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401 project mecp2duplication

11 April 2012

FOR IMMEDIATE RELEASE

A SEARCH FOR A CURE FOR A DEBILITATING NEUROLOGICAL DISEASE IS ONLY $200,000 AWAY AND NEEDS YOUR HELP TO COMMENCE

Finding out your child has a rare and debilitating disease and may never walk or talk and may not live beyond their childhood is overwhelming, utterly devastating.

The disease is the MECP2 Duplication Syndrome and the symptoms are incomprehensible: absent to minimal speech, developmental delay, seizures, recurrent infections, progressive spasticity, ataxia, autistic features. The prevalence of MECP2 Duplication Syndrome is unknown but it is likely that thousands of children and adults are affected by the disorder which is so new to the medical field that most doctors have not heard of it.

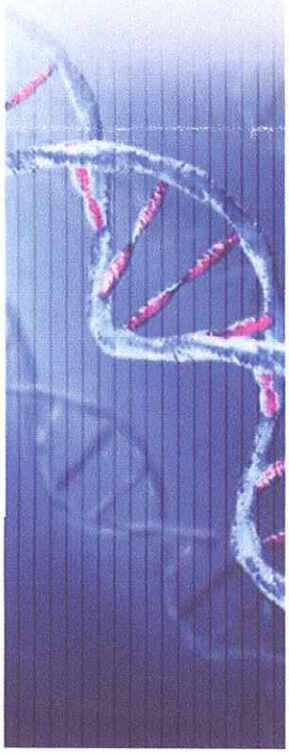
Imagine after learning of such a diagnosis, finding that the only thing preventing a search for a cure is money, $200,000 to be precise.

In January 2012, 200 families affected by the MECP2 Duplication Syndrome brought together via the internet, united to launch a global campaign to save their children. They called the initiative the 401 Project, $401 to be raised by 1st April (040112) for each child affected by MECP2 Duplication Syndrome, to go towards finding a cure. Working around the clock creating events, asking their friends, families and colleagues for donations, the 401 Project exceeded the $80,000 target and the effort continues. It is a great start but there is so much more funding required before a cure can be found for MECP2 Duplication Syndrome.

The research the 401 Project is seeking funding for is in the form of two studies:

1. A reversal experiment to identify if the symptoms of MECP2 Duplication Syndrome are reversible. Cost: $236,000 over three years, $100,000 raised as of 2 April.

2. A screening of FDA approved pharmaceutics to determine their potential to regulate levels of MeCP2. Cost: $210,000, over three years, can commence when $70,000 is raised to launch the first year.



The studies, subject to funding, will be undertaken in the lab of an eminent physician-scientist, Dr. Huda Zoghbi at Baylor College of Medicine in Houston, TX. Through sophisticated genetic engineering the Zoghbi lab will design an experiment that will carefully analyse disease symptoms in an animal model following deactivation of the second MECP2 gene. Encouraging data suggesting the disease is reversible will set the stage for a drug development initiative.

Proceeds for the projects are being channelled to the Rett Syndrome Research Trust (RSRT), the world's premiere organization devoted exclusively to promoting international research on Rett Syndrome and related MECP2 disorders. RSRT's deep knowledge base of MECP2 and well established global scientific networks are being immediately applied to the duplication syndrome. RSRT recently established the MECP2 Duplication Syndrome Fund to support scientific meetings and projects devoted to the study and means of treatment of MECP2 Duplication Syndrome.

FOR MORE INFORMATION ABOUT THE MECP2 DUPLICATION SYNDROME RESEARCH PROGRAMME CONTACT:

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rett syndrome research trust