

# **Down Syndrome and Alzheimer's Disease: New Support Group for Families and Caregivers**

## *Jane Boyle*

**Leone Murphy, RN, APN** is an advanced practice nurse whose career has been devoted to healthcare for the special needs community. She is also the proud mother of Michele, a woman with Down syndrome. Leone is the Chair of The Arc of New Jersey's Mainstreaming Medical Care Program. **Jane Boyle** is a surviving sibling and family caregiver. Together, they have launched the New Jersey Down Syndrome & Alzheimer's Family Support Group.

Leone and Jane met when Jane's sister Ellen was at the early stages of Alzheimer's Disease. Both participated in *The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) National Family Support Group* — Leone as a professional who shared information and insights on Down syndrome and Alzheimer's Disease, and Jane as a family member looking to support her sister. Through monthly on-line meetings, families across the country found support for their difficult journeys.

The NTG is an affiliate of the American Academy of Developmental Medicine and Dentistry ([www.aadmd.org/ntg](http://www.aadmd.org/ntg)). The NTG has played a leading role in 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. The NTG recently collaborated with the National Down Syndrome Society ([ndss.org](http://ndss.org)) and Alzheimer's Association to develop a Caregivers Guide for DS/Alzheimer's ([ndss.org/publications](http://ndss.org/publications)).

At the urging of The Arc of New Jersey and the NTG, Leone and Jane set out to begin a Family Support Group for New Jersey families and caregivers affected by Down syndrome and Alzheimer's disease — the first state-based support group of its kind in the nation. The *Asbury Park Press* recently featured a front page story about their plans and can be found [here](#).

“The *Asbury Park Press* story opened the floodgates,” explained Leone, “The response was overwhelming so we decided that we had to get started right away.” The group's first meeting took place in January with almost 20 family members attending in person or by calling in. “There is a tremendous unmet need for information and support,” Leone added, “We hope families and caregivers — those now dealing with Down syndrome and Alzheimer's or who are concerned about the future — will join us. We want them to know they are not alone.”

Monthly meetings will take place the last Tuesday of each month. Meetings will include presentations by experts and participation by family members and caregivers. Participants can attend in person, on-line, or by calling in. For more information and to participate, email [leonemur2@yahoo.com](mailto:leonemur2@yahoo.com) or [jboyle417@gmail.com](mailto:jboyle417@gmail.com).