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Financial Strategies for the Friends and Clients of...

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Information and Support for the Special Needs Community



MetLife®

In the Public Eye – Prenatal Testing for Down Syndrome



Just a generation ago, people with Down syndrome were commonly sent to institutions, where they most often languished in dreadful conditions without education, health care or emotional support. After a 1975 federal law granted them access to public education for the first

time, people with Down syndrome increasingly began to grow up among their families and attend school with their peers. As time went by they began to complete high school, with some going on to attend college.

Over the past 30 years, many more educational opportunities have become available for people with Down syndrome. Children with Down syndrome under the age of three are entitled to government-supported early intervention services. Schools offer an array of programs including therapy and support services, pre-school, and inclusive classrooms in which people with disabilities learn among their typical peers. Post-secondary programs for people with intellectual disabilities have emerged.

Yet these changes seem to have taken place outside of the view of the medical community. A recent survey of medical students found some 81 percent reporting that they were “not getting any clinical training” about people with intellectual disabilities. (Special Olympics, 2005)

Down syndrome organizations are seeking to make sure that physicians and expectant parents have a realistic understanding of both the difficulties and the possibilities inherent in a diagnosis of

Down syndrome. While it is true that people with Down syndrome have physical and intellectual challenges and need services and supports to help them thrive, they are also capable of learning, and of leading happy, productive and fulfilling lives.

Parents of children with Down syndrome say the stress of raising a child with Down syndrome is lower than many might expect (Hodapp et. al. 2001), and the siblings of children with Down syndrome have been found to be more compassionate and well-adjusted than their peers (Dykens 2005). Perhaps contrary to public expectations, the parents of children with Down syndrome experience a lower divorce rate than couples who do not have children with Down syndrome (Urbano & Hodapp 2007).

There are challenges to be sure, but many people with Down syndrome and their families are blossoming when given support and opportunities to learn. In fact, the Down Syndrome Association of Greater Cincinnati maintains a list of over 200 families waiting to adopt children with Down syndrome. Many of these families say they are interested in adoption because of their positive experiences with Down syndrome.

Down Syndrome Affiliates in Action (AIA) is helping Down syndrome organizations nationwide work collaboratively to address prenatal testing concerns. AIA is poised to help local Down syndrome organizations respond to the rapidly emerging developments in prenatal testing through the Informed Decision-Making Task Force, a committee of Down syndrome family members, medical professionals, and legislators who explore policy and resource solutions for prenatal diagnosis issues. Members of the task force represent different regions, ideologies, and talents. They use their unique skills to educate medical professionals, expectant parents, and the public about the meaning of a Down syndrome diagnosis. The following methods were employed in 2008:

- ◇ Speaking at local, national, and international physician conferences

- ◇ Creating materials for expectant parents and physicians
- ◇ Creating online resources and utilizing public awareness campaigns
- ◇ Collaborating on ethical guidelines for physicians
- ◇ Providing Down syndrome awareness presentations for physicians
- ◇ Carrying out local outreach programs
- ◇ Maintaining and advertising adoption awareness programs

To ensure that physicians and expectant parents receive the breadth of information about Down syndrome to make truly informed decisions, the following resources have been developed:

- ◇ Brighter Tomorrows (brightertomorrow.org) — The Human Development Institute at the University of Kentucky developed (under a grant from the Center for Disease Control) an online support program in Spanish and English that includes video demonstrations, questions and answers, “life glimpses,” and downloadable resources for new and expectant parents and physicians.
- ◇ Changing Lives: Down Syndrome and the Healthcare Professional —
 - ◇ Created by the National Down Syndrome Society (www.ndss.org), Changing Lives is a model program to educate physicians, nurses, genetic counselors, and other health care professionals about the clinical and developmental needs of people with Down syndrome and how physicians can support their parents when presenting the diagnosis.◇
- ◇ Adoption is an Option! (dsagc.org)— The Down Syndrome Association of Greater Cincinnati maintains a list of over two hundred families interested in adopting children with Down syndrome.
- ◇ Expectant Parent Guide for Receiving a Diagnosis and a Medical Professional Guide for Delivering a Diagnosis (canisterbooks.com) — Canister, a design studio, developed print materials for new and expectant parents and a free downloadable Prenatal Outreach Program for organizations who want to train parent support volunteers.
- ◇ “There’s Help and Hope” Brochure (downsyndromebrochure.org) — The Concerned Women for America, a pro-life organization, developed a downloadable tri-fold brochure.
- ◇ “Light at the End of the Tunnel” (dsaoc.org/programs/tunnelEnglish.pdf) — A collection of stories from parents who received a prenatal diagnosis produced by the Down Syndrome Association of Orange County in partnership with the National Down Syndrome Congress.

- ◇ “Gifts” books (giftsds.segullah.org) — A collection of new and expectant parent stories edited by Kathryn Leonard Soper and published by Woodbine House.
- ◇ An expectant parent informational packet, including the book *Common Threads: Celebrating Life with Down Syndrome* is available from the Band of Angels Foundation (www.bandofangels.com)
- ◇ *Babies with Down Syndrome: A New Parents’ Guide*, edited by Susan J. Skallerup, published by Woodbine House.

Online videos —

- ◇ DSACT “Down Syndrome in the 21st Century” at http://www.thebearmedia.com/pw_cm_dsact.html
- ◇ NDSC “Discussing Down Syndrome: A Physician’s Guide” at <http://ndscenter.org/physiciansguide/>



With ACOG’s new professional guidelines and the development of prenatal tests that can be used earlier and more safely in pregnancy, more expectant mothers will receive prenatal test results for Down syndrome. A diagnosis, however, is only the beginning of the information these mothers will want and need.

Down syndrome organizations across the nation are ready and willing to help provide the rest of the information about what a life with Down syndrome can be and what resources and support are available to help children and families lead full, satisfying lives.

To contact your local Down syndrome organization to learn more about their prenatal outreach efforts, see dsaia.org/affiliatelist.

MetDESK®, MetLife’s Division of Estate Planning for Special Kids, works with national non profits to help support the mutual goal of helping individuals with special needs. MetDESK® is dedicated to helping families plan for the future of children and/or dependents with special needs. Helping you answer those questions, directing you to the right resources, and just being there as a resource and advocate for you, is an important part of what we do. If you’d like to find out more, or you’d like to be referred to a local MetDESK® Specialist, please call 1-877-MetDESK, or 1-877-638-3375, or visit our website at www.metlife.com/DESK.

This article was written as a collaborative effort by the Down Syndrome Affiliates in Action (dsaia.org) which provides resources and a conference specifically for leaders of Down Syndrome organizations across the country. For more information about your local affiliate, please refer to dsaia.org/affiliatelist which provides the name and website addresses of organizations providing direct parent support.



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