Best Practices

- When delivering a diagnosis, use commonly understandable terms and convey information in a patient's native language when translation is available.
- Each condition detected with prenatal testing has different outcomes, and each expectant parent reacts differently based on their background, experience, life circumstances, and perceptions about parenting.
  - Assess the emotional reactions of the expectant parents and validate these feelings.
  - Use active listening and empathetic responses to offer support.
- If a condition does not cause premature death, instead of beginning with "I'm sorry" or "I have some bad news," use neutral language such as, "The results indicate...."
- Provide accurate and up-to-date information about the genetic condition and contact information for local support organizations.

*Adapted from www.lettercase.org/delivering-a-prenatal-diagnosis/

The Medical Outreach Alliance of the DSCBA

- We support expectant and new families as well as the medical professionals who care for our members.
- We deliver current and accurate information about Down syndrome to medical facilities to share with expectant and new families.
- We currently work with 37 hospitals and birthing centers throughout the Bay Area to provide information about programs, services, and supports the DSCBA offers.

DSCBA

Down Syndrome Connection of the Bay Area

Contact Us

101-J Town and Country Drive,
Danville, CA 94526
www.dscba.org
925-362-8660

Down Syndrome Connection of the Bay Area

Delivering

a Prenatal Diagnosis

Delivering a Prenatal Diagnosis

Communicating a prenatal or postnatal diagnosis or screening test results to a family can be overwhelming for both the clinician and the patient. That moment is often described as a flashbulb memory that a patient remembers in detail for a lifetime. Best-practice recommendations outline suggestions for discussing a prenatal or postnatal diagnosis so that clinicians can frame that moment in sensitivity and compassion.

It's also important to remember that patients consider both the moment they receive screening test results and the moment they receive diagnostic results as part of their diagnosis journey.

Best Practices

- Outline the differences between prenatal screening and diagnostic tests.
  - Screening tests (including cell-free DNA and non-invasive prenatal screening tests) indicate a patient's *chances* for having a baby with a number of genetic conditions. They are not definitive because false positives do sometimes occur.
  - Only chorionic villus sampling and amniocentesis are considered diagnostic.
  - If screening results indicate that the fetus likely has a genetic condition, make sure expectant parents understand that the results are not conclusive.
- The majority of parents want condition-specific information right away. If they do not receive that information from their clinician, they will likely perform an online search on their own, which can lead to them getting misinformation. Some parents will decline diagnostic testing and will not receive any information if your policy is to wait on giving condition-specific information until after diagnostic confirmation.
- If a pregnant woman wants to undergo testing, ask her why having a diagnosis prior to birth would be important to her. This can help better guide any future conversations about a test result.
- When possible, deliver the results in person or at a pre-established time by phone.
- Determine a standard way of handling all results and communicate that to patients so they don't get the impression that an appointment or a phone call is scheduled only if results indicate a diagnosis.
- Personally deliver the diagnosis as soon as possible following definitive prenatal testing.