

Remaining Q&A Discussion

Attendee Question	Panelist Response
<p>How do you feel about giving the pneumonia vaccine to an adult with Down syndrome in their 40s?</p>	<p>These are our thoughts on Pneumonia vaccine for adults with DS: Pneumococcal Vaccines Adult Down Syndrome Center (advocatehealth.com) We are giving Prevnar 20 for those who haven't had it and we recommend it to all adults.</p>
<p>I have a daughter with DS in her late 30s who was just diagnosed with Alzheimer's and we are struggling to find a way to get her Leqembi or Kisunla (Alzheimer's medications).</p>	<p>I would highly doubt the diagnosis at this young age. Other reasons may explain the change. Recommend you find a way to work with a research center on the AD-DS.</p>
<p>When should individuals with DS see a neurologist for a baseline assessment?</p>	<p>Neurologists most likely would not be the ones to do a baseline assessment, it would come from a primary doctor and recommend using the NTG-EDSD.</p>
<p>I have a sister with DS in her 60s. She was diagnosed with Alzheimer's 8 years ago. The support groups I have found on Facebook seem to push for increased medication, etc. This sends me away. Are there support groups not so inclined to advocate medication use?</p>	<p>I would hope that any support group is more measured in their recommendations. Not aware of any group that has an overall philosophy on this. Often these recommendations are due to a degree of advocacy and perhaps such worry and concern on what has been happening to their loved one and wish beyond anything that something can be given to "fix" the problem.</p>

<p>My brother is in his 50s with DS and has been diagnosed with AD. He has developed a jaw movement, a back and forth movement, could that be Myoclonic?</p>	<p>Yes most likely myoclonic jerks, which are a type of seizures. They should be treated with seizure medications.</p> <p>Epilepsy in Down Syndrome: A Highly Prevalent Comorbidity - PMC (nih.gov)</p> <p>Diagnosis and treatment of late-onset myoclonic epilepsy in Down syndrome (LOMEDS): A systematic review with individual patients' data analysis - ScienceDirect</p>
<p>My daughter is in her 30s. She currently has Down Syndrome Regression which is controlled by medication because she is not a candidate for IVIG. How can I tell when she gets older if she has Alzheimer's Disease?</p>	<p>A further decline in function from what she may have now would be a concern. So having some sense of this level of current function is key, using the EDSD would be very helpful as a baseline and do it every year.</p>
<p>My neurologist won't give a diagnosis for Alzheimer's/dementia unless they have a brain scan. Is that the norm?</p>	<p>That's too bad. An amyloid PET scan will always show an increasing amount in all those with DS starting at age 35 and at this point, we are not ready for using these tests to make the accurate diagnosis. It comes down with a lack of experience in being able to make this diagnosis using functional assessments as a way to make the diagnosis and excluding other reasons for this decline.</p>
<p>What is your advice/recommendation about telling</p>	<p>Would try to provide the diagnosis but be aware</p>

<p>the individual about the dementia diagnosis and the changes which are now requiring care even if they don't seem to see/understand as the dementia progresses?</p>	<p>that they may not fully understand the implications. Don't push it. Just support them and help them and support them as you do anyway.</p>
<p>The memory center that my daughter sees is not providing her with a neurologist. I've asked. Is that appropriate? What do you suggest?</p>	<p>The memory center I suspect has either a geriatrician or a psychiatrist and they may have enough experience and may not need a neurologist.</p>
<p>The Lancet Commission (UK) just came out with a list of 14 issues that could cut Alzheimer risk in half - however, this reduction may only delay Alzheimer onset by 5 years. I heard a recent news story that a Down Syndrome individual with apolipoprotein-E genotype of APOE-e2/2 lived to be 90 without developing Alzheimer's. Has anyone else heard this story (APOE-e2/2 is associate with high likelihood of living to 100 without Alzheimer). If this is true, would it spur research into understanding the implications of APOE genotype (which accounts for half of Alzheimer's disease).</p>	<p>More research will be needed in this with ApoE. Can this type of ApoE be somewhat protective to pushing back the onset of AD, we don't really know. Health and wellness is also extremely important through one's life!!!</p>
<p>Thank you for all the information. My sister is in her 50s and diagnosed with Alzheimer's about 3 years ago. She was very high functioning, similar to Amy's daughter almost to the tee. She now lives in a wonderful group home, daily workshop</p>	<p>Go to these sites for more information on research Down Syndrome Research In Action - LuMind IDSC Foundation Alzheimer Biomarkers Consortium — Down</p>

<p>supports her socially and keeps her functioning. It's a horrible thought but we are donating her brain to UCI for Downs research at the time it becomes appropriate. What other areas of research can we belong to to assist others in the future?</p>	<p>Syndrome (ABC-DS) National Institute on Aging (nih.gov)</p>
<p>Dr. Keller/Chicoine, what's your experience using Alzheimer's medication on the DS population? Are there recent approved meds?</p>	<p>The medication which have been out for many years including donepezil (Aricept), memantine (Nemanda) have very marginal benefits, and if used must have a real sense and appreciation of the side effects plus so important to know how to show while being used whether they are working, or not. The new intravenous anti amyloid medication do not yet been used or have evidence of any benefit.</p>
<p>Is Alzheimer's different for people with DS? Is treatment different? Dementia?</p>	<p>Alzheimer's in those with DS starts much earlier, sometime mid to late 40's, has a higher rate of seizures and sadly is more progressive with shortened life span.</p>
<p>As the parent of an adult with Down syndrome in their 30s, I appreciate the discussion of the family role, responsibilities, etc. However, we do have a SYSTEM of care in CA. I am interested in knowing whether we can work toward embedding best practices and recommendations to enhance our statewide systems. For example, developing</p>	<p>I suspect the DD system of care in California and the various DS and other IDD community support organizations can and should be able to focus on this and come up with those standards.</p>

<p>providers, ensuring there are more residential & service options, recommended tools and timelines, protocols for tracking, etc.</p>	
<p>How often is it NPH & not dementia, in persons with DS? Is this something to regularly screen for with gait, incontinence & memory issues? Or is it too much of a zebra, so to speak?</p>	<p>NPH is rare and much as a zebra as you state. Any brain imaging done will make a mention of the size of the ventricles. I had mentioned this in the meeting and often the changes may have been present since birth.</p>
<p>Is there a registry of neurologists that specifically have interest in DS?</p>	<p>No</p>
<p>How do you support a family member with DS and Alzheimer's diagnosis with symptoms/navigating symptoms-specifically Sun-downing? Does bringing them out of their typical environment aggravate symptoms as it can with Alzheimer's in non-DS/IDD patients?</p>	<p>These changes of behavior are common. Providing a distraction to them hour or so before these behaviors occur such as destruction and reminiscing on fun and happy times can be helpful, with photos and videos. A change of environment can sometimes be difficult. Stability and tranquility is best.</p>
<p>There has been a challenge finding a memory care facility knowledgeable about Down syndrome or a developmental disability focused group home with knowledge and ability to care for someone with dementia. Any suggestions for finding qualified facilities when it is no longer safe to stay in the home?</p>	<p>Recommend to seek out a GUIDE program in your area and reach out to them for support. Guiding an Improved Dementia Experience (GUIDE) Model CMS Check out the map that helps locate these centers, reach out to them. We all strongly suggest that the DS/IDD community can and should work with them to help support our loved</p>

	ones with DS.
We are trying to find a doctor who can administer Alzheimer's meds. How can we find this source?	Unfortunately there is no such registry. Often your local DD/DS agencies are aware of DS friendly healthcare providers that would possibly be best to do this