



Finding out that your baby has Down syndrome during the pregnancy is typically a tough time for patients, partners, and their families. This is not necessarily what you anticipated or expected for your pregnancy. Even though you may have said and known deep down that you would love and accept whatever is going on with your baby, there can still be days where it is difficult. It is hard, but there is hope. Feeling that hope may take some time, and that's okay.

If you have decided that you want to continue your pregnancy and raise your baby with Down syndrome, know that you are fully supported by professionals in the genetics field in that decision. As you learn more about Down syndrome and get connected with other families, you will likely find that there is a vast network of support for you of people who have traveled down this same path and want to be there for you.

Some of you may be in a situation where you don't feel supported in your decision to continue your pregnancy (maybe your partner, extended family members, or your provider has a differing opinion). This can add complexity to a situation that may already be emotionally difficult. It is important to remember that this is your decision, and it is important that you feel as comfortable as possible with that decision.

Finding people to support you on this journey will continue to be very important. Listed below are some great resources to get you started. Please feel free to contact us as well.

Organizations

National Down Syndrome Congress

1-800-232-6372, <http://www.ndsccenter.org>

This organization provides information, advocacy, and support for individuals with Down syndrome.

National Down Syndrome Society

1-800-221-4602, <http://www.ndss.org>

This organization advocates for the value, acceptance, and inclusion of people with Down syndrome.

International Mosaic Down Syndrome Association

1-855-IMDSA21, <http://www.imdsa.org>

This organization provides information and support for individuals with mosaic Down syndrome.



Online Resources

Understanding a Down syndrome Diagnosis

www.lettercase.org

The Joseph P. Kennedy, Jr. Foundation's *Understanding a Down Syndrome Diagnosis* is an accurate, balanced, and up-to-date booklet for use when delivering a diagnosis of Down syndrome, and can be found at this site along with other helpful information. This booklet has been prepared with assistance from the Down Syndrome Consensus Group, which includes representative of The National Society of Genetic Counselors, The American College of Medical Genetics, The American Congress of Obstetricians and Gynecologists, The National Down Syndrome Society, and the National Down Syndrome Congress.

Brighter Tomorrows

<http://www.brightertomorrows.org>

The purpose of this site is to provide families with balanced and accurate information about a diagnosis of Down syndrome either during their pregnancy or at birth.

Down Syndrome Pregnancy

<http://downsyndromepregnancy.org/>

This site includes a blog and a public dialogue board to provide support for those who have received news during pregnancy or after birth that their baby has Down syndrome.

PALS Program

<http://www.palsprograms.org/congratulations/>

The Congratulations Project is an initiative in which members of the PALS family write letters to new members of the Down syndrome community. These letters are designed to



inspire, encourage, welcome and, most importantly, congratulate new parents and siblings of a child with Down syndrome.

Publications

- *Babies with Down syndrome: A New Parent's Guide*, edited by Susan J Skallerup. Woodbine House, 2008.
- *Bebés con síndrome de Down: Nueva guía para padres*, compilado por Susan J Skallerup. Woodbine House, 2008.
- *Choosing Naia: A Family's Journey*, by Mitchell Zuckoff. Beacon Press, 2002.
- *Down syndrome: Visions for the 21st Century*, edited by William Cohen, Lynn Nadel, Myra Madnick. Wiley-Liss, Inc., 2002.
- *Expecting Adam: A True Story of Birth, Rebirth and Everyday Magic*, by Martha Beck. Random House, 1999.
- *Gifts: Mothers Reflect on How Children with Down syndrome Enrich Their Lives*, edited by Kathryn Lynard Soper. Segullah Group, Inc., 2008.
- *Road Map to Holland: How I Found My Way Through My Son's First 2 years With Down syndrome*, by Jennifer Graf Groneberg. Penguin Books Ltd., 2008.
- *What Parents Wish They'd Known: Reflections on Parenting a Child with Down syndrome*, by Kathryn Lynard Soper, 2008.

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