



Below are three sample letters asking for research funding and no cuts to Medicaid. You can use one of these as is (inserting your personal information where needed) or you can just use these as a starting point and craft your own message. If there are other issues that are important to you, feel free to add those as well.

If you don't know how to contact your members of Congress or who they are, go to <https://www.congress.gov/members/> and type in your address to see the names of your House Representative and two Senators. They typically don't publish an email address, but you can go to their official website and use the contact form to send a message.

Subject: Please Support Families Living with Dravet Syndrome

Dear [Representative/Senator Name],

I'm writing to you not only as your constituent but as a parent [or caregiver/family member/community supporter] whose life has been forever changed by Dravet syndrome. My [child/family member] was diagnosed with this rare form of epilepsy as a baby [or insert correct age], and since then, every day has been a fight – managing unpredictable seizures, navigating complex medical care, and trying to hold on to hope. There are no days off for families like ours, yet we remain strong because of the promise that research and awareness bring.

Federal support for rare disease and epilepsy research has helped us find guidance, resources, and hope for better treatments. I respectfully ask you to continue championing this support and to oppose any efforts that would reduce funding for critical research that impacts so many vulnerable families like mine.

Please also think about families like mine when there are any plans to cut Medicaid. Dravet syndrome forces an incredible economic burden on our families and for many, the only way they can afford to provide the best care and treatments for their children is through Medicaid. [Share any personal anecdotes about what help you receive through Medicaid, either in terms of insurance coverage or waiver programs]

Thank you for your time, compassion, and commitment to families living with epilepsy and rare diseases.

Sincerely,
[Your Name]

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Subject: Please Support Families Living with Dravet Syndrome

Dear [Representative/Senator Name],

As a constituent and someone directly impacted by Dravet syndrome, I'm reaching out to share how urgent and life-changing this diagnosis is for families like mine. Dravet syndrome is a rare and severe form of epilepsy that begins in infancy and brings with it lifelong medical, emotional,

and financial challenges. My [child/family member] faces daily seizures and developmental delays, and we live with the constant uncertainty of what tomorrow may bring.

Federal support for rare disease research has given our community hope. Advances driven by this research are helping families like mine access better care and work toward a brighter future. I'm asking you to continue standing with us by prioritizing funding for rare disease research and by opposing any proposals that would cut this critical lifeline for families affected by Dravet syndrome.

I also ask that you keep my family in mind when thinking about any potential cuts to Medicaid. Dravet syndrome is a devastating diagnosis and even families with private insurance depend on this critical resource to help provide the best quality of life for our children and reduce the significant financial burden that comes with caring for a child with complex medical needs. [Share any personal anecdotes about what help you receive through Medicaid, either in terms of insurance coverage or waiver programs]

Thank you for your time and your commitment to families and children living with epilepsy and rare diseases.

Sincerely,
[Your Name]

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Subject: Please Protect Funding for Dravet Syndrome Research and Medicaid

Dear [Representative/Senator Name],

I am writing to you not just as your constituent, but as a parent [or caregiver/family member/community supporter] deeply impacted by Dravet syndrome – a rare form of epilepsy that begins in infancy and brings daily, life-altering challenges.

Thanks to research funded in part by federal programs, meaningful progress has been made toward better treatments and improved quality of life for patients like my [child/family member/friend]. However, any cuts to this vital funding could halt that momentum and shatter the hope families like mine are holding onto.

I respectfully urge you to protect and strengthen funding for epilepsy and rare disease research, including initiatives that support the work of organizations like Dravet Syndrome Foundation. Please oppose any proposals that would reduce this life-saving investment.

I also want to emphasize how important Medicaid is to our family. My child did not ask for this devastating diagnosis, but we depend on Medicaid to help provide the life-saving medications and care that [he/she] needs to have the best possible quality of life. [Share any personal anecdotes about what help you receive through Medicaid, either in terms of insurance coverage or waiver programs]

Thank you for your time and for standing with families fighting Dravet syndrome and other rare diseases.

Sincerely,
[Your Name]