



A Note from the Investigators

March 2012

Since 2010, the Waisman Center at the University of Wisconsin-Madison and the University of Pittsburgh Medical Center/Adult Down Syndrome Center have been collaborating on a research study looking at the relationship of Down syndrome and Alzheimer's disease. In August 2011, we were awarded a one-year continuation to this study and hope to work with over 60 families across the country who have a healthy adult family member with Down syndrome. For those of you who have visited one of our research sites, we would like to express our heartfelt thank you for your support of our research over the past two years. We had a wonderful time meeting and getting to know your family. We greatly appreciate your dedication to the project.

In this newsletter you will find information about the study, conferences attended, and other information on Down syndrome and Alzheimer's disease throughout the life-course. As always, please feel free to contact our project offices if you have any questions or concerns in the future.

About the Investigators



Dr. Handen is a clinical psychologist with over 30 years experience in the field of autism and developmental disorders. His research has focused on the examination of psychopharmacology and psychosocial treatments. Dr. Handen has also been working in the area of dementia and Down syndrome for the past eight years. This includes participating in psychopharmacology trials as well as the use of PET methodologies to study the deposition of amyloid plaque in the brains of adults with Down syndrome and its affect on cognitive functioning.

Benjamin L. Handen, Ph.D.



Dr. Christian's research focuses on developing and translating novel PET methods for the study of neurodevelopment and neuropsychiatric illness. This involves using PET methodologies to investigate neurochemical changes in the brain and studying novel radioligands to characterize neurotransmitter-protein interactions and how they are influenced by development, genes, environment and drugs. These imaging methods are being applied to investigate the etiologies and mechanisms in diseases such as Down syndrome, affective disorders, schizophrenia, Alzheimer's disease and Tourette syndrome.

Bradley T. Christian, Ph.D.

Conferences and Day with the Experts

On November 12, 2011 Dr. Brad Christian and Dr. Sigan Hartley presented preliminary findings from our study at the second annual Down Syndrome Day with the Experts. The conference was held at the Waisman Center, University of Wisconsin-Madison. The theme this year was Basic Research to Clinical Care.

Other research topics presented at the conference included:

Using Human Stem Cells to Study Down Syndrome: Human stem cells that have trisomy 21 provide an unparalleled way to study how the formation of the brain is different in Down syndrome. What we learn from studying how Down syndrome stem cells make brain cells will help us better understand Down syndrome, explain the reasons for the specific deficits found in Down syndrome, and ultimately lead to better treatments.

Infections in Children with Down Syndrome: Infections involving both the upper and lower portions of the respiratory tract have been identified as one of the most significant health problems in children with Down syndrome. The precise explanation for the increased number and severity of infections is not known. The potential medical, anatomic and immune problems bearing on the increased susceptibility to infection was discussed.



Sigan Hartley, Ph.D.

Preliminary Results from the Study



Amyloid plaque deposits in the brain are thought to play an important role in Alzheimer's disorder. One goal of our study is to examine the neuropsychological profile of adults with Down syndrome who have significant amyloid (PiB+), but who do not show any clinical signs of Alzheimer's disorder. Preliminary analyses indicate that significant amyloid deposits do not appear in adults with Down syndrome prior to the mid-thirties. PiB+ adults have been found to score slightly lower on tests of working memory, delayed recall, and attention/processing speed in comparison to adults with Down syndrome who do not show evidence of amyloid deposition. These mild differences are predicted to become larger at follow-up time points.

Follow-Up Visits

If you initially participated in our project in 2009 or 2010, study staff may be contacting you about returning for a two-year follow-up visit. Our hope is to bring all study participants back for reassessments every two years to monitor current levels of functioning.

Future Goals of the Study

In November 2011, Drs. Handen and Christian submitted a continuation for the current grant to the NIH with the intent to follow families already participating in our study over time. The goal of the project is to look at stability and changes in adults with Down syndrome throughout the life-course. In addition to bringing this longitudinal piece to the project, we hope to recruit and additional 20-25 participants (for a total of 84) at both the Wisconsin and Pittsburgh sites.

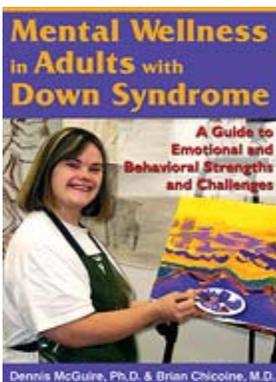


Interesting Facts

Not all people with Down Syndrome go on to develop Alzheimer's disease: Although many people with Down syndrome develop dementia in their later years, this is by no means inevitable. Research indicates that the incidence of dementia in people with Down syndrome is approximately 10% in the 40-49 year age bracket, but increases to around 36% among adults over 50 years of age.

Reducing the Risk of Alzheimer's: Research in this area is ongoing, but diet and exercise appear key. Studies indicate a lower risk among people who eat a Mediterranean diet rich in vegetables, fish, and nuts. Research also suggests those who are the most physically active are the least likely to get Alzheimer's. Exercise can help maintain some muscle strength and coordination. It also improves mood and may reduce anxiety. Always check with a doctor to learn which types of exercise are appropriate for you or your family member. Repetitive activities, such as walking, weeding, or even folding laundry may be the most effective at promoting a sense of calm.

Literature



This authoritative, easy-to-read guide clarifies what are the common behavioral characteristics of Down syndrome, how some can be mistaken for mental illness, and what are the bona fide mental health problems that occur more commonly in people with Down syndrome. As McGuire and Chicoine describe these traits and mental health issues, they also explain, through detailed observations and case studies based on their patients, how parents, caregivers and adults with Down syndrome can work together to foster mental wellness. In addition, the authors discuss the importance of regular assessment and how behavior and mental well-being can be affected by environmental conditions, social opportunities, and physical health.

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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Publications and Conference Presentations

Handen B, Cohen A, Umapathy C, Bulova P, Cannon SA, Cohen WI, Mathis CA, Price JC, Klunk WE. Imaging brain amyloid in non-demented young adults with Down syndrome using PiB-PET. *Alzheimer's & Dementia*, in press.

Hartley S, Handen B, Christian B, Murray PJ, Price J, Johnson J, Klunk W, Devenny D. Preclinical stage of Alzheimer's disease: The neuropsychological profile of asymptomatic adults with Down syndrome evidencing amyloid deposition. To be presented at the Gatlinburg Conference, Annapolis, MD, March 2012.

Cohen AD, Christian B, Handen B, Johnson S, Hartley S, Seltzer M, Murali D, Bergnic M, Matan C, Price JC, Mathis CA, Klunk WE. Imaging brain amyloid in non-demented young adults with Down syndrome using PiB-PET. Presented at the Int. Conference on Alzheimer's Disease and Related Disorders, Paris, France, July 2011.

Price JC, Christian B, Handen B, Johnson S, Hartley S, Seltzer M, Murali D, Bulova P, Bergnic M, Matan C, Mathis CA, Klunk WE. Assessing Amyloid Load in Non-demented Young Adults with Down Syndrome. Presented at the annual meeting of the American College of Neuro-psychopharmacology, Waikoloa Beach, Hawaii, December 2011.