



The National **Fragile X** Foundation
Support-Awareness-Education-Research-Advocacy

Advocacy ACTION ALERT

March 15, 2009

TO: All NFXF Advocates and Friends

FROM: Your NFXF Washington Team

Dear National Fragile X Foundation Advocates,

ACTION ALERT:

ACTION NEEDED BEFORE 3-20

PLEASE ACT TODAY

The National Fragile X Foundation is asking Congress to include provisions in the 2010 L-HHS and Defense Appropriations Subcommittees to direct additional federal resources toward research and public health activities related to Fragile X-associated disorders. Thanks to your support, last year we were able to ensure that additional funding was devoted to Fragile X initiatives and research. But there is still much work to be done!

Federal funds are again tight this year and Congress is increasingly strained to deliver additional funding to Fragile X research. **As a result, it is even more important than ever that Members of Congress hear from YOU, as constituents and as advocates.** Nothing motivates a Member of Congress more than hearing directly from YOU!

This year, our main requests are for:
Appropriations Report Language asking the National

Advocates Speak out about NFXF Advocacy Day.....

I think it was an amazing experience, especially for my first year....

This was my first Advocacy Day. My cousin, who has been there five times, assured me the nervousness would disappear after the first meeting. She was right. By the end of the day I was ready to take on all 535 members of Congress....

I'm not sure how I can express our thanks for the opportunity to attend Advocacy Day. It was an experience we will never forget, and has led to some nice things already. We discovered a few new members for our group, I learned my Congressman will co-sponsor the ABLE Act and my son spoke to his class about his trip to Washington, which in turn was told to the Principal....

What a great experience. again... thank you for convincing me to make the

Institutes of Health to:

- Enhance its efforts to translate basic science findings into viable treatments for Fragile X, and encourage clinical drug trials.
- Maximize Fragile X resources to implement the objectives outlined in the Fragile X Research Blueprint.
- Strengthen and broaden research on Fragile X, FXTAS, and FXPOI.

We're also asking for Appropriations Report Language requesting that the Department of Defense:

- Expand the Peer Reviewed Medical Research Program (PRMRP) to include Fragile X Syndrome and Associated Disorders in the 2010 portfolio.

Additionally we're seeking:

- \$2 million in new funding for the National Fragile X Public Health Initiative and other Centers for Disease Control and Prevention (CDC) activities such as collaboration with the Fragile X Clinical & Research Consortium.

If you'd like more information follow the link below to our Advocacy Day materials that were provided to all advocates on NFXF Advocacy Day [Advocacy Day Materials](#) (linked)

How It Works

To make it easier for other Members of Congress to support the requests to the Appropriations Committee, Senators Debbie Stabenow (D-MI) and Johnny Isakson (R-GA) and Representatives William Delahunt (D-MA), Gregg Harper (R-MS), and Phil Hare (D-IL) will once again circulate Senate and House letters to the LHHS and DoD Appropriations Subcommittees that other Members of Congress can sign onto to support the requests for Fragile X funding.

trip...

Fragile X Advocacy day on Capitol Hill was one of the most amazing experiences of my life...!

Next year we hope you too will join us!

A Member of Congress speaks out about Advocacy Day

You'll never know how much last week meant to my family. I do believe that God directs our paths and has given me the chance to work on something with great meaning. My staff poured their heart and soul into this effort and have done so since the day I was sworn in. The reason is not that they work for me - it's because they all know and love Livingston.

We are already planning for next year so please notify us of the date as soon as you have it so we can put in on the calendar. I'd like to arrange for a tour of the Jefferson (original) Library of Congress for our group if possible.

***Your friends,
[Representative] Gregg
[Harper], Sidney, Livingston
and Maggie***

We are asking you to e-mail your Member of Congress and Senators to encourage them to add their name to these letters before each are delivered to the Subcommittees. The more support we solidify, the more powerful we will be in moving the Appropriations Subcommittee to support our requests.

Please take a few minutes - today if you can- to personalize a draft e-mail to your Member of Congress and Senators asking him or her to sign onto the Stabenow/Isakson Senate letter and Delahunt/Harper/Hare House letter in support of increased funding for Fragile X-associated disorders. Just click on the following link and follow the simple instructions to generate all of these emails. The process should take no more than a couple of minutes and will make a big difference.

[ACT NOW](#) (linked)

If you have any questions or need assistance in completing these letters, please do not hesitate to contact:

Sara Weir
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202-312-7475

THANK YOU for taking the time to help. The National Fragile X Foundation has the attention of Congress as it never has before - and it's because of you.

P.S. Don't forget to forward this email to family and friends. EVERYONE can join the effort.

Your NFXF Washington Team