

Dear friends,

I write with an urgent request for everybody to pitch in right away to help convince your representatives in the U.S. Congress to support a budget increase for the National Institutes of Health (NIH) because the research funded by the NIH is a matter of life or death -- treatment or no treatment for all of us.

Over the next couple of days, U.S. senators and representatives will be deciding how much the NIH will be able to spend on medical research, including Friedreich's ataxia, between now and next October. They will be considering, behind closed doors, a wide range of options from cutting the NIH budget by about \$200 million to increasing it significantly.

It is important to all of us that the NIH have more, not less, to support the research we need to develop treatments and a cure. Please email your two senators and your representative in the U.S House of Representatives right away and post your message on their Face Book pages. I wrote my two senators and my representative yesterday and have already received supportive messages back from all three.

It is important that you write them right away (tonight or tomorrow if you can) because they might be making the critical decisions over the next couple of days. I will provide you, below, a template for your message and ask that you add a bit of your personal story or touch. In my messages, I told them a little bit about our son, Keith, and about FARA, and emphasized how important NIH is to us.

So, here is a template for your message based on the message I wrote yesterday. Again, I encourage you to begin the letter with your own personal story or touch.

Template:

Dear Congressman _____, (or Senator _____,)

[Insert a couple of sentences about your story here. Maybe something like: My family and I live in _____ County and we are like millions of other Americans who suffer the consequences of serious, debilitating and life-shortening diseases that have no treatments. Our particular disease is a rare, debilitating neuromuscular disorder called Friedreich's ataxia, for which there is currently no treatment. We are very active in supporting the medical research required to develop the treatments we need and we know how essential the National Institutes of Health (NIH) is in advancing that research.]

We are confident that, with the continued help of our NIH colleagues, we will treat and cure our disease in the near term. We, therefore, urge you, as final funding decisions are made for FY 2012, to ensure that medical research remains a top priority for our nation. The National Institutes of Health (NIH) is a vital agency that is improving the health of Americans while fostering strong economic growth. The NIH is a beacon of hope across our country and around the world and is the backbone of our country's longstanding world leadership in medical research.

The health of Americans is in jeopardy and smart investments in medical research are needed to improve health, develop effective treatments for currently untreated diseases, control the cost of healthcare, create jobs across our nation and sustain America's leadership in this important arena. As your constituent, I urge you to make medical research a higher priority in FY 2012 and beyond. The lives of our children and millions of other Americans depend on that research and on your leadership in supporting it.

Thank you for your leadership and consideration,

[signed]

End template.

I will also list below the senators and representatives who are members of the Appropriations Committees of the Senate and House and those who are members of the particular Appropriations Subcommittees responsible for the NIH budget. If one of your two senators or your representative is on these lists, please acknowledge in your message that you know that they play an especially important role in supporting a strong NIH budget for the medical research we all need.

To determine who your representative is in the U.S. House of Representatives, go to <http://www.house.gov/>. about two thirds of the way down the center column, enter your zip code. Your representative will be displayed. Go to the representatives website and click on "Contact." Complete the email form, enter your message and submit it. If your representative lists a Facebook page, please submit your message on that Facebook page, too.

To Determine your two state senators, go to http://www.senate.gov/general/contact_information/senators_cfm.cfm

near the top of the center column, select your state from the drop-down menu. Your two senators will be displayed. Go to their websites and click on "contact." Complete the email form, enter your message and submit it. If your senators list Facebook pages, please submit your message on their Face Book pages, too.

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