

The National Fragile X Foundation Commemorates National Fragile X Research Day

The National Fragile X Foundation (NFXF) is proud to commemorate National Fragile X Research Day, October 5, 2004. Funding research, both basic science and clinical, is an integral and increasing part of our mission. Most notably, in the last year our direct funding of research has increased 200%.

Research Grants Funded 2003-2004

Hyperarousal and Aggressive Behavior in Fragile X Syndrome

David Hessel, Ph.D.

U.C. Davis M.I.N.D. Institute and Department of Psychiatry and Behavioral Sciences

Manifestations of Anxiety in Children with Fragile X Syndrome

Patricia J. Gammon, Ph.D.

Duke University Child and Family Study Center

Relationship of multiple molecular measures and phenotypic expression in young children with FXS and their carrier mothers

Jane Roberts, Ph.D.

Frank Porter Graham Child Development Institute, University of North Carolina

Cytoskeletal-dependent trafficking of FMRP and target mRNAs to neuronal synapses: a role for FMRP as an adapter between localized mRNAs and molecular motors

Jason B. Dichtenberg, Ph.D.

Albert Einstein College of Medicine of Yeshiva University, Rose Kennedy Center for Mental Retardation

Is the GABAA receptor a therapeutic target for the Fragile X Syndrome?

Frank Kooy, Ph.D.

University of Antwerp, Dept. of Medical Genetics

Role of Intranuclear Neuronal Inclusions in the Pathogenesis of the FXTAS

Rob Willemsen, Ph.D.

Eramus University, Clinical Genetics

Designing and Evaluating a Model Early Intervention Program for Young Children with Fragile X Syndrome and Their Families

Don Bailey, Ph.D.

FPG Child Development Institute, University of North Carolina at Chapel Hill

"What about adolescence? Living with genetic risk."

Allyn McConkie-Rosell, PhD, CGC

Medical Genetics Program

Duke Children's Hospital & Health Center

Scientific and Clinical Advisory Committee

At the NFXF the grant review process is based on the system at the National Institutes of Health (NIH), where important scientific decisions are made by scientists. While our fifteen member Board of Directors assumes responsibility for approving the foundation's yearly budget, and the allocation of dollars between the components of our mission and research, it is our nineteen member Scientific and Clinical Advisory Committee (SCAC) that assumes complete responsibility for evaluating the merits of all requests for research funding and makes final decisions on which projects the NFXF funds. The SCAC is currently co-chaired by Don Bailey, Ph.D. from the University of North Carolina and W. Ted Brown, M.D., Ph.D. from the Institute for Basic Research in New York. They are joined by the seventeen other members listed on the back of this quarterly journal.

Summer Student Fellowships

In addition to funding basic science and clinical post doctoral grants to senior researchers, the NFXF will continue to fund Summer Student Research Fellowships through the William and Enid Rosen Research Fund. These \$2,500 grants afford undergraduate and graduate level students the opportunity to work alongside senior investigators to encourage students to consider research as a career option and attract bright new investigators to the field of fragile X research. We asked Dr. Duane Alexander, Director of the National Institute of Child and Human Development, to comment on the importance of such programs:

“Summer research fellowships can be life-changing, career-shaping experiences. I know this from personal history, and see it happen to others again and again. The summer research fellowships I had as a medical student changed my career path from practitioner to researcher. It is essential to keep these opportunities available to students in order to introduce them to research at a critical time, and attract many of them to research careers.”

International Conference Series

Our commitment to research will also continue to include financial support for members of the international fragile X research community to attend and participate in biannual NFXF International Conferences. The collaboration and sharing of ideas made possible through these conferences advances the pace at which the science of fragile X progresses. By assisting with the costs associated with researchers attending these conferences the NFXF creates these invaluable opportunities for collaboration *and* allows senior researchers to dedicate research funding from government and other sources to the important work taking place at their respective research centers.

Legislative Advocacy

Finally, our commitment to research will continue to include a comprehensive advocacy campaign to assure that our elected officials in Washington devote the resources necessary to fund additional scientific research and address the far reaching public health implications of fragile X.

So as we acknowledge this national day declared by Congress to promote and support fragile X research, we invite you to join us in this exciting effort. While we continue our support of the fragile X community with record levels of funding for awareness, education, *and research*, our board remains committed to doing even more. Please help us continue to increase our research funding.