



## *Delivering a Diagnosis of Down Syndrome*

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### **POSTNATAL:**

1. OB's 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 on the birth of the child.
7. Provide accurate, up-to-date information.
8. Limit discussion to medical conditions that the infant has or might develop within one year of age.
9. Connect the family to the North Carolina Down Syndrome Alliance.
10. Follow-up appointments should be arranged, as desired and needed.



### **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 prenatal testing, 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 is 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 to connect them with the Triangle Down Syndrome Network.
7. Use non-directive language.
8. Offer up-to-date materials or bibliography ([www.ncdsalliance.org](http://www.ncdsalliance.org) or 984-200-1193)
9. Make follow-up appointments, including specialists, as needed.