

NTG CAREGIVER NEWS

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NTG Caregiver News

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DOWN SYNDROME RESEARCH

Down syndrome research has been in the news a lot in the past few weeks. It is exciting to see that scientists are focusing on issues related to Down syndrome and doing research on topics that may benefit those we care about and others.

DS Connect®

A short time ago, Sujatta Bardhan, Ph.D. of the National Institute of Health presented an interesting breakout session at the Down Syndrome Adult Summit. She provided attendees an overview of the DS Connect® registry and how adults with Down syndrome can be involved in research efforts.

To learn more about this opportunity, visit the website at: <https://dsconnect.nih.gov/>.



Alzheimer's Biomarker Consortium – Down Syndrome

An update about the Alzheimer's Biomarker Consortium – Down Syndrome (ABC-DS) was recently disseminated. The ABC-DS was funded in the fall of 2015 by the National Institute on Aging (NIA) and the National Institute on Child Health and Human Development (NICHD), both part of the National Institute of Health (NIH).

The Consortium includes two major investigations: the Alzheimer's Disease in Down Syndrome (ADDS) and Neurodegeneration in Aging Down Syndrome (NiAD).

A total of 405 adults with Down syndrome are to be enrolled in the two studies and are to be assessed on three occasions, spaced 16 months apart. It is now nearing the end of year three with 266 participants enrolled. They hope to have enrollment complete by September 2018. The first papers from the project were presented at a meeting in Miami in January 2018, and a symposium has been accepted for the Alzheimer's Association International Conference® and will be presented in Chicago this July.

If you have a loved one with Down syndrome who is over 25 years of age, and are interested in learning more about, or participating in a study organized by ABC-DS, contact one of the clinical sites. Volunteers must be willing to provide samples and undergo tests to help researchers identify and track Alzheimer's-related changes in the brain and cognition.

The ADDS is being conducted at the following locations:

- Columbia University in New York, NY
- The University of California—Irvine
- Massachusetts General Hospital, Boston, MA
- NYS Institute for Basic Research, Staten Island, NY
- The Johns Hopkins University, Baltimore, MD

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DS Connect®

Through DS Connect®, it is possible to:

- Learn about new studies for people with Down syndrome,
- Connect with scientists who study Down syndrome,
- Help scientists develop new treatments for people with Down syndrome.

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OH MY GOODNESS... DID YOU KNOW?



There is something called “fake or pseudo seizures?” These events have several name, but the most accurate names are “psychogenic non-epileptic seizures (PNES),” or “paroxysmal non-epileptic seizures.”



Recently, Dr. Brian Chicoine, Medical Director of the Advocate Medical Group Adult Down Syndrome Center in Park Ridge, Illinois, wrote about these events. He explained that pseudo seizures look like seizures, yet when witnessed at the same time an EEG is administered, show no abnormalities consistent with a seizure on the EEG.

Symptoms of a PNES event “may include involuntary movements, lack of awareness of his/her surroundings, shaking movements, stiffness and others.” Dr. Chicoine wrote that “a traumatic event (including some that result in post-

traumatic stress disorder), depression and anxiety can be associated with the onset of PNES.” It is important to note that the person experiencing PNES events is not deliberately causing them and has no control over them.

The article has been uploaded to the Clinic website. Here is the link: <https://www.advocatehealth.com/assets/documents/subsites/luth/downsyndrome/new-format-documents/fake-seizures.pdf>

The link to the Facebook post (with the comments) is: <https://www.facebook.com/adultdownsyndromecenter/posts/10155542119108576>

The general link to their Resources page is: <https://www.advocatehealth.com/luth/health-services/adult-down-syndrome-center/resources/>

The general link to their Facebook page is: <https://www.facebook.com/adultdownsyndromecenter/>



ON OUR RADAR

In each issue we want to bring you information that family caregivers have found to be useful, as well as links to materials that are current and timely.

Supporting Individuals with IDD through Serious Illness, Grief, and Loss, Hospice Foundation of America, 2013

Although this online, self-study webinar was created several years ago, the information contained is timeless. In this webinar, expert panelists (including our own Matt Janicki, Ph.D. and Rick Rader, MD) discuss the ethical, medical management and psychosocial issues for individuals with intellectual and developmental disabilities who face death, grief and loss. This two-hour educational program (online course or DVD) focuses on the critical challenges of providing and accessing optimal end-of-life care and bereavement support for this population. CE credits are available for this course; contact HFA at 202-457-5811 or email them at educate@hospicefoundation.org for information. <https://hospicefoundation.org/Shop-HFA/Products?Category=2&Topic=5&page=3>



National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers: Recommendations, U.S. Department of Health and Human Services, 2018

The management team of the National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers has issued its final report. This was formally presented on Friday, April 27, 2018 at the National Alzheimer's Project Act (NAPA) federal council meeting in Washington, D.C. You can access and download the Summit report as well as Summit recommendation materials -- including the cross-cutting and stakeholder group papers -- on the Summit Recommendations page at <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-recommendations>.



NDSS ADULT SUMMIT GOES ON THE ROAD

The Down Syndrome Adult Summit—the first of its kind—was a huge success! For a day and a half, adults with Down syndrome, their families, friends and providers of services were gathered in Arlington, Virginia to educate, advocate and celebrate all adults who are continuing to rock that extra chromosome. It was exciting to see the smiling faces and listen to the chatter that was evidence that the National Down Syndrome Society, the National Task Group and the National Alliance for Caregiving had filled a long-overdue need.



Just prior to the start of the Summit, the NDSS Board of Directors gave Sara Weir, President and CEO, approval to take the Summit on the road and provide this much needed information in future years at locations around the country. NDSS is partnering with the Down Syndrome Guild of SE Michigan and all affiliates in Michigan to bring the Second Annual Adult Summit to Detroit, in April 2019. Planning has begun as the local affiliate is researching venues and the Summit Planning Team is preparing to conduct a Call for Presentations. Watch this newsletter and visit the NDSS website for more information as it becomes available. <https://www.ndss.org/ndss-adult-summit/>

DOWN SYNDROME RESEARCH

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- The University of North Texas Health Center, Tyler, TX

The NiAD is being conducted at:

- The University of Pittsburgh—PA
- The University of Wisconsin, Madison—WI
- The University of Cambridge—UK
- The Barrow Neurological Institute, Phoenix, AZ

Contact information for study locations can be found at the NIA-NIH website:

<https://www.nia.nih.gov/health/abc-ds-information-patients-and-families#how>

Clinical Trials Consortium

Researchers focused on medical issues related to people with Down syndrome from the U.S. and their colleagues from Europe, who are members of the Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART), have formed an international consortium. Members of the Down Syndrome and Alzheimer's Disease Professional Interest Area (PIA) are looking at ways to prevent Alzheimer's Disease in Down syndrome. Funding in the U.S. is provided by the Lumind Research Down Syndrome (RDS) Foundation and the European counterparts receive funds from the Lejeune Foundation.

A short-term goal is to understand the history of Alzheimer's disease in Down syndrome and to establish key features of the aging process. The consortium members will develop multiple sites to recruit sufficient numbers of people to participate in clinical trials.

For more information on ISTAART : <https://action.alz.org/PersonifyEbusiness/Default.aspx?TabID=1516>

To learn more about this PIA: <https://action.alz.org/PersonifyEbusiness/Default.aspx?TabID=1516>

Alzheimer's Disease—Down Syndrome Research Grants

Five scientists have been awarded \$1.2 million in grants for research exploring the development of Alzheimer's disease in people with Down syndrome. Through a joint grants initiative of the Global Down Syndrome Foundation, the Alzheimer's Association and the Linda Crinic Institute for Down Syndrome, senior investigators received funds in the amount of \$150,000 or \$300,000 each.

Huaxi Xu, Ph.D. at *Sanford-Burnham Medical Research Institute, La Jolla, CA* has a study that will determine how a specific protein (SNX27), which is low in people with Down syndrome, is involved in Alzheimer's disease and Alzheimer's-like changes in the brain. This research may help iden-

tify new target for drugs that prevent or slow the progression of the disease.

Ann-Charlotte Granholm, Ph.D. at the *Medical University of South Carolina, Charleston, SC* is conducting research to clarify the role of neuron damage in people who have Down syndrome and Alzheimer's disease. A mouse model is being used to measure how various levels of the neurons may affect the creation of a hormone-like molecule that is known to protect brain health and promote memory.

Karen Chang, Ph.D. at the *University of Southern California, Los Angeles, CA* is attempting to clarify whether a protein (DSCR1) located on the 21st chromosome protects people with Down syndrome from brain cell damage that is characteristic of Alzheimer's disease.

Donna Wilcock, Ph.D. at the *University of Kentucky Research Foundation, Lexington, Ky* received funding for her research to examine biomarkers of brain inflammation and how they relate to the development of Alzheimer's. This will be done by studying whether level changes in molecules in the blood correspond to changes seen in brain images.

Eitan Okun, Ph.D. at the *Bar-Ilan University, Ramat-Gan, Israel* is working to develop a new type of vaccine for Alzheimer's disease. He will alter a virus to produce a short version of beta-amyloid protein with hope it will trigger the immune system to remove the protein and possibly restore memory.

What This Means

It means we are living in exciting times. Never before has there been such a tremendous emphasis on research related to Down syndrome. It means the babies and children with Down syndrome may lead even healthier lives. It means that the future is brighter than ever. It also means that we need to do our part to help create this future!

One of the most important things that can be done is to get our family members included in the DS Connect® Registry. Research and future studies will only work if there are enough people to take part in these investigations. In the world of Alzheimer's disease, we are a small population with a high risk, so it is essential that we participate in every way possible.

Don't Forget...



- Read more about the research taking place.
- Sign up my family member in the DS Connect® Registry.

LET'S TALK DECLINE & ASSESSMENT

In 1974, babies with Down syndrome had a life expectancy of about 25 years; today it has increased to more than 60 years. As we age, we all face decline and it is no different for our family members with Down syndrome.

With aging come normal changes like being more forgetful; we walk more slowly and our balance may not be as good.

Many factors play a part in aging and decline, including the person's life story—what they did when they were in their best health, what type of support they had and currently have, as well as existing personal, social and health conditions.

Before people with Down syndrome start showing decline of any type, it is very important to have a record of the skills they have gained. Start a diary (written or video) of the activities the person is able to do while they are in good health. Remember to update the information every six to twelve months.

Regression

Although rare, some teenagers and those in their 20s may experience a regression that can look like dementia. Regression is notable when the person has a rather dramatic loss, and decline in their speech and mobility, often occurring over days and weeks.

To uncover a possible cause for regression, create a thorough life-timeline to include any unusual health, and psycho-social events that may have been stressful to the person (death of a close family member or friend, any type of abuse, or any other major change in their life).

In addition, it is very important



that the Primary Care Provider (PCP) do a thorough evaluation conducted over a period of time to allow him to rule out possible causes of decline. Brian Skotko, M.D., and others use a 5-Tier approach to assess for the underlying cause of this rare regression in teens and young adults with Down syndrome.

The assessment includes a health history, comprehensive blood work to rule out hypo/hyperthyroidism, or vitamin deficiencies, as well as screening for sensory losses and depression. Further studies may include brain imaging, an EEG, and a sleep study. Treatment for individuals experiencing regression at a young age usually involves the use of various antidepressants. Other treatments may be considered in very extreme cases.

To learn more about the 5-Tier approach to evaluation, read the clinical report, *Rapid clinical deterioration in an Individual with Down syndrome* by Julia Jacobs, Christopher J. McDougle, Alison Schwartz, and Brian Skotko at: www.onlinelibrary.wiley.com/doi/full/10.1002/ajmg.a.37674

Depression

One possible reason for decline can be depression. Sometimes people fail to realize the depth of emotions that folks with Down syndrome have. If there is limited language, it may be more difficult to know if someone is depressed. Depression can lead to a poor quality of life and can become chronic if not treated. If your family member has begun making statements such as, "I can't." or, "I don't know." it may be a clue he or she is depressed. If what you observe looks like agitation and confusion, rule out depression before thinking it is dementia.

Delirium

Delirium is a disorder that affects attention, memory and perception. It is a treatable condition but is often over-

looked. Delirium has an acute onset (sudden) and symptoms may include:

- Fluxuation in severity throughout the day
- Confusion and disorientation
- Lack of awareness of time or place
- Memory loss, including short-term
- Disorganized thinking
- Incoherent, disorganized speech
- Emotional or personality changes
- Frequent mood changes—anger, agitation, anxiety, apathy depression, fear, euphoria, and suspicion

Finding an underlying cause for delirium is extremely important (differential diagnosis). If left untreated it progresses and can be life threatening. Typical causes of delirium include underlying infections, and reaction to medications.

Mild Cognitive Impairment

You may observe your family member having difficulty with immediate recall and word finding. He or she may have difficulty with complex problem solving skills, such as finding a creative way to do something he or she has not encountered previously. Approximately one-half of those diagnosed with Mild Cognitive Impairment (MCI) will develop dementia within five years.

In the next issue of the NTG Caregiver News we will discuss dementia—addressing the various types of dementia, including Alzheimer's disease which is the one most often seen in older adults with Down syndrome.

This is the fourth in a series of articles on aging in Down syndrome. Previous issues of this newsletter contained articles on Common Medical Conditions and Healthy Aging and Quality of Life. Future pieces will address the stages of Alzheimer's, and palliative and hospice care.

NATIONAL TASK GROUP ON INTELLECTUAL DISABILITIES AND DEMENTIA PRACTICES

The NTG is a coalition charged with ensuring that the interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and related dementias – as well as their families

and friends – are taken into account as part of the *National Plan to Address Alzheimer's Disease*.

We produce materials related to dementia, including practice guidelines, screening tools, education and training curricula and workshops, agency and family-based information, and other technical materials – as well provide technical assistance.

The NTG is affiliated with the American Academy of Developmental Medicine and Dentistry and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago and other partners, such as various university centers and the Gerontology Division of the AAIDD. [Read more about us.](#)

The NTG is a member of LEAD - 'Leaders Engaged on Alzheimer's Disease' - a Washington-based coalition working to focus attention on Alzheimer's disease and related disorders.

We're on the web!
AADMD.org/NTG

"Caregiving often calls us to lean into love we didn't know possible."



Tia Walker,
The Inspired Caregiver:
Finding Joy While Caring for Those You Love

NTG FAMILY SUPPORT

In May 2016, the NTG began hosting a monthly online support group meeting for family caregivers. We have long recognized the valuable role family members play in supporting one another and are all constantly

learning as we share our family stories. Support group participants and those who join us via email have expressed their gratitude for the opportunity to connect with others who are having comparable experiences. Over the past 1.5 years NTG members from a variety of disciplines have joined us for selected meetings and have shared their knowledge and expertise. Family caregivers have also noted the benefit of hearing from NTG members who specialize in Medicine, Occupational Therapy, Gerontology and Psychology.

If you would like more information about the online support group contact, Jadene Ransdell at the email address listed in the resource section below.

CHECK OUT THESE WEBSITES

Global Down Syndrome Foundation is dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy. <https://www.globaldownsyndrome.org/>

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. <https://www.alz.org/>

The Linda Crinic Institute for Down Syndrome is the first global institute to encompass basic research, clinical research and clinical care specifically for people with Down syndrome. The mission of the institute is to eradicate the medical and cognitive ill effects associated with Down syndrome.

<http://www.ucdenver.edu/academics/colleges/medicalschool/institutes/lindacrnica/Pages/lindacrnica.aspx>

NTG CONTACTS

For general information about the NTG:

Seth Keller, Co-Chair: sethkeller@aol.com or Matt Janicki, Co-Chair: mjanicki@uic.edu

For information about *Family Advocacy*:

Mary Hogan, Chairperson—Family Advocacy Workgroup: maryhogan@comcast.net

For information about *Family Caregiver Online Support Groups*:

Jadene Ransdell, Online Support Groups Facilitator: jadeneransdellal@gmail.com

For information about *NTG Training*:

Kathie Bishop, Co-Chair—Education and Training Workgroup: bisbur1@earthlink.net

GOT IDEAS?

If you have an idea for a newsletter article, would like to share information, or have questions about the newsletter, contact the editor of the NTG Caregiver News at ntgfamiladvocate@gmail.com.

