




NEW PARENT SUPPLEMENT

OUR MISSION

- To enhance the welfare of people with Down syndrome and their families through the development and promotion of education, counseling, employment, and recreational programs
- To increase public awareness, understanding, and acceptance of Down syndrome

NEW BABY PACKETS

The DSALA provides a New Baby Packet for each family who contacts the office at the birth of their child. The packet can be mailed or delivered to the family by trained peer counselors, other parents who have been trained to answer the many questions a new family might have about their child. A new baby with Down syndrome is cause for celebration, this new life will take the family on an amazing journey and the DSALA will be there to provide support along the way. 



WELCOME TO HOLLAND Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes

"It's just a different place."



in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's

slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away...because the loss of that dream is a very very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland. 🌸

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BIENVENIDOS A HOLANDA Emily Perl Kingsley

A menudo me piden que describa lo que es la experiencia de criar a un niño con una discapacidad. Para ayudar a entender lo que esta experiencia única significa, a aquellos que nunca la han tenido; para poder imaginar lo que se siente, dejenme decirles que es algo parecido a lo siguiente...

Cuando se va a tener un bebé es como planificar un viaje de vacaciones fabulosas a Italia. Se compran un montón de guías turísticas y se hacen planes maravillosos: el Coliseo, el David de Miguel Angel, las Góndolas de Venecia. Uno se prepara incluso para aprender algunas palabras en italiano. Es muy emocionante.

Luego que se han pasado meses en expectativa, finalmente llega el esperado día. Horas más tarde, el avión aterriza. La aeromoza se acerca y anuncia: "Bienvenidos a Holanda."

"Holanda?!" se pregunta uno. "Como que Holanda?!?" Mi vuelo

era para Italia! Se supone que debía estar en Italia. Toda mi vida he soñado con ir a Italia.

Pero, ha habido un cambio en el plan de vuelo. El avión aterrizó en Holanda y debe quedarse aquí.

Lo importante es que no le han llevado a un lugar horrible, desagradable y sucio, lleno de pestilencia, hambre y enfermedad. Es sólo un lugar diferente.

Así es que usted debe salir a hacer compras y adquirir nuevos mapas y guías. Y debe aprender un nuevo idioma. Y conocerá a un montón de gente que nunca habría conocido.

Sólo que es un lugar diferente. Con un ritmo un poco menos ajetreado que el de Italia, menos bullicioso y aparatoso. Pero, luego

"Sólo que es un lugar diferente."



de estar allí por un tiempo, una vez que la agitación ha pasado, usted mira a su alrededor y comienza a darse cuenta que Holanda tiene los molinos de viento, y Holanda tiene los tulipanes. Holanda incluso tiene los Rembrandts!

Pero todo el mundo está muy ocupado yendo y viniendo de Italia, y todos se ufanan de las maravillosas vacaciones que han pasado allí. Y por el resto de su vida, usted se dirá "Si, allí es donde yo debía haber ido. Eso es lo que tenía planeado."

Y ese dolor nunca, nunca jamás se irá, pues la pérdida de ese sueño es una perdida muy significativa.

Pero, si usted se pasa la vida lamentando el hecho que no llegó a Italia, nunca tendrá el espíritu libre para disfrutar lo más especial, lo más precioso de Holanda. 🌸

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LETTER FROM THE EXECUTIVE DIRECTOR Gail Williamson

Babies With Down Syndrome In The 21st Century; How Far Have We Come?

In 1979 when my son was born with Down syndrome I was very fortunate to have a pediatrician who gave us hope and understanding. My son Blair was born prematurely and weighed only 3 pounds and 6 ounces. His first few weeks in the hospital were full of preemie issues, nothing that pointed to Down syndrome and his physical appearance was without many typical trisomy characteristics as well. Blair's official diagnosis came a few months later. When the test results were returned our doctor called and said "What I am going to tell you about Blair will not change who he is. After I say these words he will still be the same baby that you know and love. Blair does have an extra twenty-first chromosome, he has Down syndrome, and now that we know that we can help him to reach his highest potential." He went on to say "Please don't spend a lot of time looking at adults with Down syndrome thinking that Blair's future will be the same, there are so many opportunities for Blair that today's adults haven't had so we know that Blair will far exceed their development and accomplishments." Oh don't we all wish our doctors could use that example while giving such life changing news to new and expectant parents.

Study Shows Many Physicians Still Have Far To Go.

Recent studies show that many doctors including obstetricians, pediatricians and geneticists are still missing the mark when it comes to giving accurate and unbiased information to their patients. The findings of Brian Skotko's research study *Prenatally Diagnosed Down Syndrome: Mothers Who Continued Their Pregnancies Evaluate Their Health Care Providers* which was published in the March 2005 issue of

the American Journal of Obstetrics and Gynecology, explores the experiences of mothers in the U.S. who received a prenatal diagnosis of Down syndrome. The study found that for the most part, doctors who inform expectant moms that their baby has Down syndrome are not communicating the positive potential of people with Down syndrome or providing enough up-to-date information or referrals to parent support groups. The study received significant media coverage, including articles in U.S. News and World Report, The Washington Post and Child magazine.

BRIAN SKOTKO'S PRESCRIPTION FOR HEALTH CARE PROVIDERS communicating a diagnosis of Down syndrome

Results from the prenatal screening should be clearly explained as a risk assessment, not as a "positive" or "negative" result.

Results from the amniocentesis or CVS should, whenever possible, be delivered in person, with both parents present.

Sensitive language should be used when delivering a diagnosis of Down syndrome.

If obstetricians rely on genetic counselors or other specialists to explain Down syndrome, sensitive, accurate and consistent messages must be conveyed.

Physicians should discuss all reasons for prenatal diagnosis including reassurance, advance awareness before delivery of the diagnosis of Down syndrome, adoption, as well as pregnancy termination.

Up-to-date information on Down syndrome should be available.

Contact with local Down syndrome support groups should be offered, if desired.



Senate Bill Introduced

Washington hopes to meet the needs brought to light by Skotko's project. Senators Sam Brownsback of Kansas and Ted Kennedy of Massachusetts have introduced S. 609, the *Prenatally Diagnosed Condition Awareness Act*, to the Senate. The bill would require physicians to provide up-to-date, scientific information about life expectancy, development potential and quality of life for a child born with Down syndrome or other prenatally diagnosed condition. By law, doctors would also have to refer women who receive a positive diagnosis to key support services and ensure that they receive up-to-date, scientific information about the accuracy of the prenatal test.

National Down Syndrome Advocacy Groups Respond

The National Down Syndrome Society and the National Down Syndrome Congress responded with several concerns about the bill in a joint position statement. They stated that they advocate that efforts to improve access to accurate information should target women who receive postnatal diagnosis as well as those who received prenatal diagnosis. Also, they advise that consideration should be given to how patients' privacy will be protected, how funding

allocated to this bill will be distributed, and how new programs will complement already-existing services by the NDSS, the NDSC and other like-minded organizations.

Meeting The Needs Of Health Care Professionals Locally

In an effort to assist health care professionals in providing better diagnosis and care for their patients with Down syndrome the DSALA has joined with the NDSS in their program *Changing Lives: Down Syndrome and the Health Care Professional*. DSALA uses the program to better educate physicians, nurses, genetic counselors and other medical professionals in our local Los Angeles area about the clinical and developmental needs of people with Down syndrome. DSALA volunteers make themselves available to the medical community presenting an informative videopresentation and helpful printed materials including tips on presenting the diagnosis, growth charts and comprehensive lists of health care guidelines. DSALA is always looking for opportunities to present to medical professionals as well as volunteers to help present the program.

DSA of Orange County, *Light at the End of the Tunnel*. It features reflections from parents whose child with Down syndrome was diagnosed before birth. The book encourages parents to grieve for the child they have longed to have and allow themselves to learn about the child to come. It is a very helpful tool at a very emotional time in expectant parents' lives.



All new babies born with Down syndrome in the Greater Los Angeles area should receive a bag of gifts and valuable information from the DSALA. The new baby packets can be sent

by mail or delivered in persona by a peer counselor. A new parent or healthcare professional can call and request a new baby packet.

The Future

Together we can make our world more inclusive, accessible and accepting. But sometimes the steps are very small. In the quarter of a century since my son Blair was born I have seen so much advancement for individuals with Down syndrome. Today with the medical research being done I know that the next generation will have even more opportunities to pursue their dreams and to advocate for themselves. Blair has a good life and my life is better for having him in it. As scary and unexpected as his diagnosis was, I see that he has touched more lives as an individual than I could have ever touched in my lifetime. 🌈

NOW WHAT? Gail Williamson

So you have a new baby who is diagnosed with Down syndrome, what do you do now? We suggest you get ready for a new journey. You will find that as beautiful as your new baby is you will still need time to grieve the loss of the baby you were expecting and didn't come. Separating this from celebrating the child that you have may be helpful. You can do both at the same time. We suggest you let your family be a support to you. Let them be a part of the new journey; share what you learn with them. Let your other children get use to the name Down syndrome. This is helpful as questions arise in the future. Depending on their age, you can let them know that this sibling will develop a little slower and that being a brother or a sister is very important. Learn what you want to learn. If you like to dig in and get all the info as soon as possible, search the internet and learn about the research that is going on that soon might be able to help our children's cognitive development and other areas of their lives. If you want to just take it a day at a time, do. Just loving your new baby is the most important thing you can do and if you need any support along the way please give us a call at the DSALA. 🌈



Gail Williamson with baby John

Meeting The Needs Of Each Family One At A Time

The DSALA provides materials for expectant and new parents of children with Down syndrome. For families with a prenatal diagnosis we provide an honest booklet published by the

MORE INFORMATION

Local Support

- **Down Syndrome Association of Los Angeles (DSALA)**
315 Arden Avenue, Glendale, CA 91203
818-242-7871 www.dsala.org

National Support

- **National Down Syndrome Society (NDSS)**
800-221-4602 www.ndss.org
- **National Down Syndrome Congress (NDSC)**
800-232-6372 www.ndsccenter.org

