



The National **Fragile X** Foundation

Dear Conquer Fragile X Supporters,

It has now been more than one year since the National Fragile X Foundation and the Conquer Fragile X Foundation became one. Many exciting things have happened since that time and I am pleased with the direction of our combined efforts. Here are a few highlights.

Thanks to your generous support the NFXF provided the final research installments for critical basic science projects originally identified and funded by Conquer Fragile X. Those projects are:

Project 1) Imaging of the Fragile X protein and role in mRNA translation and spine-synapse regulation in hippocampal neurons: Menahem Segal PhD, at the Weizmann Institute of Science in Israel. Gary Bassell PhD, Emory University School of Medicine in Georgia. Claes Wahlestedt MD PhD, Scripps Research Institute in Florida. Project 2) Sharon Eden PhD at Hebrew University of Jerusalem, Israel. Project: Regulation by Rac of the Fragile-X mental retardation protein activity

As you may know, I have been serving on the President's Committee for People with Intellectual Disabilities and in that capacity, I was able to see that the NFXF's Fragile X Clinical & Research Consortium was cited as a model of how to provide services to people with genetic conditions and speed the process by which new treatments, including new medications, are brought to those who need them the most. In my second term with the committee I am helping bring attention to the needs of adults with intellectual disabilities, including the NFXF's Collaboration to Promote Self-Determination, a growing group of national disability organizations who want to see that no opportunities are denied to those with fragile X syndrome and similar conditions such as autism.

At the NFXF's 11th International Fragile X Conference last summer in St. Louis, Conquer Fragile X organized a very important conference within a conference for up and coming Fragile X researchers. We are now organizing an even bigger and better, free-standing "Young Investigators" conference for this coming April in Florida. So thanks to the combined efforts of the NFXF and Conquer Fragile X, we know that there will be a steady supply of bright, creative young minds working on better treatments now and an ultimate cure for fragile X syndrome.

Of course we couldn't do this without you, and now – more than ever – we need you to think about how you can make a difference. Here are my suggestions:

- The NFXF holds a Conquer Fragile X fundraiser in Palm Beach each January. We'd love for you to attend, but if you can't make it, show your support anyway by sending a generous donation. Your contribution will be used to help find a cure for fragile X syndrome.
- Each year you'll receive the NFXF's Annual Fund solicitation. We depend on this campaign to provide funds for all of the other things that we do in addition to research, including education and the emotional, informational and referral support that makes sure that no family impacted by a Fragile X related condition ever has to be alone.

By the way, the remittance card in your NFXF mailer provides a great way for you tell us how you want to be kept informed of the latest Fragile X news. Just check the options that work the best for you and send it off with your generous support. If this just isn't a year for you to be able to provide financial support we still want to hear from you, so send the card in anyway.

So I hope you can see how the merger of Conquer Fragile X Foundation and the National Fragile X Foundation is making a real difference and that we want you to stay involved and informed.

My best to you and your loved ones.

Harris Hollin
Emeritus Director, National Fragile X Foundation