
SOUTH CAROLINA

Date: 2017-09-23 22:01:23

To: My Senator

From: Theresa Kendall

State: South Carolina

Email: [REDACTED]



My son has a rare genetic disorder EIEE12. He is the rarest of those other 3 known cases with this genetic disorder. He requires 24/7 hands on care, is nonverbal, uses adaptive equipment to help in his daily care. He can struggle daily when any budget cut is made to the Medicaid program. The domino effect impacts his life and well being. My son suffers from rare drop spells and seizures daily. He relies on Medicaid to allow him the much needed medical supplies he uses daily which is a manual wheelchair, adaptive walker, adaptive toilet and assistive technical devices to allow him to communicate his daily needs. Medicaid has allowed for him to continue to have well visits, receive therapies to help with his daily living skills, helps with his seizure meds and thrive with dietary supplements. Taking away from the Medicaid budget is going to shun a life in our own country. Would you be able to sleep at night knowing that extra penny taken from a precious life could literally kill someone? Please consider budget cuts from other resources before taking away from Medicaid.

Thank you for your consideration,

Theresa Kendall

Date: 2017-09-23 22:01:10

To: My Senator

From: Theresa Kendall

State: South Carolina

Email: [REDACTED]



My son has a rare genetic disorder EIEE12. He is the rarest of those other 3 known cases with this genetic disorder. He requires 24/7 hands on care, is nonverbal, uses adaptive equipment to help in his daily care. He can struggle daily when any budget cut is made to the Medicaid program. The domino effect impacts his life and well being. My son suffers from rare drop spells and seizures daily. He relies on Medicaid to allow him the much needed medical supplies he uses daily which is a manual wheelchair, adaptive walker, adaptive toilet and assistive technical devices to allow him to communicate his daily needs. Medicaid has allowed for him to continue to have well visits, receive therapies to help with his daily living skills, helps with his seizure meds and thrive with dietary supplements. Taking away from the Medicaid budget is going to shun a life in our own country. Would you be able to sleep at night knowing that extra penny taken from a precious life could literally kill someone? Please consider budget cuts from other resources before taking away from Medicaid.

Thank you for your consideration,

Theresa Kendall

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Thank you*

Nicole Jorwic

From: Yvette Hering [REDACTED]
Sent: Saturday, July 15, 2017 3:05 PM
To: Nicole Jorwic
Subject: South Carolina

In the state of South Carolina there are 29,445 residents with disabilities who receive Medicaid services. Our adult son with disabilities is one of those residents. He relies on Medicaid to be able to continue to live in the community. His disability will not improve and he will need help all of his life. At this time, there are more than 8,000 SC residents waiting for services through the Department of Disabilities and Special Needs. Please have a heart! No cuts or caps to Medicaid! Our most vulnerable citizens need your continued help.

Yvette & Rich Hering

Nicole Jorwic

From: Trina Morgan [REDACTED]
Sent: Saturday, July 15, 2017 11:11 AM
To: Nicole Jorwic
Subject: South Carolina

My name is Trina Morgan and I'm very concerned about the Better Care Act. My husband and I have been married for over thirty years and we have a severely disabled child, Marge. He works for a small company over 15 years that does not provide health insurance for families. Marge has severe Cerebral Palsy, Epilepsy, G-Tube, Bacolfen Pump and Spinal Fusion. Recently, she has had uncontrollable pain and she was diagnosed with Eosinophilic Esophagus, which is too many white blood cells in her esophagus. Marge is on the Ketogenic Diet, which controls her seizures and saves money because she does not have to be on expensive seizures medication. Unfortunately, the modifications that are now medically necessary are very inexpensive, as shown below.

Nutricia Complete Amino Acid Mix

58 grams daily

1,740 grams monthly

200 grams cost \$239.45

9 cans a month = \$2,155.05

[REDACTED]

Abbot Elecare Jr Powder

55 grams daily

1,640 grams monthly

400 grams costs \$49.94

5 cans = \$249.70

<https://www.walmart.com/ip/Elecare-Jr-Hypoallergenic-Powder-Vanilla-Flavor-14.10-Oz/48319378%3Fwmlspartner%3Dwlpa%26selectedSellerId%3D1150%26adid%3D22222222228035762638%26wl0%3D%26wl1%3Dg%26wl2%3Dm%26wl3%3D56994512258%26wl4%3Dpla-89140724498%26wl5%3D9010606%26wl6%3D%26wl7%3D%26wl8%3D%26wl9%3Dpla%26wl10%3D112549851%26wl11%3Donline%26wl12%3D48319378%26wl13%3D%26veh%3Dsem>

Nutricia MCT Oil Emulsion Liquigen

55ml daily

Nicole Jorwic

From: Gilbert, Germaine (GE Healthcare) [REDACTED]
Sent: Friday, July 14, 2017 7:04 PM
To: Nicole Jorwic
Subject: Medicaid Matters to Me (SC)

Dear Senators

Medicaid waivers allow my 35 year old son and his wife, both of whom are physically disabled since birth and unable to work, to obtain personal assistance in their daily care with bathing, medications, meals, household chores, shopping etc. Without the assistance given by the waivers, I would have to quit my job and obtain something part time and/or after hours in order to care for them. This would put their aging parents in a significantly difficult situation.

The waivers also purchase and maintain wheelchairs and wheelchair transportation in a specially equipped wheelchair lift van.

Medicaid allows them to obtain medications and physician visits at a greatly discounted rate.

I don't think I could pay for all these expenses on top of their expenses I already pay with a reduced paying job I might be lucky enough to find.

Please reconsider Medicaid cuts for this most vulnerable population.

Sincerely,

Germaine Gilbert

Nicole Jorwic

From: [REDACTED]
Sent: Friday, July 14, 2017 6:52 PM
To: Nicole Jorwic
Subject: SC

My son is 20 years old and has Down's Syndrome. Even though that does not define him, it does mean that he has life long health issues. My husband and I both work and have insurance, but it is not enough to cover his life long health care needs. Among other reasons, I oppose this bill because:

(1) Home- and community-based services, employment and family supports and other Medicaid waiver programs that are optional services states are not mandated to provide will be the first to be cut because states will receive significantly less funding as a result of reimbursement caps and other cuts; and (2) states will receive significantly less funding for adults with Down syndrome; those adults face significant and expensive co-occurring conditions that contribute to the medical complexity of Trisomy 21 throughout their lifespan.

Please vote NO on the Health Care Reform and save Medicaid for people like our son.

Lori Chappelle
[REDACTED]

Walhalla, SC [REDACTED]

Sent from Mail for Windows 10

Nicole Jorwic

From: Pam Mack [REDACTED]
Sent: Friday, July 14, 2017 1:30 PM
To: Nicole Jorwic
Subject: Why Medicaid matters--South Carolina

Medicaid matters to my family because even people who are well off can't pay the cost of long term care for people with disabilities. My sister has serious developmental disabilities and seizures that can't fully be controlled. She gets wonderful care in her group home and day program, but the private pay cost is over \$100,000 a year. My rich great aunt set up a trust to pay for her care but my sister is now 58 years old and still enjoying life and the trust has run out. I am so thankful that Medicaid is there as a safety net. It isn't just for the poor!

Pam Mack

Clemson SC 29631

1650ml a month

250ml costs \$24.99

7 bottles = \$174.93

<http://www.hightidehealth.com/liquigen-mct-oil.html>

Nestlé Microlipid Oil

335ml daily

10,050ml monthly

Case of 48 (88.7 ml per bottle) costs \$162.95

3 cases equal \$488.85

<https://www.healthykin.com//p-394-microlipid.aspx>

Total cost monthly is \$3,041.53. Please remember that this is buying in on my own and the supply companies are usually more expensive because they have to figure out their expenses.

My husband's monthly salary after his insurance and taxes is \$1,849.72.

THERE IS NO WAY WE COULD AFFORD TO PAY FOR THIS WITHOUT MEDICAID. NONE!

This **DOESN'T** include the multiple prescriptions, feeding supplies, diapers and wipes, personal care aid and respite and multiple doctors visit monthly.

AGAIN, THERE IS NO WAY WE COULD TAKE CARE OF MARGE AT HOME WITHOUT MEDICAID. WE HAVE NO FAMILY TO HELP WITH EXPENSES. HOW DO YOU EXPECT ANY FAMILY WITH A DISABILITY TO AFFORD TO TAKE CARE OF THEIR LOVED ONES WITHOUT MEDICAID? WHAT DO YOU EXPECT US TO DO IN THAT SITUATION? BECAUSE IT WILL HAPPEN TO ME AND OTHERS IF YOU PASS THIS BILL.

Because of the severe nature of Marge's disability, I am unable to have a job. Without Medicaid, we would have to child screaming 24 hours a day in pain with no relief. We went through several weeks of no sleeping for any of us.

I am not lying to you, if you wish I can provide medical records for these issues. Nor do I want to take advantage of Medicaid. I'm just a desperate

Mother scared to death of losing her services for a child that cannot speak on her own. Yes, I am a Republican and a Christian and I'm disappointed that the party that has pro-life values finds it acceptable to cut Medicaid for the grand majority of the disabled. I DON'T SEE HOW THAT IS PRO-LIFE?

I would love to have a few minutes to talk to you and the Senator. Advocates for the disabled have tried to see you with no success and they have kids that make Marge look simple! Please consider a meeting with them and you can reach me by phone the grand majority of time so I can tell you the whole story on Marge. I know that YOU are busy but PLEASE listen to both sides of the story before you vote.

Sincerely:

Trina Morgan
[REDACTED]

Greenville SC [REDACTED]
[REDACTED]
[REDACTED]