



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

NFXF Advocacy Update

(and some great news about NIH funding of Fragile X Research just announced today)

September 6, 2007

From: NFXF Washington Team

To: All NFXF Advocates

Dear Advocates:

We hope that you are all enjoying the last weeks of summer and that your families have made a smooth transition into the new school year. Members of Congress have also just returned from their summer vacations.

We want to take this opportunity to inform you of some very exciting news for Fragile X research funding that was announced just today by the National Institutes of Health.

As you know, unlike at the CDC, Congress does not appropriate specific dollar amounts for specific projects at the NIH. Rather, an overall NIH budget is approved and the various institutes that make up the NIH determine how their budget is spent. However the Appropriations Committees do provide direction to the NIH Institutes through specific directive language which strongly *suggests* how Congress would like to see health research dollars spent. Here's an example of such a directive that NFXF Advocates successfully asked for and received this year:

Fragile X.—The Committee strongly endorses accelerated funding for basic and translational Fragile X research, especially efforts to analyze the linkages among Fragile X syndrome, autism, and autism spectrum disorders. The Committee urges the NINDS to participate in the scientific session described under the section on the NICHD and to collaborate with the Fragile X Centers of Excellence as well as the Fragile X Clinics Consortium.

Over the last 3-4 years the overall NIH budget has been relatively flat, barely keeping pace with the rate of inflation. As a result, Fragile X research funding at NIH Institutes has likewise been flat at about \$22 million per year.

But as a result of directives from Congress like the one above, which directives were only made because advocates like you called and wrote and traveled to Washington and

asked, the NIH has responded and today awarded the **largest Fragile X research grant in history**. The NIH has just announced a **\$21.8 million Fragile X research grant** which has been awarded to Dr. Paul Hagerman at UC Davis and a large research team that includes his wife, Dr. Randi Hagerman.

Dr Hagerman, his colleagues at the UC Davis School of Medicine, the UC Davis M.I.N.D. Institute and at four allied institutions (Erasmus Univ. in the Netherlands, Univ. of Washington in Seattle, Scripps Institute in Florida and Univ. of Colorado in Denver) will be working on *translational* research to help those affected by Fragile X. The research will focus on fragile X-associated Tremor/Ataxia Syndrome (FXTAS), along with fragile X syndrome. This research effort will include clinical trials in FXTAS, animal studies, molecular interventions, neuroimaging, as well as basic research to identify new treatments for these disorders.

The Hagermans are honored by the award of this grant and the confidence that the NIH and private research funding organizations like the National Fragile X Foundation have shown in them. Dr. Hagerman has asked that we pass along his sincere appreciation to all NFXF Advocates who made this largest ever FX grant possible. He also wants to thank everyone who has donated to the NFXF and explained that it was the NFXF that provided the seed grants to him and his wife Randi that supported the early stages of their research, which led to this grant. These \$50,000-\$100,000 seed grants were awarded by the NFXF's Scientific and Clinical Advisory Committee (SCAC) <http://www.fragilex.org/html/advisorycommittee.htm> which is responsible for reviewing and awarding all grant requests received by the NFXF.

With regard to our current legislative effort to secure FX funding in 2008.....

On September 4th, Congress returned to Washington following the month-long August recess. Prior to the break, the House passed the last of their annual appropriations bills. The Senate was unable to complete as much work on their versions of these bills and had only one bill completed before the end of the summer. With Congress' return, the Senate is getting back to work on their bills in an effort to catch up to the House. Nonetheless, since all the bills aren't expected to be completed by the end of the fiscal year on September 30th, a continuing resolution will likely be needed to keep the federal government running past that date.

Even with these delays, Congress is off to a better start this year than in the past and the Fragile X program is very strong compared to other programs in the bills (a doubling of the CDC's Fragile X Program). So long as the bills are completed, the Fragile X program provisions remain in a relatively solid position. As action moves forward, the real combustible element will be the Administration which is seeking to restrain funding increases contained in most of the measures. To get around a potential veto, Congress may attempt to combine one or more spending bills or make across the board cuts to reduce funding levels hoping to create veto-proof legislation. We expect this process to continue through the late

fall. As these funding measures move through Congress there will be opportunities for you as Advocates to reach out to your Members of Congress to reinforce the message that has taken us this far. Please watch for NFXF ACTION ALERTS and be sure to respond.

So our message to all of you who actively participate in the NFXF advocacy efforts is.....KEEP UP THE GREAT WORK!

Your generous donations of your time, your effort, your dedication and your dollars are really paying off.

All our Best,
Your National Fragile X Foundation Washington Team

.....*Share the good news-Forward this email*.....