

OMRDD's IBR receives \$1.6 million for research for Fragile X

ALBANY, NY (09/11/2008; 1546)(readMedia)-- The New York State Office of Mental Retardation and Developmental Disabilities' (OMRDD) Institute for Basic Research in Developmental Disabilities (IBR) has been selected to receive a nearly \$1.6 million, three-year cooperative agreement grant from the National Center on Birth Defects and Developmental Disabilities (NCBDDD) of the Centers for Disease Control and Prevention (CDC) for research on Fragile X syndrome, Commissioner Diana Jones Ritter announced today.

The grant will be used to coordinate a project that will speed research into emerging treatments for Fragile X syndrome and bring better care to the more than 100,000 Americans affected by the condition. Fragile X syndrome is the most common known cause of inherited intellectual or developmental disability, as well as the most common known single-gene cause of autism. Approximately 4,000 males in New York State are affected by Fragile X syndrome, and 1 in 250 women are carriers of this sex-linked condition.

The project will advance the core activities of the Fragile X Clinical and Research Consortium (FXCRC), which the National Fragile X Foundation (NFXF) initiated in 2006 to advance clinical practice and facilitate coordinated, collaborative multi-site research. The FXCRC currently consists of 14 clinics in the U.S. and one in Canada, with five additional US sites expected to establish clinics within the next three years. IBR, located on Staten Island, NY, is the site of one of the Fragile X clinics.

In addition to IBR, collaborators in the project consist of the NFXF; the Association of University Centers on Disabilities (AUCD), which will distribute the funding from the CDC; and the Data Coordinating Center at Columbia University.

IBR Director W. Ted Brown, MD, PhD, a renowned researcher in Fragile X syndrome, will serve as principal investigator for the project. He will provide overall supervision of the project to meet the proposed goals and will maintain close cooperation and contact with the CDC, the AUCD, the NFXF, the Data Coordinating Center at Columbia University, and the Steering Committee of the FXCRC.

"This collaborative grant will provide the resources necessary to best advance research and medical care for those afflicted with Fragile X syndrome and their families," said Commissioner Ritter. "All of this is right in line with OMRDD's mission of helping individuals with developmental disabilities lead richer lives."

"I am extremely pleased to be receiving this grant on behalf of the newly formed FXCRC and in support of the many families affected with Fragile X syndrome," said Brown. "In collaboration with the NFXF and the CDC, we will now be able to develop the organizational infrastructure necessary to establish standards of

care, facilitate much needed clinical research, build a dynamic patient registry, and work toward improving the tracking and surveillance of Fragile X.”

About OMRDD and IBR:

The Institute for Basic Research in Developmental Disabilities (IBR) is the research arm of the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD.) The Office of Mental Retardation and Developmental Disabilities (OMRDD) provides high-quality, person-centered services, supports and advocacy to approximately 140,000 individuals with developmental disabilities and their families. OMRDD works with a network of 800 not-for-profit providers to help people with developmental disabilities lead richer lives that include meaningful relationships, good health, personal growth and productivity and homes in their community.