Update from the Investigators

We want to thank you and your family for participating in our study. Without your commitment, we would not be able to conduct this important research which we hope will have a significant contribution to the field of treating and preventing the progression of Alzheimer’s disease.

Much of our efforts on this project have been recruitment, seeing families, presentations, and continued grant writing to support this study. This newsletter will update you on what we have learned to date, plans for our future work, and other important information we would like to share.

Preliminary Information about the Study Participants

Since 2010, both the Waisman Center and the University of Pittsburgh Medical Center have spoken with over 120 families who live across the United States about participating in this study. At this point, 80 individuals with Down syndrome have been screened and deemed eligible to participate in the clinic visit as well as the MRI and PET scans. Of these 80 people, 63 have visited one of our testing sites. Below are some preliminary characteristics of our group:

- 31 are male (49%), and 32 are female (51%)
- Participants ranged in age from 30 to 50 years old, with the average age being 37.9 years old
- 39 live with parents, 10 in supported homes/apartments, 9 in group homes, 5 independently
- What do they do during the day: 20 individuals have full or part time work (31.8%), 11 have supported employment (17.5%), 17 attend a supported workshop (27%), 7 volunteer (11.1%), 2 attend a day activity program (3.2%), and 6 are not involved in a job or program (9.5%)

We also asked Caregivers (those who are primarily responsible for the well-being of the adult with Down syndrome) to complete questionnaires describing their experiences caring for an adult in later life. Below are some preliminary characteristics of the Caregiver group:

- 85.8% are mothers, 7.2% are siblings, 2.4% fathers, 4.7% group home staff
- Caregivers ranged in age from 22—88 years old
- 96.5% are white, non-Hispanic
- 72.7% of caregivers have almost daily contact with the adult with Down syndrome
Future Goals of the Study

An important piece of this project is to look at stability and changes in adults with Down syndrome throughout the life-course. We plan to contact every family for a “30-month” and also a “60-month” follow-up reassessment to monitor and document current levels of functioning in each individual with Down syndrome. We feel it is important for families to continue to visit our sites for follow-up as there is impressive scientific interest to measure the rate of amyloid development and plateauing of this protein throughout the life-course. We feel it will prove fruitful for future development of interventions, medications, and therapies for individuals who go on to develop Alzheimer’s disease in later life.

In addition to bringing this longitudinal piece to the project, we are looking for 20 more participants at both the Wisconsin and Pittsburgh sites. If you know of any families who are interested in our research please have them contact one of our research coordinators who are listed at the end of this newsletter.

Meet some of the People who work the Project

Dr. Bulova is an Associate Professor of General Internal Medicine at the University of Pittsburgh Medical Center. He has been the Medical Director of the University of Pittsburgh Adult Down Syndrome Center since 2003. He has worked clinically with several hundred patients, and gives lectures on the care of adults with Down syndrome both locally and nationally. Dr. Bulova is also the co-director of the Magee Center for Women with Disabilities at the University of Pittsburgh. He is a member of the University of Pittsburgh Medical School Academy of Master educators.

Dr. Hartley’s research examines the individual resources and family contexts underlying positive well-being in adolescents and adults with developmental disabilities and their families. Her areas of expertise are developmental disabilities such as autism spectrum disorders, Down syndrome, and fragile X syndrome. Dr. Hartley’s research also explores the biological and environmental risk and resiliency factors related to psychological and physical well-being in aging parents caring for adult children with developmental disabilities. The long-term objective of this research is to develop interventions aimed at promoting effective emotion regulation and adaptive coping to improve the psychological well-being of adults with autism spectrum disorders and other developmental disabilities.
The authors of the bestselling book Mental Wellness in Adults with Down Syndrome turn their attention to the physical health of teens and adults with Down syndrome. Drs. Chicoine and McGuire provide invaluable insight into what health problems are more common in their patients, and how medical issues can "present" differently in people with Down syndrome. In a clear, empathetic style, they discuss how to promote a healthy lifestyle to prevent problems, and how to recognize health problems early on to ensure appropriate care and the best outcome. The Guide to Good Health is a resource families and caregivers can refer to over and over again, whether it is to find strategies to get a teen or adult to cooperate with treatment, or to consider if a symptom is being misdiagnosed or misunderstood.

Did you know . . .

- There are three types of Down syndrome: trisomy 21 (nondisjunction) accounts for 95% of cases, translocation accounts for about 4% and mosaicism accounts for about 1%.

- Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies in the United States is born with Down syndrome.

- There are more than 400,000 people living with Down syndrome in the United States.

- The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.

- People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways.

- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.

- Quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives.

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Publications and Conference Presentations

Publications

Three pending articles each by Dr. Christian, Dr. Handen, and Dr. Hartley are to be submitted for publication in 2014.


Presentations of 2013


Handen, B. (2013, April). Imaging Molecules for Studies of Alzheimer's Disease in Down Syndrome. Read before the National Institutes of Health meeting on Advancing Treatments for Alzheimer’s Disease in Individuals with Down Syndrome, Potomac, MD.


Contacting Study Staff

We are always happy to hear from families and receive updates from you. Please feel free to contact study staff below or visit our study website at: www.waisman.wisc.edu/amyloid

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