

CHANGING HOW THE WORLD SEES A CHILD WITH DOWN SYNDROME

Special Needs

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By Wendy Bulawa

“When I first learned that my daughter had Down syndrome, I wasn’t sure where to turn,” said Tony Agudelo, a North Andover resident and father of a child with Down syndrome. “Our daughter’s diagnosis was completely unexpected and the emotions I felt seemed to paralyze me.”

Down syndrome, also known as Trisomy 21, is a genetic condition in which an extra chromosome present in all or some cells alters an individual’s physical and mental development. Down syndrome knows no boundaries and appears within all nationalities, socio-economic classes, ethnic groups and races. Some of the most recognizable physical characteristics for individuals with Down syndrome are almond-shaped/upward-slanting eyes, smaller and lower-set ears, and broad hands with short fingers and a single crease across the palm. These physical attributes aren’t always readily recognizable however life-threatening cardiac or gastrointestinal issues plague these individuals and often require medical procedures within a few days of birth. Children with Down syndrome also have increased susceptibility to infection, respiratory problems and childhood leukemia. However, not every baby with Down syndrome develops health problems and most of these health concerns are now treatable.

Once a diagnosis of Down syndrome has been delivered, the joy of becoming a parent is often shadowed by a range of indescribable feelings and hundreds of questions. For new parents lacking medical expertise or knowledge of Down syndrome, these initial moments can be even more challenging. In Massachusetts however, an array of resources exist including a statewide network of families raising children with Down syndrome.

The Massachusetts Down Syndrome Congress (MDSC) Parent’s First Call Program is comprised of 26 parent volunteers available to speak with couples who have learned of their child’s Down syndrome diagnosis—whether prenatally or after birth.

“Parent’s First Call connects new parents with other local families who listen, provide up-to-date information and welcome them into a community of parents who have had similar experiences,” said Sarah Cullen, coordinator of the Parent’s First Call Program for the MDSC and parent of a child with Down syndrome.

Through the MDSC, parents are offered a free package of information, a complimentary one-year membership and connection to a network of resources including local support groups and families. Cullen further explained that a parent volunteer from the First Call Program can also visit new parents in the hospital where lifelong decisions are often made.

“Parents tell us all the time that the most credible and important information they receive comes from other families,” said Dr. Allen Crocker, director of the Down syndrome Program at Children’s Hospital, who also serves as a member of the MDSC Board of Directors.

Fast Fact:

Approximately one of every 1,000 children in the U.S. is born with Down syndrome.

Strides have been made to educate the public about Down syndrome, yet continuous updates are still needed as individuals with Down syndrome continue to break through societal and health barriers and rise above set-forth expectations. For those interested in learning more about the genetic condition, local libraries remain a resource. Through its successful Library Book Project, the MDSC has placed

resource materials including *Babies with Down Syndrome*, *My Best Worst Brother* and *Count Us In – Growing Up With Down Syndrome* in more than 370 public libraries across the state.

“Down syndrome impacts more than 350,000 individuals in the United States,” said Suzanne Shea, president of MDSC. “Through the Library Book Project, we aim to celebrate the lives of those with Down syndrome and help educate the public of the benefits these individuals bring to society.”

Local Families Extend Net of Support

As important as information is for families affected by Down syndrome, so is the need to connect with others living a similar life. The MDSC provides such opportunities through its annual picnics, Buddy Walk and fundraisers including a hockey event with Boston Bruins alumni. Supplementing these activities are playgroups for families with children with Down syndrome which have sprung up across the Bay State



Amanda Russo, 3, giggles as she pops bubbles from a bubble maker during a playgroup for families with a child with Down Syndrome.

One in particular, Morning Travelers, has welcomed more than 50 families residing in and around the North Shore and southern New Hampshire to its monthly get-togethers. The founders of Morning Travelers--Sharon Randall, Maura Russo and Charlotte Gray-- met at a support group a few years ago at which time they discussed creating something for themselves as well as their children. Their ultimate goal in creating the playgroup was to foster fun and lasting friendships for the years ahead.

"When you walk into a room full of families where having a child with Down Syndrome is the norm, you can take a deep breath, relax and know that you belong," said Sharon Randall of North Andover.

Morning Travelers meets the third Saturday of each month at 10 a.m. at the First Calvary Baptist Church in North Andover, arranges occasional outings for apple picking and hay rides, and schedules a monthly 'Mom's Only' dinner during which mothers exchange experiences, advice and camaraderie.

Local Research Reveals Physician Shortcomings

In a widely publicized research study completed in 2005 by Brian G. Skotko, a joint degree student at Harvard University's John F. Kennedy School of Government and Medical School, it was found that physicians often fall short and remain overwhelmingly negative when communicating a diagnosis of Down syndrome.

"Doctors continue to find it very challenging to deliver a diagnosis like Down syndrome to an otherwise happy expectant mom," said Skotko, who co-authored the award-winning book, *Common Threads: Celebrating Life with Down Syndrome*, and also has a sister with Down syndrome.

Skotko continued, "But the results of this study are conclusive: Delivering a prenatal diagnosis of Down syndrome does not have to be a gloomy affair. In fact, mothers in this study have written the prescription on how best to explain the diagnosis in a loving manner."

After publishing his research paper on Down syndrome diagnosis in the *American Journal of Obstetrics and Gynecology*, Skotko was invited to Washington, D.C. for a joint press conference with Senator Edward Kennedy (D-MA) and Senator Sam Brownback (R-KS) who plan to jointly introduce a new bill

motivated by Skotko's study. The bill--"Prenatally Diagnosed Condition Awareness Act" -- proposes \$25 million in federal funding so that women who receive prenatal test results for conditions like Down syndrome receive accurate, up-to-date information and referrals to support groups.

Resources for Parents

Massachusetts Down Syndrome Congress - Parent's First Call

Contact: Sarah Cullen

1-800-664-MDSC (1-800-664-6372); www.mdsc.org

Children's Hospital Boston – Down Syndrome Program Parent Group

Contact: Angela Lombardo; 617-355-2209

Morning Travelers (North Shore)

Contact: morningtravelers@yahoo.com

Professional Center for Child Development (Andover/Lawrence)

Contact: Sue; 978-475-3806

www.theprofessionalcenter.org

South Shore Down Syndrome Parent Group (Plymouth)

Contact: 781-585-1310

MetroWest Parents of Children with Down Syndrome (Hopkinton)

Contact: Patricia; 508-881-2519

The Parent Support Group (New Bedford)

Contact: Addie; 508-996-8551

National Down Syndrome Congress

Contact: 800-232-NDSC

www.ndsccenter.org

National Down Syndrome Society

Contact: 800-221-4602

www.ndss.org

Author: Wendy Bulawa is a North Andover resident and mother to Abigail, a child with Down syndrome. She is also an active member of both the Massachusetts Down Syndrome Congress and Morning Travelers.