

Name This Newsletter

(See details on page 3)

September 2007

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PUBLISHED BY THE NORTHWEST DOWN SYNDROME ASSOCIATION
CELEBRATING EVERY PERSON WITH DOWN SYNDROME

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All Born In

Inclusion Conference Draws Big Crowd

By Kim Jarvis

The second annual *All Born In* cross-disability inclusion conference took place on April 28 at Portland State University. Created by NWDSA board members Angela Jarvis-Holland and Roberta Dunn, the conference attracted approximately 200 participants and offered 20 informative sessions focusing on the importance of fully including children with disabilities in classrooms and our community.

"I saw a really good mix of parents and professionals. Anyone who is teaching kids could learn a lot from this conference. It will widen your perspective," Angela said.

Highlights from the day included keynote speeches by Kathie Snow and Jeff Strully. Both are parents who have fought hard for inclusion for their children. They addressed the civil and moral rights of children with disabilities and were inspiring as well as informative.

Jeff talked about the importance of creating desirable futures for our children that will allow them to live fulfilling lives as members of our community. He told the story of his "two daughters". One was a college

Please see *All Born In* on page 5

Celebration

Welcome Makena

By Nancy Korf

I was a wreck the first weeks after our daughter, Makena, was diagnosed prenatally with Down syndrome. Knowing very little about the condition, I was afraid for her health, depressed for the things I assumed she would never be able to do, and terrified for her future. I had a hard time believing that my feelings were normal and that our family would be okay. Books about Down syndrome gave me even more issues to worry about, so I stopped reading and started asking friends and neighbors for help. That's when I started to meet some amazing people, like Esther Fletcher and her family.

We met Esther through neighbors, the Atacks, who attend the same church as the Fetters. Esther has Down syndrome. As a church project, she made a baby blanket, planning to donate it to a local hospital to give

Please see *Celebration* on page 7

"Trouble knocked on the door, but hearing laughter, hurried away."

Benjamin Franklin

NWDSA

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This Newsletter is published quarterly by the Northwest Down Syndrome Association (NWDSA), a non-profit organization managed by a board of parent volunteers.

To be added to our mailing list please visit www.nwdsa.org and click on the resources link, or send your mailing info to the address above. There is no subscription fee, but if you would like to make a donation, you may send a tax deductible contribution to NWDSA at the address listed above or use PayPal on our website.

Readers are welcome to submit letters and articles to the address above or e-mail editor@nwdsa.org. Please include your name, address, phone number and e-mail. All submissions will be reviewed and edited for content and style.

The NWDSA Mission;

Create and nurture a loving and inclusive community celebrating every person with Down syndrome.

NWDSA will accomplish this mission by empowering and supporting families and individuals who have been touched by Down syndrome. We will work to increase education, promote public understanding and acceptance, and toward full inclusion of individuals with Down syndrome in our community.

Opinions published in *This Newsletter* are not necessarily those of the NWDSA

Photo on front and back cover by Jodi Collins of Urban Photography www.urban-photography.com

Letter from the Board

NWDSA's New Home Base

By Steven Holland, NWDSA President

We are very pleased to announce that the NWDSA has a new home! As of June 1, 2007, we have established our "world headquarters" at 6826 NE Glisan Street in Portland Oregon. It is just down the street from Providence Hospital. We are excited to be able to have a centralized home for our resources, files, information systems, a meeting place, and a location to support the work of NWDSA.

Although it is a storefront location, it really will serve as a home base, and not as an "office or clinic". It will not have the look and feel of a boring, drab, colorless office. Instead it will have bright colors, lively decorations, pictures of our kids, a space for children to play, storage for our large collection of resources, and an area to conduct meetings. We are a parent driven organization, and we see it first and foremost as a support center for our work.

We are excited by this opportunity to centralize our efforts, and we appreciate the help of our community and especially our business friends, who have made this move a reality. A big thank-you to Charles McCleod, owner of the business next door, PC Paramedix, who is sub-letting the space to us at a discount rate. Many thanks also to NWDSA Board members, Christy Reese, Angela Jarvis-Holland, Jen Brandse, and Jamie Burch for their work in cleaning, painting, decorating, and for sourcing the furnishings.

On July 21st, we had an open house and celebration for our families and friends. We met some new families and "christened" our new home. The star guest was a 9 day old baby with Down syndrome who captured the hearts of everyone there. In the fall we will have a more formal open house and will invite other groups and agencies to visit with us.



President Steven Holland, far right, welcomes families at the open house

Community Voice

By Abby Braithwaite

As many of you will have noticed, our newsletter has been on a lengthy sabbatical. After several months of beauty rest, we are back in circulation with a fresh new look. We hope you find it easy on the eyes and full of useful and inspiring information. We would like to celebrate our return with a new name for the paper, but the newsletter committee has been working so hard assembling articles and putting the newsletter together that we haven't had time to come up with a new title. So we are putting a call out to all of you in the NDWSA community to send us your ideas. Here is a chance to wield your pencils and come up with a creative name for the newsletter, celebrating our kids and our community.

Speaking of pencil-wielding, we welcome submissions from our readers. The NWDSA community is diverse and spread out. Although we come together a couple of times a year for the Buddy Walk and socials, and meet in smaller groups at the RLCs and playgroups, there are few opportunities to reach out to all of our families at one time. In addition to using the newsletter as a way for the Board to communicate with the families who make up our members, we would also like to provide a voice for the community as a whole. As we all know, the parents are the experts here, so we don't want to miss the opportunity to tap into a resource as vast as the parents who make up our readership.

Whether you are a new family just starting out on your journey, a grandparent with a lot to brag about, or a sibling with some funny stories to tell, we want to hear your voice on these pages. If you are the parent of an older child with Down syndrome, you have an incredible amount of knowledge and experience to pass on to the newer families. Perhaps you are a self-advocate who would like to share your story in your own words. We would love to hear your voice and give you an opportunity to share your story with the community. The NWDSA world spreads far beyond the board members and the newsletter committee. Let us do the dirty work of assembling the articles, editing and laying out the paper; you just put your words down on paper and send them on to us.

We will be working under space constraints, so we may not be able to publish everything that comes our way. If you are interested in writing a piece for an upcoming issue, please contact the newsletter committee at editor@nwdsa.org (or attn: editor c/o NWDSA, PO Box 9127, Portland OR 97207). We are very excited to have the newsletter back on the presses, and we hope you are as excited to flip through these pages and get back in touch with your community. We welcome your feedback, and don't forget to submit your ideas for our "Name this Newsletter" contest!



Strength in Numbers

If you are interested in writing a piece for an upcoming issue, please contact the newsletter committee at editor@nwdsa.org or Editor c/o NWDSA PO Box 9127 Portland OR 97207

Family Corner – A Brother’s Perspective

By Jack Loneragan

I remember when she first came to the house, I loved her, she was so cute and kissable. The only time I didn’t like her as much was when she screamed - but that wasn’t much.

On the other hand, her liking me, no one knows - because they’re not her and she’s not them - but I think she liked me because whenever I walked up to Kate, her face suddenly exploded with happiness and she smiled as bright as the sun.

I guess I could call her “The Little Dragon” because in the Chinese Zodiac she was a Dragon, which is very energetic and full of fun and she was exactly that!

It’s easy to remember when she first rolled over, we were in our first house in Oregon on Skyline Blvd. Me, my mom and Kate were on our play structure in our back yard. We were just minding our own business when my mom said, “Jack look! She rolled over, she rolled over!” But she wasn’t doing it anymore, and then she did it again. “You’re right,” I said “She did, she did!” I ran to get the phone. When I came back my mom called my dad and my dad called his mom and she told her friends and on and on and on. From then on I called everything that she learned her “tricks” and even now that I am nine I can still remember that day.

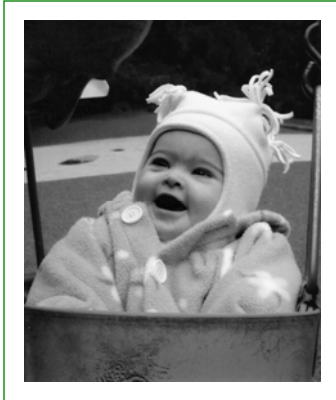
One day my mom told me that Kate had a small disorder called Down syndrome. Of course, not knowing what Down syndrome was, I asked what it was. She explained that Kate would do everything that other people could do but it would take her a bit longer. Then I said, “so what you are really saying is that she was clever.”

I thought Kate was very smart even though she did have Down syndrome. She could roll over, commando crawl, sit and even talk. To me there is completely no difference between her and anyone else.

In the year 2005 my mom had twins - Joe and Ewan.

They help me remember Kate a lot. Joe reminds me most of Kate. He has a small round head, short brown hair and brown eyes - and that was Kate, exactly Kate.

Editor’s note: Kate was born in November 2000 and died unexpectedly of a rare metabolic disorder in 2002. Using money donated at her memorial, her parents established the Kate Loneragan Resource Center for families of children with disabilities.



Visit the Kate Loneragan Resource Center at the Sunset EI/ECSE site

“Her face suddenly exploded with happiness and she smiled as bright as the sun.”



Kate and Jack

Portland Buddy Walk 2007

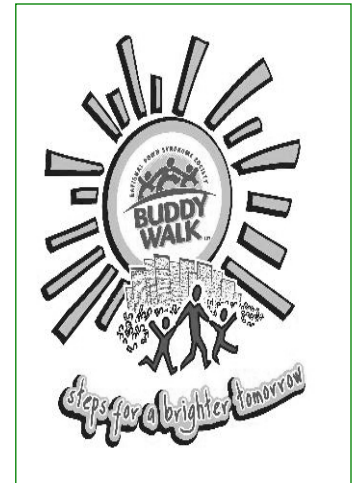
Say it Loud, Give a Cheer, Buddy Walk Time is Almost Here

By *Whitnie Trost*

HOORAY! It's that time of year again. Mark your calendars for Saturday, September 29 for the 2007 NWDSA Buddy Walk. Gather your family, friends, coworkers and everyone else you can think of and come join one of the best events of the year. We'll have treats, goodie bags, games, and special guests for fun photo opportunities. Live music will be provided by Pristine Blue. Best of all, Buddy Walk is a great chance to connect with old friends and make new ones along the way. It will all be here for you to enjoy.

To get a head start this year we are providing two ways you can register and get pledges. We will be mailing out our pledge form like we do every year (it will also be available to download from our website at www.nwdsa.org.) You can share the pledge form with your family and friends, or you can register online and e-mail the pledge info to all of your friends and family all over the world.

To register online just go to <http://buddywalk.kintera.org/nwdsa>. This website is easy, fun and it leads you step by step through the registration process. Once you register, you are on your way. You can personalize your website, build a team, and get all your friends and family involved. Whether you register online or with your pledge form, just remember that this is a day of celebration and fun, so you don't want to miss it. We will see you there.



Join us September 29, 2007
at the Portland Rose Garden Arena

All Born In

Continued from page 1

graduate who owned her own day care business and home, traveled the world and had plenty of friends. The other was a severely handicapped dependent who had no concept of how to communicate, had difficulty seeing, learned to walk at 10 years of age and endured debilitating seizures. The surprise twist: the two daughters were the same person, his daughter Shawntell. The story illustrates how perception can influence your point of view and what is possible.

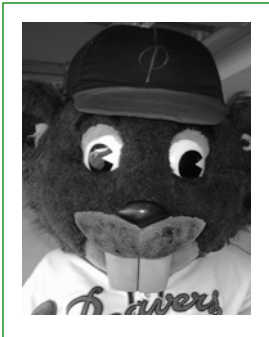
Kathie talked about how her son is more like people without disabilities than he is different from them, and the struggles she's had breaking free from what she terms "Disability World". Her message, "Disability is Natural," points out that people with disabilities don't need to change, we need to change the way we think about them.

Paula Stanovich, Ph.D, professor of Special Education at PSU gave the closing remarks and was very involved with organizing the day with the help of a group of her students. Professor Ruth Falco was instrumental in securing the PSU site for the conference and numerous local agencies and volunteers worked together to make the conference a success. "It was great having the students involved this year," Angela said, "the partners and sponsors helped tremendously and people felt it was a cohesive day that left them feeling encouraged."

"People with disabilities don't need to change, we need to change the way we think about them."

Events

Open Arms Playgroup: Join other parents and their children on the third Friday of every month from 10:00 - 11:30 AM at the Rainbow Preschool in Bethlehem Lutheran 1244 NE 39th Ave. in Portland, just off I-84. A great opportunity to ask questions, share ideas, and learn from others' experience. For more information contact Jamie Burch at 503-704-3883 or butterflyburch@yahoo.com.



Go Beavers!

Beaver's Baseball: It's the 3rd Annual Dads 'n' Kids Baseball Outing on Sunday September 2 at 2:05 PM. Lots of prizes to celebrate Kids Appreciation Day at PGE Park, Portland vs. Fresno. Tickets will be provided by the NWDSA. Please RSVP Jamie Burch at 503-704-3883 or butterflyburch@yahoo.com.

Buddy Walk: Saturday, September 29 starting at 10 AM, join friends and family at the Rose Garden Arena in Portland. Don't miss this awesome day filled with fun and entertainment, meet new people and catch up with old friends. See page 5 for more information.

Et Cetera

... Tune in to OPB on Sunday morning for a treat. *Signing Times* is now being broadcast weekly on Public Television stations across the country. This award winning show makes learning American Sign Language easy and there are many fun tricks to help you remember all the signs. A great way to give kids an alternative way to communicate before they are able to verbalize. Check your local listings for scheduling.

... Now available on DVD: *My Brother*. A dying mother knows she will leave her children behind. How can she safeguard the bond between the brothers? Starring Vanessa Williams as the mother and introducing Christopher Scott in a powerful role. This film uses people with disabilities instead of taking the easy route and using non-disabled actors.

... Oregon will see the biggest expansion of its Head Start program for preschoolers in years. The last Legislature increased state money for the programs by \$39 million, making room for about 3,100 more children. Oregon Head Start coordinator Dell Ford says the new money is enough to enroll 75 percent of eligible children, up from the current 57 percent.

... From the folks at The Down Syndrome Educational Trust; Down Syndrome Online, www.down-syndrome.org, provides trustworthy, current information. The site covers all areas of development, education and health for people with DS. It's pertinent to everyone involved in the support of people with DS; families, teachers, therapist, doctors. All the information published is reliable and research based. Selected *Down Syndrome Issues and Information* books are also available online. The Down Syndrome Educational Trust is dedicated to advancing the understanding of effective ways of help the development and education of people with Down syndrome.

Catch *Signing Times* on OPB, Sunday mornings. Check your local listings for scheduling.

Celebration

Continued from page 1

to a newborn with Down syndrome. Tracy Attack knew of Esther's project and Makena's birth, she connected our two families.

Esther and her mother, Nancy, visited us in mid-April when Makena was four weeks old. Esther is an impressive young lady. She attends school at Westview High. She enjoys singing, is active in her church, dreams of marriage and family life and has set a goal of becoming a special education teacher. Esther snuggled Makena and sang to her, giving her the blanket. Nancy told me a bit about Esther's early intervention, very relevant to us since Makena was about to receive her first assessment. She also reminded us not to plan so far ahead for Makena that we forget to simply enjoy the present.

Their visit was short, but it taught me more than any book about the condition. With her determination and her family's effort, Esther will live a fulfilling and productive life, and I can envision the same possibilities for Makena.

Makena will treasure her blanket for many years. I will treasure Esther's lesson forever.



Makena and Esther

Editor's note: If you have received a prenatal diagnosis or have a new baby with Down syndrome, please contact the NWDSA. We have an excellent New Parent Guide loaded with useful information. We are available to visit on the phone, in person, or e-mail. We would also like to present you with a welcome blanket and provide contact with families who are in similar situations and can help new parents overcome some of their concerns and worries.

NWDSA

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NWDSA is organized for charitable, scientific & educational purposes to provide families and individuals with Down syndrome social opportunities, support, education and information.

NWDSA is a registered non-profit corporation in Oregon and has 501(c)3 tax-exempt status with the federal government.

Down syndrome is a genetic condition that occurs in approximately one of every 800 live births. The chance of having a baby with DS is not affected by where you live, social class or race. Also, having a baby with DS does not mean you did anything wrong: nothing done before or during pregnancy causes DS. Recent advances in our understanding have resulted in dramatic improvements in the potential and life span of individuals with Down syndrome.



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A Message from the NWDSA

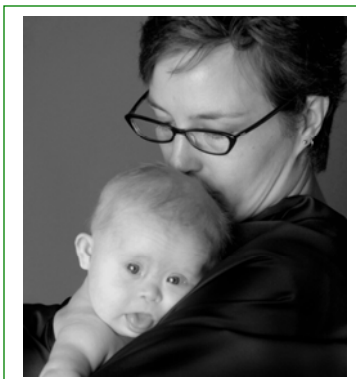
As proud parents to children with Down syndrome, each board member of the NWDSA has firsthand experience with the joys and the hardships of raising a child with individual needs. We understand the importance of connecting with other families and how much we rely on these relationships when we encounter the inevitable challenges. We also celebrate each others victories, making the journey so much richer. The entire Board of Directors of the NWDSA consists of volunteers and is supported by enlightened professionals. For more information on our organization and ways in which you can become involved or donate, please visit our website at www.nwdsa.org or call 503-238-0522.

Para comunicarse en español, llame a Maria O’Harra al 971-570-9942 o Sheyla Hirshon 503-239-1509

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