

**Additional Down syndrome Questions  
October 5, 2017 Grand Rounds Presentation**

1. Would it be possible for DSACT and other associations to develop an agreement with hospitals so they can immediately speak with new parents of a Down syndrome (DS) child?

*Yes, although an agreement is generally not necessary. Most Texas Down syndrome associations (full list is in the DSHS brochure <https://www.dshs.texas.gov/birthdefects/downsyndrome/>) offer outreach to new parents, through personal visits, phone calls or email correspondence. If your nearest Down syndrome association does not respond to your inquiry, contact the Down syndrome association in Houston, Dallas, Austin or San Antonio, whichever is closest to you.*

2. Since the accuracy rate of the new test for younger woman is so misleading, why is it being done?

*In my opinion, marketing efforts to OBGYN's in connection with the cfDNA tests have been robust; it is possible that some OBGYN's may not realize that marketing materials for these tests have not received FDA oversight.*

*The September 2015 ACOG Committee Opinion on Cell-Free DNA Screening for Fetal Aneuploidy states in part "Given the performance of conventional screening methods, the limitations of cell-free DNA screening performance, and the limited data on cost-effectiveness in the low-risk obstetric population, conventional screening methods remain the most appropriate choice for first-line screening for most women in the general obstetric population."*

3. In your experience, was Early Childhood Intervention a useful resource?

*Yes, absolutely. Most research confirms that early intervention offers the greatest benefit, especially since many young children with Down syndrome benefit from a combination of physical therapy, speech therapy and occupational therapy.*

4. Is there any relationship between Down syndrome and early dementia?

*Yes. According to the National Down Syndrome Society website topic "An Introduction to Alzheimer's:"*

*While all people with Down syndrome are at risk, many adults with Down syndrome will not manifest the changes of Alzheimer's disease in their lifetime. Although risk increases with each decade of life, at no point does it come close to reaching 100%. This is why it is especially important to be careful and thoughtful about assigning this diagnosis before looking at all other possible causes for why changes are taking place with aging. Estimates show that Alzheimer's disease affects about 30% of people with Down syndrome in their 50s. By their 60s, this number comes closer to 50%.*

*The physical manifestations of Alzheimer's in the brain (plaques and tangles) affect a far greater segment of the Down syndrome population than the cognitive decline associated with Alzheimer's. One leading researcher has speculated that the same general preventive strategies for the general population may be effective for the Down syndrome population: maintaining low blood pressure, avoiding obesity and cardiovascular disease, socializing, getting good sleep, continuing to learn new things, moderate use of caffeine.*

5. Are there statistics on the rates of employment for persons with DS?

*I was not able to find employment statistics specifically for people with Down syndrome. The following information about people with intellectual disabilities (including Down syndrome) is from Special Olympics:*

*Nationally, 34% of people with intellectual disabilities are employed.*

*Of employed people with intellectual disabilities, 53% are employed competitively (i.e., work alongside people without disabilities at a market-driven wage); 38% in a sheltered workshop (work centers specifically for people with disabilities), and 9% in other settings (e.g., are self-employed).*

6. What's the status of research on identifying and treating the genes that cause Downs syndrome?

*With the mapping of the human genome, a great deal of progress has been made in identifying the genes responsible for the phenotype of Down syndrome. One easy way to stay abreast of cognition and other research is to visit the research page of Lumind Research Down Syndrome Foundation, <https://www.lumindrds.org/research/>.*

7. Great presentation! Could you please describe some of the commonly used developmental assessment tools?

*A case manager from an Early Childhood Intervention agency may have his/her own preferred developmental assessment tools.*

*One excellent resource on this topic is published by the New York State Department of Health, "Down Syndrome: Assessment and Intervention for Young Children." Appendix C of this lengthy document lists assessment tools commonly used.*

*[www.health.ny.gov/.../early\\_intervention/docs/guidelines\\_down\\_syndrome\\_assessment\\_and\\_intervention.pdf](http://www.health.ny.gov/.../early_intervention/docs/guidelines_down_syndrome_assessment_and_intervention.pdf)*

8. Is there a link between obsessive-compulsive behaviors and Downs syndrome?

*The following article may be helpful on this topic. <https://www.down-syndrome.org/case-studies/299/>*

9. What has contributing factors to the longer life expectancy rate (more than doubled since the 1980s)?

*Better medical care and greatly reduced rates of institutionalization are usually cited as the reason for the doubling of life expectancy for people with Down syndrome.*

10. At what point in the pregnancy can DS screening take place?

*The new cell-free DNA testing can be done as early as 9 weeks. The timeframes for performing amniocentesis or CVS are not affected by the timing of the cf DNA tests.*

11. What is the incidence of behavioral health issues with DS adolescents?

*The following article may be helpful on this topic.*

*<http://www.ndss.org/resources/health-care/associated-conditions/mental-health-issues--down-syndrome/>*

12. How can we get in touch with DSACT to volunteer my time and efforts?

*Just email [admin@dsact.org](mailto:admin@dsact.org) or register on our volunteer webpage*

*<http://www.dsact.org/volunteer/>. We love volunteers – thanks for wanting to get involved!*

I am happy to answer any other questions by email. [Suzshepherd@sbcglobal.net](mailto:Suzshepherd@sbcglobal.net).

-Suzanne Shepherd