Dear Doctor,

You changed my life. You might not have known it in the moment, but you have a very large place in my memory of my child’s Down syndrome diagnosis. I remember every word you said, I remember where we were in the room, I remember the look on your face. I remember it all. In fact, there is research that shows that women remember that moment with specific detail. It is a pinnacle moment in a parenting career.

I imagine it is difficult, having to tell a parent that their child has Down syndrome. Having to point out ultrasound results, discuss the possibility of further testing, and explain to them about a potential future with gross motor delays and intellectual disabilities. Explaining all this not knowing how they might react and maybe even seeing them cry. I imagine it is also a pinnacle moment in a medical career.

Knowing that it is such an important moment for a parent and a medical provider, I’m passionate about making sure that future diagnosis conversations go well, for everyone involved. That is why I’m writing this letter to you now; to share with you the evidence-based recommendations on how to deliver a Down syndrome diagnosis that are published in Pediatrics and also in the Journal of Genetic Counseling.

Some points within that stand out to me are:

- The plan for discussing results should be agreed upon between patient and counselor during the pretest counseling session.
- Provide accurate and up-to-date information, including opportunities to connect with other families.
- Provide the information in a sensitive and caring, yet confident and straightforward manner, using understandable language that is clear and concise.
- Avoid using phrases such as “I’m so sorry” or “Unfortunately, I have bad news”.
- Use person-centric language, emphasizing that this is a baby who has Down syndrome, rather than a “Downs baby” or a “Down syndrome child”.

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. 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/caregivers:

- 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

I know I was emotional when you shared the news with us, but I can tell you now that I couldn’t be prouder of my baby. I am excited to see all that lies ahead for us, and I hope that you don’t think that this diagnosis was a bad thing for us, based on my initial reaction. We are in a very good place now, and getting to know my child has shown me that the unexpected can sometimes be the best thing for us. If you ever find yourself delivering a Down syndrome diagnosis again, I hope you reflect on this letter and these recommendations, and realize the opportunity you have to shape the way a family receives this news about their child. Staying positive, supportive, and genuinely happy for a family that has brought a new life into this world is always a best practice, and is one that will always be remembered, especially after the tears have dried.

Kindly,

PS- If you are looking for any resources on Down syndrome, delivering a diagnosis, or support groups for families, I’ve listed a few below.

- Down Syndrome Diagnosis Network [www.dsdiagnosisnetwork.org](http://www.dsdiagnosisnetwork.org)
- The Joseph P. Kennedy, Jr. Foundation’s Understanding a Down Syndrome Diagnosis [www.lettercase.org](http://www.lettercase.org)