A Balanced Approach to Delivering a Diagnosis of Down Syndrome
Facts about Down Syndrome

- Down syndrome is the most common genetic condition; 1 in 691 or 6000 per year.
- There are 200,000 people living with Down syndrome in the United States.
- The average LIFE EXPECTANCY has increased from 25 years in 1980 to 60 years today.
  As medical advances continue, life expectancy will continue to increase.

- People with Down syndrome possess many strengths and individual talents.
- The cognitive impacts of Down syndrome tend to range from MILD TO MODERATE.
- People with Down syndrome are able to meet the same milestones as their peers, just at a slower pace.
- Government funded programs, such as Early Intervention, are available to help.
  Children who begin therapies at a young age show significant gains in life skills compared to those who wait.

- Children are able to be part of general education classrooms, continue with higher education, and have jobs within the community.
- People with Down syndrome are able to live independently or in group homes, take part in meaningful relationships, and get married.
It cannot be stressed enough that everything you do and say when giving the diagnosis will have a profound impact on the parents. It is something they will remember for the rest of their lives.
Presenting a Diagnosis

Give the diagnosis in person, sooner, rather than later, though if delivering a postnatal diagnosis, consider giving the parents time to bond with their baby first.

Tell both parents together, if possible. If you are working with a single mother, be sure she has a support person present.

Ask the parents what information would be helpful to them.

Avoid words or tone that imply tragedy or convey pity.

Validate their emotions and feelings.

Ask the parents if they would like to visit with experienced parents.
Delivering a Prenatal Diagnosis

Pressure to make a particular decision or a quick decision is not appropriate.

Be factual and clear, discuss the child’s potential and abilities as well as possible limitations and disabilities.

Remember no one can predict a precise outcome for any child.

Provide current written materials about Down syndrome.

Current research suggests a prenatal diagnosis termination rate approaching 90%. Remind parents that adoption is always an option.
Delivering a Postnatal Diagnosis

Congratulate the parents on the birth of their baby.

Touch the baby, use his/her name.

Evaluate the parents understanding of the diagnosis.

Stress that their child is a baby first and foremost.

Be factual and clear, discuss child’s potential and abilities as well as possible limitations and disabilities.

Remember that no one can predict a precise outcome for any child.
Be sure the entire team of health care professionals working with the new parents understands consistent messaging is important.

Provide current and accurate information on Down syndrome – nothing more than 10 years old!

Make sure ALL health care professionals on the Labor/Delivery floor know where this information is housed.

It is extremely helpful for new parents to meet other parents of children who have Down syndrome. They may do so through the DSPG or the Family and Friends Down Syndrome Association of Niagara.
While the birth of a child with Down syndrome may initially be viewed as unwelcome, this interpretation usually changes dramatically over time.

*Parents’ first reactions are profoundly influenced by the attitudes and actions of their health care providers.*

The simple fact that when a baby with Down syndrome is delivered, a child is born, is often overlooked in the storm of emotional upheaval that surrounds the birth.
How will the Family be Affected?

Brian Skotko, Co-director of Massachusetts General Hospital Down Syndrome Program led a research study in 2011.

The study evaluated:
- 2000+ parents or guardians
- 800+ siblings
- 248 individuals with Down syndrome

Research found:
- 87% of families surveyed expressed overwhelming feelings of love and pride for family members with Down syndrome.

Individuals with Down syndrome also reported feelings of happiness towards many areas of their lives.

The extent to which individuals with Down syndrome were impaired had little or no relation to the attitudes within the family.
What does the Future Hold?

Post secondary education opportunities.
Real jobs for real people.
Relationships and marriages.
Actively participating in their communities.
Living independently or in semi-supported environments.
Amazing medical advances.
Research which will result in therapies and medications to enhance cognition.
Where you can Find Help

21_Connect
https://21Connect.org

Down Syndrome Parent Group of WNY
716-832-9334
http://www.dspgwny.org

Prenatal and Birth – 5 Year Old Support Group
716-946-0429
emily.mondschein@gmail.com

Family and Friends Down Syndrome Association of Niagara
716-870-4904
http://www.dsaniagara.org

National Down Syndrome Congress
800-232-6372
http://www.ndsccenter.org

National Down Syndrome Society
800-221-4602
http://www.ndss.org

National Down Syndrome Adoption Network
513-213-9615
http://www.ndsan.org