

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

ACTION REFERRAL

TO <i>Myers</i>	DATE <i>6-22-09</i>
--------------------	------------------------

DIRECTOR'S USE ONLY	ACTION REQUESTED
1. LOG NUMBER <i>101592</i>	<input type="checkbox"/> Prepare reply for the Director's signature DATE DUE _____
2. DATE SIGNED BY DIRECTOR <i>Claud velayo letter attached.</i>	<input checked="" type="checkbox"/> Prepare reply for appropriate signature DATE DUE <i>7-1-09</i>
	<input type="checkbox"/> FOIA DATE DUE _____
	<input type="checkbox"/> Necessary Action

	APPROVALS <small>(Only when prepared for director's signature)</small>	APPROVE	* DISAPPROVE <small>(Note reason for disapproval and return to preparer.)</small>	COMMENT
1.				
2.				
3.				
4.				

South Carolina
Department of Health and Human Services
Post Office Box 8206
Columbia, South Carolina 29202-8206

April 22, 2009

*I would like
to see how
this will look
in work*

Memorandum

To: Charles "Mike" Blakely, Division of Hospitals
From: Vastine G. Crouch, ^{PR} Director
Division of Appeals, SCDHHS
Subject: Timothy T. Carter, ID#2780143475

*back
APRIL
B2*

As we discussed.

Since the Dr. states this is an initial request, there is no reason to respond back to me.

thanks

RECEIVED
Dept. of Health
& Human Services

JUN 22 2009

Bureau of
Health Services

RECEIVED

JUN 22 2009

Department of Health & Human Services
OFFICE OF THE DIRECTOR

Scan - M1385706

MUSC

CHILDREN'S HOSPITAL

Genetics and
Developmental Pediatrics

135 Rutledge Avenue
PO Box 250567
Charleston • SC 29425

Ph (843) 876-1511
Fax (843) 876-1518

Date: April 9, 2009

Division of Appeal & Hearing
Department of Health and Human Services
PO BOX 8206
Columbia, SC 29202

RE: Timothy T. Carter

DOB: 01/14/1999
Medicaid I.D. 2780143475.



Dear Sirs:

This is an appeal to help me take care of Timothy Carter's current medical needs. I have known this child and his family since August, 2003 when I diagnosed with a genetic disorder Hunter syndrome also known as MPS type II.

His mother has done a heroic and exceptional job of taking care of his multiple special needs over the years while struggling as a single mother to take care of her young daughter Althea as well.

Timothy became eligible to receive Elaprase therapy in December 2006. The weekly intravenous infusions require him to be in the Children's Hospital Special Care Clinic for several hours. Over the last 2 years the disease has progressed to a point where this child's care has become immensely more complex due to the onset of seizures, neurological deterioration to a point where he cannot walk even with a walker. He has a stroller to assist mobility. He requires special accommodation to get him to school.

Currently his mother, a single mom, dependant on public transportation to get him to medical appointments, is further pushed due to her increasing need to take time off from work.

Thus, it would help her a great deal if Timothy's weekly Elaprase infusions can be done at home. He has a port in place to access the central venous system and will require appropriate equipment such as IV tubing, fluid, BP monitoring, oxygen source, mask etc to deal with unexpected events. He has tolerated the treatment very well since December 2006 and adverse events are not expected at this stage.

I truly appreciate a favorable and expedited review of this request.

Sincerely,

G. Shashidhar Pai, M.D.

Cc: Ms. Amanda Gladney (mother)

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Dept. of Health
& Human Services

JUN 22 2009

Bureau of
Health Services



Statement of Medical Necessity
for the treatment of Hunter syndrome (Mucopolysaccharidosis II, MPS II)

Patient Information

Name (Print, Middle Initial Last) Adult Juvenile Child Infant
1615 Norman Street Charleston SC 29403
Signal Address 843 1452 8141 1813 723 8022
Home Telephone (Area Code) (843) 723 8022
Patient Body Weight 24.3 kg Height 111 cm
SC Medicaid
Insurance Company Name
Insurance Telephone
Policy #
Group #

Physician Information

Physician Name (Print, Last) Paula J. Proven
Diagnosis: Mucopolysaccharidosis II (MPS II) Oct 27/75 Date Diagnosis: 05 2003
Method of Diagnosis: Enzyme Assay Activity 0 Serum Skin Fibroblasts
Urinary GAG 141 mg coordinate
Additional comment: Timothy has elevated skeletal and (aggressive multiple) on X-ray & typical clinical phenotype of MPS II gene mutation identified by the Proven Group

Diagnosis and Treatment Information

Treatment Recommendation: Enzyme? (Indicate if available) NO (MPS 1-6)
Dose: 0.6 mg/kg of body weight Frequency: Weekly IV route:
G. Skasidhan Pay SC 10267
Name (Print Last) Paula J. Proven
135 Ruffledge Avenue South License # Charleston SC 29425
Street Address 843 1876 1576 1845 896 1518
Telephone Fax
Identify that the rationale for prescribing ENZYME is necessary, necessary and the treatment provided on this form is accurate to the best of my knowledge.

Physician Signature

Paula J. Proven

RECEIVED
APR 17 2003
SCDHHS

RECEIVED & HEARING
APR 19 2006
SCDHHS

From: Vastine Crouch
To: Charles "Mike" Blakely
Date: 6/18/2009 2:42 PM
Subject: Re: Timothy Carter

okay, thanks

>>> Charles "Mike" Blakely 6/18/2009 2:20 PM >>>
Pharmacy can't help, I have sent it back to you this morning.

>>> Vastine Crouch 6/18/2009 2:08 PM >>>
mike, i really need to get this back if Pharmacy isn't going to be able to make this go away.

Mr. Vastine G. Crouch, Director
SCDHHS Division of Appeals
PO Box 8206
Columbia, SC 29202
803-898-2600
803-255-8206 (FAX)
vcrouch@scdhhs.gov

>>> Charles "Mike" Blakely 6/12/2009 2:12 PM >>>
I found the letter from Dr. Pa re Timothy Carter, you have a cover stating that since this is an initial request, there is no reason to respond to you. I can send the original letter back to you.

This is an infused drug, the letter should probably go to hospital services for potential outpatient infusion closer to the mother's home. However it appears that they live in Charleston, close to MUSC.

Should not really be considered for home infusion even if the child qualifies for home health. Needs to be supervised with medical support available. I'm sure the physician would probably disagree with this.

I included an excerpt from the manufacturer below re use:

Life-threatening anaphylactic reactions have been observed in some patients during ELAPRASE infusions. Therefore, appropriate medical support should be readily available when ELAPRASE is administered. Biphasic anaphylactic reactions have also been observed after ELAPRASE administration and patients who have experienced anaphylactic reactions may require prolonged observation. Patients with compromised respiratory function or acute respiratory disease may be at risk of serious acute exacerbation of their respiratory compromise due to infusion reactions, and require additional monitoring.

From: Vastine Crouch
To: Charles "Mike" Blakely
Date: 6/12/2009 3:12 PM
Subject: Re: Timothy Carter

It would be great if you could send me back a copy of whatever I sent.
The reason I was following up now is that the Dr. said no one ever contacted/responded to his request.
I also checked with Zenovia after you pointed me her way. She said we spoke and she pointed me toward CLTC. I haven't gotten a response from CLTC as yet as to whether they looked into this. thanks
I remember reading similar precautions when I googled Hunter syndrome to try and figure out what this was.

Mr. Vastine G. Crouch, Director
SCDHHS Division of Appeals
PO Box 8206
Columbia, SC 29202
803-898-2600
803-255-8206 (FAX)
crouch@scdhhs.gov

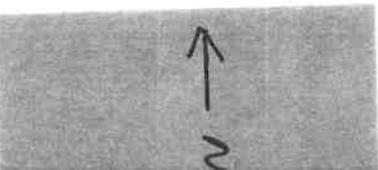
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Division of Appeal & Hearing
 Dept. of Health & Human Services
 PO Box 8206
 Columbia, SC 29202



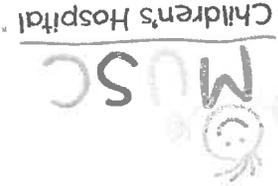
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 04/10/2009
 Mailed from 29403
 US POSTAGE

Master



PRESORTED
 FIRST CLASS

Genetics and Developmental Pediatrics
 135 Rutledge Avenue
 MSC 567
 Charleston • SC 29425-5670
 RETURN SERVICE REQUESTED





State of South Carolina
Department of Health and Human Services

Log # 692

Mark Sanford
Governor

Emma Forkner
Director

June 24, 2009

G. Shashidhar Pai, MD
MUSC Children's Hospital
Genetic and Developmental Pediatrics
135 Rutledge Avenue
P.O. Box 250567
Charleston, SC 29425

RE: Timothy T. Carter
Medicaid ID #2780143475

Dear Dr. Pai:

Thank you for talking with me regarding this young Medicaid beneficiary. Based on our conversation and your experience with this home infusion process and the participants in it, I am comfortable with supporting payment for these services.

This mother has profound logistics and transportation difficulties related to the distance they have to travel from home to your office in order to receive the Elaprase. Since you have had considerable experience with the local infusion venter in other cases, I believe it is appropriate for him to receive his weekly therapy at home. Please keep a copy of this letter in you files in case there is any difficulty in the future.

Thank you for you advocacy regarding this young patient and for caring for South Carolina Medicaid beneficiaries. If I could help further, please call me at 803-255-3400 or 803-898-2580,

Sincerely,

A handwritten signature in blue ink that reads "Marion Burton".

O. Marion Burton, MD
Medical Director



State of South Carolina
Department of Health and Human Services

Mark Sanford
Governor

Emma Forkner
Director

FAX COVER SHEET

“CONFIDENTIAL INFORMATION ENCLOSED”

DATE: 6-25-09

TO: G. Shashidhar Pai, MD

Telephone #: 843-876-1511

Fax #: 843-876-1518

FROM: Dr. O. Marion Burton

Total Number of Pages Transmitted: 1 (Including Cover Sheet)

COMMENTS:

Letter you have requested

Confidentiality Note

This message is intended for the use of the person or entity to which it is addressed and may contain information, including health information, that is privileged, confidential, and the disclosure of which is governed by applicable law. If the reader of this message is not the intended recipient, or the employee or agent responsible to deliver it to the intended recipient, you are hereby notified that any dissemination, distribution or copying of this information is **STRICTLY PROHIBITED**. If you have received this in error, please notify us immediately and destroy the related message. Thank you.



State of South Carolina
Department of Health and Human Services

Mark Sanford
Governor

Emma Forkner
Director

June 24, 2009

G. Shashidhar Pai, MD
MUSC Children's Hospital
Genetic and Developmental Pediatrics
135 Rutledge Avenue
P.O. Box 250567
Charleston, SC 29425

RE: Timothy T. Carter
Medicaid ID #2780143475

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Thank you for you advocacy regarding this young patient and for caring for South Carolina Medicaid beneficiaries. If I could help further, please call me at 803-255-3400 or 803-898-2580,

Sincerely,

A handwritten signature in cursive script, appearing to read "O. Marion Burton".

O. Marion Burton, MD
Medical Director

TRANSMISSION VERIFICATION REPORT

TIME : 06/25/2009 09:48

DATE, TIME
FAX NO./NAME
DURATION
PAGE(S)
RESULT
MODE

06/25 09:47
918438761518
00:00:15
02
OK
STANDARD

From: Marion Burton <Marion.Burton@uscmed.sc.edu>
To: Brenda James <JAMESBR@scdhhs.gov>, Marion Burto...
Date: 6/24/2009 5:08 am
Subject: RE: Re: Timothy Carter

CC: Felicity Myers <MYERSFC@scdhhs.gov>
Brenda, I am reviewing this case and will prepare a letter this morning. Copy will be e mailed to Marga and I will sign it when I come to the agency this afternoon. thanks

-----Original Message-----

From: Brenda James [mailto:JAMESBR@scdhhs.gov]
Sent: Tuesday, June 23, 2009 10:36 AM
To: Marion Burton; Marion Burton
Cc: Felicity Myers
Subject: Re: Timothy Carter
Importance: High

**** High Priority ****

Good morning Dr. Burton,

Per Felicity, we have a log that has been pending for 2 months regarding Timothy Carter, a patient of Dr. G. Shashidhar Pai. Need a response to this log ASAP. Let me know if you would like for me to fax it to Pat or just put in your chair. Thanks, bj

Confidentiality Note

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If you have received this in error, please notify us immediately and destroy the related message.

From: Marion Burton <Marion.Burton@uscmed.sc.edu>
To: Felicity Myers <MYERSFC@scdhs.gov>, Marion Bur...
Date: 6/24/2009 5:47 am
Subject: RE: Re: Timothy Carter

CC: Melanie Giese <GieseM@scdhs.gov>
Felicity, I actually heard about this request earlier but it was not sent up as a log. I will prepare a response this morning and we can get a letter out this afternoon. thanks

-----Original Message-----

From: Felicity Myers [mailto:MYERSFC@scdhs.gov]
Sent: Tuesday, June 23, 2009 12:25 PM
To: Marion Burton; Brenda James; Marion Burton
Cc: Melanie Giese
Subject: Re: Timothy Carter

Marion,
This just got logged in, but has been floating around the agency for two months and was not elevated to BC level until yesterday as I understand it. It is a request from a physician that I'd appreciate you looking at. Sorry about the ASAP but I feel bad that we, as an agency, dropped the ball.

>>> Brenda James 6/23/2009 10:36 AM >>>

Good morning Dr. Burton,
Per Felicity, we have a log that has been pending for 2 months regarding Timothy Carter, a patient of Dr. G. Shashidhar Pai. Need a response to this log ASAP. Let me know if you would like for me to fax it to Pat or just put in your chair. Thanks, bj

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