

DSConnect®: The Down Syndrome Registry

Families have frequently expressed frustration that many studies focus on younger people with Down syndrome, or that they are excluded from participation in important research because they have Down syndrome. A recent announcement from the DSConnect® Registry Coordinator may be of interest to those who have older family members with Down syndrome.

In June 2018 the INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome) Project was launched following a Congressional directive. This initiative will focus on research that affects people with Down syndrome, as well as the general population, including Alzheimer's disease and other dementias.

New funds have been released specifically for the INCLUDE Projects. The grants will address three components of the INCLUDE Project:

1. Basic science aimed at improving the health of people with Down syndrome

2. Developing a research cohort for Down syndrome
3. Clinical trials that include people with Down syndrome to improve their health and quality of life.

To be successful it will be important that adults with Down syndrome participate in NIH-funded research projects. By participating in the DSConnect® Down Syndrome Registry you can learn about current research opportunities. The Down Syndrome Registry is a secure online resource that gathers health information as a way to learn more about Down syndrome and the health of those who have it.

All information is kept confidential and no personal information is required. For example you won't be asked to give a social security number or credit card information.

When healthcare information is in the Registry, you can print out a health history summary, find health care providers in your area, and learn about new studies that include people

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*"Diversity
is being invited to
the party.*

*Inclusion
is being asked
to Dance!"*

Verna Myers

DSConnect®: The Down Syndrome Registry

Continued

with Down syndrome. If you would like to know more about it, check out this video at https://www.youtube.com/watch?v=83kQ21CL3_k#t=16

To join DSConnect and participate in the Down Syndrome Registry, go to <https://DSConnect.nih.gov>. Click on “Join the registry” on the homepage. Create an account with a username and password. Complete the consent form. Complete Health Questionnaires. (And write your password down somewhere secure—you will be required to change it periodically.)



OAA Amendments:

The NTG Proposes New Legislation to Expand Knowledge about Dementia Diagnostic Clinics

Matthew Janicki, PhD

The NTG has been in discussions with various aging and disability organizations, including those involved with family caregivers, about amending the Older Americans Act, which is being considered by Congress this year. When there are suspicions that dementia may be present, we have heard from many families that they have had difficulty finding clinicians and diagnostic centers familiar with Down syndrome and other intellectual disabilities in their area.

The Act already recognizes the role of State aging agencies in raising awareness about Alzheimer’s disease and dementias. This amendment would strengthen the agencies’ role in identifying intellectual disability geriatric assessment clinics, and geriatricians and other practitioners with expertise in later age, brain health issues.

Examples of suggested amendments include:

- designate one or more specialty diagnostic centers for adults with disability (including intellectual disability).
- amend sections of the Older Americans Act to increase availability of reliable diagnostic resources for this special population and increase the provision of post-diagnostic supports.

More information about the proposal can be found on the NTG’s website (www.aadmd.org/ntg). Readers interested in amendments to the Older Americans Act are advised to contact their federal Representative or Senator.



NTG Members Receive National Awards

Congratulations to three members of the NTG who have been recognized recently for their work supporting and advocating for individuals with intellectual and developmental disabilities. We are proud to have such wonderful examples of leadership in our ranks.

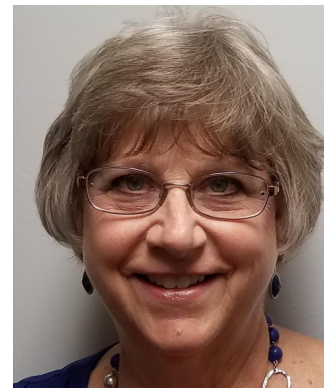
Dr. Alan Crocker Health Services Award



Dr. Julie Moran, a long-time advocate for persons with Down syndrome and other intellectual disabilities, was recognized by the Massachusetts Department of Developmental Services and the DDS Statewide Advisory Council, with the receipt of the Dr. Alan Crocker Health Services Award. The distinction is presented each year to a clinician who most exemplifies a total dedication to excellence and an unyielding belief in the worth and dignity of the lives of individuals with disabilities – characteristics to which Dr. Crocker devoted his career. Dr. Julie Moran is a geriatrician in Tewksbury, Massachusetts and has been the main author of several publications produced for the National Down Syndrome Society on Down syndrome and aging, and Down syndrome and Alzheimer's disease. A member of the Steering Committee for the NTG, Dr. Moran has been instrumental in expanding clinical expertise with respect to dementia in adults with Down syndrome.

2019 Sprit of the NTG Award

A member of the Medical Center Munroe-Meyer Institute at the University of Nebraska-Omaha, **Janet Miller**, is to be honored by the NTG with its 2019 Sprit of the NTG Award. The award is given annually by the NTG to a person or organization that has provided exceptional support, education, or training to individuals, families, and/or community supports that have been affected by Alzheimer's disease and related dementias in adults with intellectual and developmental disabilities. Mrs. Miller, a family advocate, has tirelessly promoted increased awareness of the possibility of dementia in people with intellectual and developmental disabilities. Currently, she is involved with creating a Caregivers' Guide for families living in Nebraska. The award will be given at the 2019 National Adult Down Syndrome Summit to be held in Detroit in April. Her daughter Jennifer, a woman with Down syndrome, recently passed away at the age of 41 from complications of Alzheimer's disease.



2019 Stephen Beck, Jr. Advocate of the Year Award



Jadene Ransdell was honored, earlier this month, by the National Down Syndrome Society at their 2019 Buddy Walk on Washington. She was selected as a recipient of one of their annual **Champions of Change Awards** given to those who have significantly impacted policy change for individuals with Down syndrome. Mrs. Ransdell, the mother of a 44 year old son with Down syndrome and Alzheimer's, was presented with the 2019 Stephen Beck, Jr. Advocate of the Year Award, which is given annually in memory of Stephen Beck, Jr., the father of a daughter with Down syndrome, and one of the "kitchen table parents" who championed the original ABLE Act. Jadene's mission is to raise awareness of the changing needs of older adults with Down syndrome and their families, and is the founder of the Down syndrome Adult Summit that is hosted by the NDSS, in partnership with the NTG.

Time for a Road Trip!

It's Not Too Late to Register!

We're building on the momentum created by the success of the *2018 NDSS Down Syndrome Adult Summit*, hosted by NDSS and its Self-Advocate Advisory Board (SAAB) in collaboration with the National Task Group on Intellectual Disabilities and Dementia Practices (the NTG) and the National Alliance for Caregiving (NAC).

The conversations will focus, again this year, on important and critical topics for all adults with Down syndrome. As the life expectancy for individuals with Down syndrome continues to increase, NDSS is committed to ensuring our adults with Down syndrome, their families, caregivers and other key stakeholders have the best, most accurate information throughout adulthood.



Who should attend?

- ♥ Individuals with Down syndrome (especially adults)
- ♥ Family members
- ♥ Caregivers
- ♥ Professionals who serve adults with Down syndrome

Summit Checklist

- 2nd Annual NDSS Adult Summit Registration:** Registration for the NDSS Adult Summit can be completed through this link:
<https://www.classy.org/event/2019-ndss-adult-summit/e181498>
- Hotel reservation:** the **Detroit Marriott at the Renaissance Center**. To reserve your hotel room, do it online through this link:
<https://book.passkey.com/event/49730712/owner/437/home>
- Travel Arrangements:** Guests can begin picking up their Adult Summit material on the afternoon of April 4th. All sessions will be completed by the evening of Saturday, April 6th.

NDSS Second Annual Adult Summit

Following is a sample of breakout sessions presented by NTG members that have been selected to be part of the Adult Summit program. These aging and Alzheimer’s workshops are part of nearly 50 breakout sessions being offered at the Adult Summit.

For a complete listing (understand that the sessions may change) please visit the NDSS website at: <https://www.ndss.org/ndss-adult-summit/2019-adult-summit-schedule/>

Breakout Session	Description
<p>Aging Well Together</p> <p>Seth M. Keller, MD, Co-Chair, NTG, Chair, Special Interest Group Adult IDD, American Academy of Neurology</p> <p>Mark Peterson, PhD, Associate Professor, Physical Medicine & Rehabilitation Research Non-Clinical Faculty, University of Michigan</p> <p>Beth Marks, PhD, RN, Research Associate Professor, University of Illinois at Chicago</p> <p>Sarah Lenz Lock, JD, Senior Vice President for Policy, AARP; Executive Director, Global Council on Brain Health</p> <p>Mitchell Levitz, Self-Advocate</p>	<p>Getting older holds a great number of promises as well as challenges and uncertainties. A large body of research has shown that caring for oneself throughout life does matter and can have an impact upon the aging process. This panel will bring together national experts on wellness and health promotion as well as advocates who will discuss the current research, and provide a practical approach that everyone should consider following. Aging Well Together will also describe how a team approach is best to ensure that living well as one ages can lead to a positive and productive future</p>
<p>A Conversation about Peer Support for Families and Caregivers</p> <p>Jadene Ransdell, BS, Down syndrome & Alzheimer’s Family Advocate</p> <p>Mary Hogan, MAT, Family Advocate</p> <p>Phillip McCallion, PhD, Temple University</p> <p>Lisa Ferretti, MSW, Temple University</p>	<p>Please join our conversation about peer support—what it means to families, what works and what doesn’t work, for example. The NTG and Temple University are collaborating on a project to increase the availability of online peer support for families and caregivers of people with Down syndrome and Alzheimer’s Disease. We’ll share information about the Peer Support Project and how you or an organization in your community can be involved. To be most effective we need to learn from you!</p>
<p>Advanced Care Planning</p> <p>Jane Boyle, Sibling, Fundraiser and Strategic Planner</p> <p>Jeanne R. Kerwin, DMH, CT</p>	<p>Individuals with Down syndrome and their families have a right to excellence in palliative and end of life care. This session will provide a personal and professional perspective on end of life planning and share important tools (such as POLST- Physician’s Orders for Life Sustaining Treatment) to ensure maximum quality of care through the end of life.</p>
<p>Things You Want to Know – Using Group Homes for Dementia Care for Adults with Down Syndrome</p> <p>Matthew P. Janicki, PhD, University of Illinois at Chicago, Co-Chair, NTG</p> <p>Kathy Service, ARNP</p>	<p>Little information is available related to facility-based care of people with Down syndrome and Alzheimer’s Disease. In this session you will hear about one dementia group home care project as the residents have been followed over time. Information shared on best practices through the stages of dementia may be helpful to families seeking residential care for their loved one. In addition, those who may be planning homes that provide specialized dementia care may also find the session helpful.</p>



Peer Support

We are extremely pleased to announce that a new state-wide support group has started in New Jersey. This group has already had tremendous impact on the community. Families have chosen to meet in person monthly, and the option to join through an internet connection is also available. The NTG wants to thank Jane Boyle and Leone Murphy for the work they are doing to support families in New Jersey. For more information about this group, contact Jane or Leone at jboyle417@gmail.com or leonemur2@yahoo.com.

On Friday afternoon, April 5th, Jadene Ransdell, Mary Hogan, Phil McCallion, Lisa Ferretti will lead a breakout session at the Down Syndrome Adult Summit in Detroit. *A Conversation about Peer Support* will give us a chance to have a dialog with those who have an interest in starting a peer support group, those who have conducted peer support and those who just want more information. We plan to use the results of that conversation as guidance as we move forward with the Online Support Group Expansion Project in which the NTG and Temple University are partnering.

The NTG is also creating a short-term workgroup whose task will be to develop a strategic plan for family support. There is a tremendous need for support and we want to be sure we are working with as many as possible—both individuals, organizations and Down syndrome groups—to maximize our efforts. If you would like to be part of this workgroup, please contact Jadene Ransdell at jadeneransdellal@gmail.com. Put *Peer Support Project* in the subject line of your email.



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



The NTG is a coalition of professionals and family members whose focus is on quality of life for people with intellectual and developmental disabilities who are affected by dementia. Through the work of NTG members, people with intellectual and developmental disability are included in the *National Plan to Address Alzheimer's Disease*. In addition, our many volunteers provide technical assistance and have developed tools to help others deliver the best services and supports to individuals with IDD and

dementia. 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 American Association on Intellectual and Developmental Disabilities (AAIDD). The NTG is also a member of **LEAD** - "Leaders Engaged on Alzheimer's Disease" a Washington-based coalition working to focus attention on Alzheimer's disease and other dementia.

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, Co-Chair, Family Advocacy Workgroup: maryhogan@comcast.net

For information about *Online Support Groups*: Jadene Ransdell, Online Support Group Facilitator: jadeneransdellal@gmail.com

For information about *NTG Training*: Kathie Bishop, Co-Chair, Education and Training Workgroup: bisbur1@earthlink.net