

DELIVERING A DIAGNOSIS OF DOWN SYNDROME

Brian G. Skotko, M.D., M.P.P., Children's Hospital Boston, Massachusetts General Hospital and Brigham and Women's Hospital

POSTNATAL

1. OBs and Pediatricians should coordinate their messaging. Ideally, they would meet together with parent(s) to deliver the news.
2. Inform parents of suspicion for Down syndrome immediately, even if diagnosis is not yet confirmed.
3. Deliver the diagnosis in a private room.
4. Parents should be informed together.
5. The infant with Down syndrome should be present and referred to by name.
6. Begin conversation with positive words, such as congratulations on the birth of the child.
7. Provide accurate, up-to-date information.
8. Limit discussions to medical conditions that the infant has or might develop within one year of age.



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9. Connect to local parent support groups and/or other families (MDSC Parents' First Call Program 800-664-MDSC or mdsc@mdsc.org).
10. Follow-up appointments should be arranged, as desired and needed.

Skotko, B., Capone, G., & Kishnani, P. for the Down Syndrome Diagnosis Study Group (2009). Postnatal diagnosis of Down syndrome: Synthesis of the evidence on how best to deliver the news. *Pediatrics*,124: e751-e758.

PRENATAL

1. Results from the prenatal screening should be clearly explained as a risk assessment, not as a "positive" or "negative" result.
2. Prior to CVS or amnio, discuss all reasons for prenatal diagnosis.
3. Healthcare professional(s) most knowledgeable about Down syndrome should deliver the news – most likely OB and genetic professional together.
4. If in-person visit not possible, news should be delivered over the phone at a pre-arranged time.
5. Answer: What is Down syndrome? What causes the condition?
6. Answer: What are realistic expectations for individuals with Down syndrome today? Offer connection with parent support groups (MDSC Parents' First Call Program 800-664-MDSC or mdsc@mdsc.org).
7. Use non-directive language.
8. Offer up-to-date materials or bibliography (MDSC Parents' First Call Program 800-664-MDSC or mdsc@mdsc.org).
9. Make follow-up appointments, including specialists, as needed.

Skotko, B., Kishnani, P., & Capone, G. for the Down Syndrome Diagnosis Study Group (2009). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics, Part A*, 149A: 2361-2367.