Ms. Allison W. Shipman
204 Alton Plantation
Columbia, South Carolina 29210

Dear Ms. Shipman:

Senator Jim DeMint asked our agency to assist with your questions concerning Medicaid eligibility.

Your fair hearing for the denial of Grayson's application for Medicaid's Tax Equity and Fiscal Responsibility Act (TEFRA) was held on October 13, 2008. You requested that your appeals case remain open until you submit additional medical documentation from Dr. Valerie Hudson to support your case. As requested, your case will remain open until November 3, 2008. Once the information from Dr. Hudson is received, it will be reviewed and you will be notified of our decision promptly. If you have any questions regarding the appeals process, please contact your hearing officer, Robert French, at (803) 898-2714.

Enclosed is information on other programs and organizations that may be able to assist with prescriptions, inpatient hospitalization and healthcare needs. If you have questions about the Medicaid program, please contact Jennifer Lynch at (803) 898-3965 or 1-888-549-0820, Ext. 3965 (toll-free). We hope this information is helpful.

Sincerely,

Alicia Jacobs

Alicia Jacobs
Acting Deputy Director

AJ/col
Enclosures

Medicaid Eligibility and Beneficiary Services
P.O. Box 8206 • Columbia, South Carolina 29202-8206
Phone (803) 898-2502 • Fax (803) 255-8235

State of South Carolina
Department of Health and Human Services

Mark Sanford
Governor

Emma Forkner
Director

October 28, 2008

The Honorable Jim DeMint
United States Senate
1901 Main Street, Suite 1475
Columbia, South Carolina 29201

Dear Senator DeMint:

Thank you for referring Ms. Allison Shipman to our agency with her concerns about Medicaid coverage for her son, Grayson.

A member of our staff has been in direct contact with Ms. Shipman regarding the Medicaid appeals process. We mailed her information on programs and organizations that may assist with Grayson's prescription medications, inpatient hospitalization and other healthcare needs.

Thank you for your continued interest and support of the South Carolina Medicaid program. If I may be of further assistance on this or any other matter, please let me know.

Sincerely,

Emma Forkner
Director

EF/jcol