

Brianna's Story



Our pediatrician came in as soon as he heard of our "suspicions". I really appreciated that he came to see us immediately. He walked in, evaluated Brianna and calmly said "It does appear that your daughter has Down syndrome." I cried and he sat with us and answered all of our questions. It was so helpful to know and not be left wondering for days.

Ellie's Story



The news was shared when my husband and I were alone in my hospital room (Ellie was in the NICU). When delivering our diagnosis, I can remember that the language was upbeat and positive, and never for a moment did we feel slighted.

Luca's Story



We were completely surprised when the pediatrician shared his suspicions of Down syndrome with us. The way my obstetrician shared her experiences growing up with a friend with Ds, and offered to put us in touch with another mom with a young boy with Ds really helped to address our fears of the unknown.

The Recommendations

Postnatal Diagnosis of Down Syndrome: Synthesis of the Evidence on How Best to Deliver the News (Pediatrics)

brianskotko.com/images/stories/Files/pediatricsprenatalguidelinesfinal.pdf

Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome: Recommendations of the National Society of Genetic Counselors (J Genet Counsel)

obgyn.duke.edu/sites/obgyn.duke.edu/files/NSGCPPracticeGuidelinesCommunicatingDiagnosisDS.pdf

Discussing Down syndrome: A Physician's Guide (National Down Syndrome Congress)

ndsccenter.org/physiciansguide/

A Promising Future Together: A Guide for New and Expectant Parents (National Down Syndrome Society)

www.ndss.org

To request a complimentary copy of these NDSS materials, call 800-221-4602 or email info@ndss.org

Health Supervision for Children With Down Syndrome (Pediatrics)

pediatrics.aappublications.org/content/128/2/393.full

Brighter Tomorrows Diagnosis Tutorial

brighter-tomorrows.org

"I Can" video tutorial for delivering a Down syndrome diagnosis sponsored by the Down Syndrome Network Oregon:

vimeo.com/album/2165160/video/66687709



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How to Deliver a Postnatal Diagnosis of Down Syndrome (Ds)

Evidence & Examples



Visit us at
dsdiagnosisnetwork.org
for more information.

The Opportunity

Down syndrome is the most common chromosomal condition, present in 1 out of 832 babies born each year. Despite the recent advancements in prenatal screening, the majority of Ds diagnoses are made postnatally.¹

Physicians delivering a Ds diagnosis postnatally have the opportunity to shape the early phase of a family's journey to understanding the diagnosis. Unfortunately, in a recent survey of more than 100 families who received a postnatal diagnosis of Down syndrome, 24% reported negative experiences with medical professionals during the diagnosis phase. The reasons these experiences were perceived as more negative included²:

According to the literature:

- *Lack of compassion when explaining the diagnosis (70%)*
- *Pressure to have had prenatal testing (15%)*
- *Lack of information provided or perceiving that their doctor was not educated about Ds (11%)*
- *Lack of support and low expectations for their children (11%)*
- *Medical professionals did not tell the parents the diagnosis at the time of birth (7%)*

1. Shin M., Besser L. M., Kucik J. E., Lu C., Siffel C., Correa A.; Congenital Anomaly Multistate Prevalence and Survival Collaborative. (2009) Prevalence of Down syndrome among children and adolescents in 10 regions of the United States. *Pediatrics*. 124(6):1565-71.

<http://dx.doi.org/10.1542/peds.2009-0745>

2. B.S.N. Goff et al. Receiving the Initial Down Syndrome Diagnosis: A Comparison of Prenatal and Postnatal Parent Group Experiences. *Intellectual and Developmental Disabilities* 2013; Vol. 51, No. 6, 446-457

The Recommendations



In an effort to support clinicians in the distinct position of delivering a Ds diagnosis, we have compiled advice and recommendations from the literature.

Key points to consider when delivering a Ds diagnosis include:

- *Deliver the news to the parents together when possible³*
- *Have the conversation in a private setting as soon as a physician suspects a diagnosis of Ds³*
- *Provide accurate and up-to-date information, including opportunities to connect with other families³*
- *Avoid using phrases such as "I'm sorry" or "Unfortunately, I have bad news"³*
- *Use person-centric language, emphasizing that this is a baby who has Down syndrome, rather than a "Downs baby" or a "Down syndrome child"⁴*

3. Skotko, et al. Postnatal Diagnosis of Down Syndrome: Synthesis of the Evidence on How Best to Deliver the News. *Pediatrics* 2009; 124:e751-e758

4. Sheets, et al. Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome: Recommendations of the National Society of Genetic Counselors. *J Genet Counsel* 2011.

The Outcome

The news of a Ds diagnosis may trigger an emotional response from families. It is important to allow time for silence and time for tears, and offer the family time alone.⁴

Likewise, research shows that when families have time to bond with their child, and get to know them as they grow and develop, those feelings of fear and worry evolve into love and pride.

According to a survey conducted of more than 2,000 parents/caregivers⁵:

- *99% love their son/daughter with Down syndrome*
- *97% are proud of their son/daughter with Down syndrome*
- *79% felt outlook on life was more positive because of son/daughter*
- *5% felt embarrassed, in general, by son/daughter with Down syndrome*
- *4% regretted having their son/daughter with Down syndrome*



5. Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers. *American Journal of Medical Genetics Part A* 155:2335-2347.