

## **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.

### **Continuing the Pregnancy - Online Resources**

#### **Understanding a Down syndrome Diagnosis**

[www.lettercase.org](http://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.

## **Adoption - Online Resources**

**[National Down Syndrome Adoption Network- http://www.ndsan.org](http://www.ndsan.org)**

The National Down Syndrome Adoption Network (NDSAN) helps facilitate adoption of infants and children with Down syndrome. If you are finding out during the pregnancy that your baby has Down syndrome and you feel like placing the baby for adoption is something you may consider, this is the resource for you. In the past two years alone, this organization has helped facilitate over 100 adoptions of infants and children with Down syndrome.

Reference paper: Lindh, HL, Steele R, Page-Steiner J, Donnenfeld AE. 2007. Characteristics and perspectives of families waiting to adopt a child with Down syndrome. Genet Med. 9(4):235-40.

## **Termination - Online Resources**

### **A Heartbreaking Choice**

**<http://www.aheartbreakingchoice.com>**

This website supports women who have made the "Heartbreaking Choice" to terminate a much wanted pregnancy due to a poor prenatal diagnosis, problems with their own health, or for the health of another fetus (selective reduction).

## **Publications**

- [A Mother's Dilemma](#), by Wendy Lyon, Molly A. Minnick. Pineapple Press, 1993.
- [A Time to Decide, a Time to Heal: For Parents Making Difficult Decisions About Babies They Love](#), by Molly A. Minnick, Kathleen J. Delp, edited by Mary C. Ciotti. Pineapple Press, 1992.
- [Difficult Decisions: For Families Whose Unborn Baby Has a Serious Problem](#), by Patricia Fertel. Centering Corporation, 2004.
- [Our Heartbreaking Choices: 46 Women Share Their Stories of Interrupting a Much-Wanted Pregnancy](#), by Christie Brooks. IUniverse, 2008.

- [Precious Lives, Painful Choices: Prenatal Decision-Making Guide](#), by Sherokee Ilse. Wintergreen Press, 1993.