



STEPPING UP

December 2009

Issue 9

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

NDSC Conference

Road trip to Sacramento

By Tammy Miller

The National Down Syndrome Congress held their 37th Annual Convention this past July in Sacramento, California. More than 2,500 people gathered from across the United States and from overseas. The convention included the Youth & Adult Conference, the Brothers & Sisters Conference and many group facilitators and speakers who generously donated their time and expertise.

Several families from this area attended the convention, and my husband and I were glad to be there, too. Oregon was well represented by keynote speakers and award winners. Joseph Pinter, M.D., head of the Down Syndrome Clinic at OHSU won the Theodore D. Tjossem Research Award for research in the area of neuroimaging of individuals with Down syndrome, and Joan Medlen, R.D., L.D. was awarded the Exceptional Meritorious Service Award for her tireless efforts in promoting healthy lives for people with Down syndrome.

Keynote Presentations by our own Eleanor Bailey and Karen Gaffney were a major highlight of the weekend. They made Oregon proud!! Those ladies spoke with such confidence, eloquence and power. No one will forget Eleanor raising her fist into the air and shouting, "Free our people!" These remarkable young women showed families with young children the possibilities for their lives; there is no ceiling.

Please see *Conference* on page 3

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Celebration

Building the family of my dreams

By Emily Braman

"They are so cute, I bet families will be lining up to adopt them," I said of the two gorgeous little girls.

This is the statement that started me on the path of becoming Leah and Eden's mom. I was reviewing the bulletins of children available for adoption in Oregon with my case worker, who had told me that, as a single person, I was unlikely to be chosen as an adoptive parent for a child under three. With so many married couples looking to adopt young children, my best chances would be with a school-aged child or sibling set.

"No, it is going to be hard to find an adoptive family for those two," stated the adoption worker.

Please see *Celebration* on page 11

*"Now let us welcome the
new year, full of things
that have never been..."*

Rilke

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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 *Stepping Up* 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

An exciting year comes to an end

By Steven Holland, NWDSA President

Hello and Happy Holidays from all of us at the Northwest Down Syndrome Association. It is hard to believe another year has passed, but with the recent cold weather, it's easy to believe it's almost winter!

2009 has been another busy year for the NWDSA. In January we launched our first Advisory Board, bringing members of the broader community together to help raise our profile and come up with creative new ways to fund our work. We have especially enjoyed our relationship with Advisory Board member Sherry Kucera, co-owner with her husband Brett of Tony Starlight's Supperclub and Lounge in Northeast Portland. Together Sherry and Brett (aka Mr. & Mrs. Starlight) hosted the first annual 007 Benefit, with a casino-themed evening of James Bond fun back in July. Since then they have also held a Frank Sinatra benefit night and a Johnny Mercer night, where all door proceeds went to NWDSA. It has been wonderful to work with Brett and Sherry, and they have in turn worked to encourage musicians, vendors and customers to donate their services to the NWDSA. We would like to thank all members of our Advisory Board for helping to expand our profile in the community and raise much-needed funds.

I am sad to announce that two of our Executive Board members have moved on. Open Arms founder Jamie Burch served on the board of the NWDSA for 6 years, and her passion for inclusion and dedication to the NWDSA mission will be missed. Jamie's legacy lives on in the continued success of the Open Arms playgroup, and we wish Jamie and her family all the best as she pursues the next steps in her career. Kyle Holmgren, this year's Buddy Walk Chair, was on the Board for just a year, and her work and dedication will also be well missed. We are pleased that she has committed to a key role on next year's Buddy Walk Committee, and will be filling in as the host for Open Arms in Portland as needed this winter.

As we enter into the heart of the holiday season, coming together with family and friends around the dinner table, I am reminded of the heart of the work of the NWDSA – supporting families and building a community that embraces all children, and working toward full inclusion.

The NWDSA believes we are at a crossroads in history. A generation ago, children with Down syndrome and other disabilities often grew up in institutions, and would have been “celebrating” the holidays without their families. Now they come home to their families, and live with their parents and siblings, joining them around the dinner table.

But there is more to do than just eat! Just a few weeks ago my wife Angela's brother and his family joined our family for what has become an annual holiday tradition. We drove out to Boring, Oregon to cut a fresh Christmas tree for each family. Daniel really enjoyed helping pick our tree, cutting it down with some help from his older brother Quinn. Then we grabbed a burrito (Daniel's favorite health food) and went home to decorate our 7-foot-tall Douglas fir. We all enjoyed pulling out all the old ornaments, along with some new ones, and decorating the tree!

Continued on next page

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Our children with disabilities do face obstacles, and we are committed to knocking down those obstacles. We do this work not to prove that we can prevail, or because we relish a fight, but because we genuinely believe our kids belong in this world – that they should not be segregated because of their disability.

As a family, we are committed to giving our sons the opportunity to be their best selves, and as an organization the NWDSA is committed to helping families find their own paths to an inclusive world. As you come together with your families this season, look around your table at your child's first "inclusive setting" and dream with us to make this world a better, more welcoming place for all children.

Wishing you all the best of Holidays!

Conference

Continued from page 1

The convention took over the capital of California. We attended workshops, swam, shopped, and dined. We know Down syndrome is normal, but it's a nice experience to be in a community where it is the norm. We met families and amazing individuals from all around the world, including two recently engaged young couples with Down syndrome, a missionary family from Africa, an adult advocate working in Governor Schwarzenegger's office, and a young man who had recently earned his drivers license! A highlight of the weekend was the dance on Saturday night. This crowd knows how to party – we danced for hours! The energy, love and acceptance were intoxicating. We had a blast and left renewed and rejuvenated!

But it wasn't all play. We were in workshops daily from morning to evening. There truly was something for everyone. The information was current and accurate and the presenters were professionals who also showed sincere warmth and concern for enhancing the lives of people with Down syndrome.

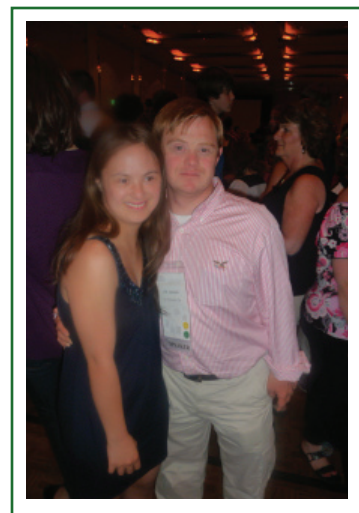
As my husband came with me, we divided and conquered. I attended sessions pertaining to speech intelligibility, handwriting development, behavior and communication. My husband was interested in Sue Buckley's Teaching Children to Read and a workshop conducted by a gentleman who has a sister with Down syndrome called, What Your Other Children Without Ds are thinking: Sibling Issues.

We took away much from the convention. It was educational, inspirational, but most of all it was a celebration! We are so blessed to have our children and this was a celebration of how awesome they are today, just the way they are.

Editor's note: Notes from presentations will be made available to NWDSA through the Resourcefulness Center. Keep your eyes peeled for the date and time!

The 2010 National Down Syndrome Congress will be held in Walt Disney World, Florida, July 16-18. More information can be found at ndscenter.org.

*We do this work...
because we genuinely
believe our kids belong
in this world.*



A young couple enjoying time together at the NDSC conference

Community Voice

Norton and Barbara Peck Family Foundation Donation

By Abby Braithwaite

Sometimes the greatest gifts we receive are the least expected. As a small, non-profit organization, the NWDSA is always on the lookout for new and unique sources of funding. When Advisory Board member and nightclub owner Sherry Kucera of Tony Starlight's Supperclub and Lounge offered to put together a benefit last summer, we were excited and grateful. When she and her husband Brett mentioned a James Bond theme, we knew we were in for a rollicking good time. What took us by surprise was the amount of support that Brett and Sherry were able to garner from their community of musicians, vendors and customers. Musicians donated their time and talents, vendors donated to the raffle, and customers came to the event, donated raffle prizes and silent auction items, and more.

While the evening on a whole was fantastic, one gift deserves special recognition. Sue Robertson and Don Peck are regular guests at the club, and they sent Sherry a note saying they were unable to make it to the NWDSA benefit, but would like to learn more about our organization. Their family's charitable foundation, the Norton and Barbara Peck Family Foundation, would be holding a meeting in August, and wanted to consider our group as a possible recipient of a gift. We were touched to be considered by virtual strangers, and worked to get a packet together about our work, mentioning in particular that we are hoping to put out a new edition of our New Parent Guide soon.

A couple months later, we received notice through Sherry that we had been chosen as a recipient, and we agreed to meet the donors at Tony Starlight's to receive the check and pay our thanks. After a night of good music and a tasty meal, we met with Sue and Don and they handed us a check from their foundation for \$5,000 – enough to get us well on our way to a third edition of the New Parent Guide. We had our cameras with us, but unfortunately none of the pictures we took that night came out. But suffice it to say we were all very touched by the occasion, and glad to have the opportunity to meet one another.

I had a chance to talk with Don and Sue for a bit, and I asked them what their connection was to our community, other than a shared appreciation for Tony Starlight's. It turns out they have a close family friend who had a son with Down syndrome, and they asked that the gift be noted as being in memory of Darren Mallett of Beaverton, who sadly passed away recently at the age of 48. Sue said Darren was the first person she had ever met who had Down syndrome, and she enjoyed many years of friendship and camaraderie, going on adventures on the boat owned by Darren's parents, Don and Anona Mallett of Beaverton. We are sorry for the Malletts' loss, and are honored to be the recipients of such a moving memorial. Thanks to the legacy of Darren, we can soon share our New Parent Guide with many new parents in the coming years.



Darren, Don and Anona Mallett

Sue and Don handed us a check from their foundation... enough to get us well on our way to a third edition of the New Parent Guide



Buddy Walk News

2009 - Our biggest walk yet

By Kyle Holmgren

When I was asked to co-chair the 11th annual Buddy Walk, I jumped at the chance. As a family we have only missed two walks since Isaac was born eight years ago, and we are proud of our collection of colorful shirts. As a participant I know what an important day this is for hundreds of families, and I was delighted to take on the challenge of making one of my favorite annual events happen.

This year's walk was a roaring success and all the planning and hard work paid off in a big way. The sun was shining and a huge crowd gathered in anticipation of the day's events. Registration was smooth and efficient and the wait didn't seem too long while listening to the lively Latin sounds of the Aquilas Montas Trio. Tobias the Adequate mesmerized the children with his magical skills and sleight of hand. We enjoyed inspiring speeches by community advocate Eleanor Bailey and dad John Rhodes on the subject of Down syndrome pride. The games were fun, the food delicious, and the entertainment fantastic

Many thanks to Gustav's, New Seasons, Clif Bar, Dreyers, Beaver Marine Services, Nestle Water, Providence, Kidz with Ice and Starbucks for their donations and support. These companies and their employees provided food, drinks, the goodie bags and the contents and prizes for our raffle. The raffle was a great success this year; we even had to dash out and get more raffle tickets when the booth ran out!

An estimated 900 walkers joined in the excitement of the countdown and start of the Buddy Walk, making this our biggest walk yet. After walking a full circle around the Rose Garden, the kids were excited to join the cheer squads from Lincoln and Central Catholic high schools who psyched up the crowd and encouraged the walkers. After the walk, Bev and The Boys rocked the plaza with tunes old and new. Breaking from long-standing Buddy Walk weather tradition, it was such a warm, sunny day that the fountains came on during their set, soaking the dancers to everyone's delight!

It was a hectic, bustling, exciting day filled with love and support. As a mother, watching Isaac and Ryan with all the other brothers and sisters, parents and grandparents, aunts and uncles, friends and neighbors was an emotional and wonderful way to end the day. I want to personally thank

each and every person that made this possible. We could not have pulled this off without everyone's help and support. I know that this day will stick with many for a long time. I can't wait to see all of you next year!



A sunny buddy walk led to some wet fun in the fountain

900 people joined the NWDSA for the 11th Annual Buddy Walk, making it our biggest walk to date.



Eleanor Bailey

BUDDY WALK™

2009 Sponsors

Thank you for your support!



Tobias the Adequate



*Tasty sweets provided by
Kidz with Ice*



The NWDSA would like to thank the following individuals and companies who gave generous donations of their time and/or products to bring you this year's entertainment and refreshments, donations for our raffle prizes, and goodie bags.

Clowns Unlimited LLC • Tobias the Adequate • Madrona Studios • Franz • Kidz with Ice • Old Spaghetti Factory Vancouver • Wild Roots Salon • Michael Bailey • Woodbine House • North Clackamas Aquatic Park • Dollar Scholar • Applebees Lloyd Center • Sorell • Lloyd Center Ice Rink • Borders • Rhodes Piano Tuning • Lori Krampetz • Downs Ed • Kindermusic • La Bonita • Cinetopia • Columbian • Oregonian • Portland Timbers • Portland Beavers • Olive Garden • Petes Coffee • Chuck E Cheese • Safeway Vancouver • Joe's Crab Shak • City Disability Commission • blue bear woodworks • KINK • Army Corps of Engineers • Best Buy

Thank you also to all the families and individuals who raised money and built teams through pledge forms and the Kintera web site. Thanks

to your efforts, we were able to raise much-needed funds to support our work throughout the next year. Your contributions are a large part of what makes the NWDSA able to offer continued education and support to our community.



2009 Buddy Walk Committee

Buddy Walk Coordinator – Kyle Holmgren

Committee – Jamie Burch, Eleanor Bailey, Heather Greene, Sue Dobrunick, Angela Frome, Steve Holland, and the NWDSA Board of Directors

Volunteers – Central Catholic Cheerleading Team, Lincoln Cheerleading Team, Heather Durham, Nancy Korf, Portland Fire Bureau, Jared Holmgren - Photography, Rose City Rollers, WOU Latino Club, Yahoo!, Girl Scout Troop 40145 - Camas



Buddy Walk Coordinator
Kyle Holmgren



Photo Wall



Photography on these two pages
by Jared Holmgren

Support the Work of the NWDSA

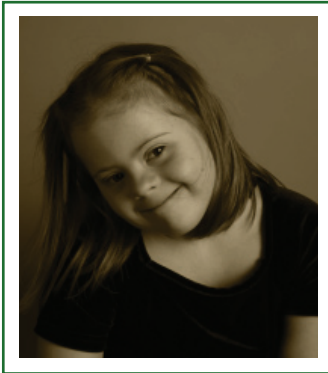
Making each donation count

By Angela Jarvis-Holland

“Three keys to more abundant living: caring for others, daring for others, sharing with others.”

- William Arthur Ward

The Northwest Down Syndrome Association needs your help as we head into 2010.



Why Support the NWDSA with a Year-End Gift?

We are not a member organization and do not charge dues or registration fees. Accessibility is very important to us, and most of our events are free. We also offer phone support and open access to our Resourcefulness Center. We are careful with our resources; with the help of volunteers and many partners we more than double each dollar donated. In-kind donations are one of our greatest assets. We are given space at churches for our meetings and playgroups, pro-bono design and artwork from local professionals, free tech support at our office, and much, much more from others who see the value in our work.

Because of this support, any financial gifts we receive are put straight to work enhancing our projects and community. You can trust that your money will be spent thoughtfully, and not a penny will be wasted. Please join the circle of support and help to create a community where every one of us can thrive.

How Will Your Donation Be Used?

Here are a few examples of how your money may be spent:

- \$25 pays for the mailing of 5 New Parent Guides to new families
- \$35 pays for a scholarship to the All Born “In” inclusion conference
- \$50 pays for one month’s snack for Open Arms playgroups
- \$100 pays for volunteer stipends for an RLC event
- \$600 pays one month’s rent at the Resourcefulness Center
- \$1500 pays for printing and mailing of one edition of Stepping Up, our quarterly newsletter
- \$3000 pays for one RLC event
- \$2500 pays for a keynote speaker at the All Born “In” conference
- \$2500 pays for a family social

...any financial gifts we receive are put straight to work enhancing our projects and community.

A Special Request for 2010

Some of you may remember hearing reports of our Board’s trip to Washington, DC last winter to join other groups from across the country for an advocacy day on Capitol Hill. This year the National Down Syndrome Society is organizing a similar event in our nation’s capital, and we would like to attend to take your message to our country’s law-makers. Last year’s trip was made possible by the donation of frequent flyer miles from a local

Continued on next page

Continued from previous page

family, and it made a tremendous difference in our ability to afford the trip. If this is something you can help with, please contact our Resourcefulness Center at (503) 238-0522 to discuss the details.

Thank You for Considering a Gift to the NWDSA

We know these are challenging times for individuals and businesses alike. As a group, we focus on what we do well and we are driven by the love we have for our children. Our work does not slow down, and we need your help to keep building on the love and skills we bring together to help and empower families. We are growing our outreach to genetic counselors and other medical providers in order to get current information to families who receive a prenatal diagnosis of Down syndrome, and this important work does require extra time and resources, but we consider it a vital part of our support.

If you are able to give us a gift this year, please send your tax-deductible donation to:

NWDSA
 P.O. Box 9127
 Portland, OR 97207

If you prefer, you can visit our website at www.nwdsa.org and make a contribution using PayPal. The NWDSA is a registered 501(c)(3) and contributions are tax-deductible.

In closing, we would like to take a moment to thank some local families who have made a tremendous contribution to our organization by setting up memorial funds in memory of family members who have passed away. We were humbled and grateful to get news that funds had been set up in memory of William Fallis, Lauren Kersavage and Gideon Buhman, and it is difficult to express the depth of our gratitude to these families who thought of the NWDSA in their time of loss. The contributions that we have received this



fall went to help pay for this year's Holiday Social for all of our families, making it possible to come together and celebrate the strengths of our community.

We wish you the best for 2010, and hope that we see you at one of our events in the year to come. Thank you for taking the time to read this letter, and for your continued support.

Our work does not slow down, and we need your help to keep building on the love and skills we bring together to help and empower families.

Photos on these two pages by John Campbell

Events

Portland Open Arms Playgroup: Join other parents and their children on the 3rd Friday of every month from 10 - 11:30 AM at the Rainbow Preschool in Bethlehem Lutheran Church, 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 Abby Braithwaite at 971-998-8744.

Vancouver Open Arms Playgroup: We meet at Church of the Good Shepherd, 805 SE Ellsworth Road, Vancouver, WA 98664. Join us every month on the 3rd Thursday from 5 - 7 PM; dinner will be provided. For more information see contact info for Portland Open Arms listed above.

Down syndrome community drop-in session: Join NWDSA Board Members for a casual afternoon exploring our resources and getting to know other parents. We will meet every Thursday, from 12:30 - 2:30 PM at the NWDSA Resourcefulness Center, 6826 NE Glisan Street, in Portland. Enjoy light refreshments and a chance to share stories and ideas. Please RSVP at 503-238-0522 or to Angela Jarvis-Holland at ajarvis-holland@nwdsa.org.

All Born "In" cross-disability inclusion drop-in session: Join us on the 4th Wednesday of every month from 5:30 - 7:30 PM to discuss IEP goals and inclusion, and explore our resources. For location and contact info, see DS community drop-in session listed above.

2010 All Born "In" cross-disability inclusion conference: April 17th at the Ambridge Event Center in Portland. Tools, networking, and inspiration for parents and professionals committed to inclusive education opportunities for children (birth - 21) with disabilities. More conference information coming soon on www.nwdsa.org.



Open Arms playgroup circa 2003

Et Cetera

... The NWDSA would like to acknowledge the generous support of businesses within our community. The Campbell Group has made several substantial contributions in 2009, allowing us to fund our ongoing awareness work with the local medical community. PC Paramedix provides ongoing technical support free of charge at the Resourcefulness Center, an invaluable service. If you know of a business that would like to be involved with supporting the NWDSA, please get in touch! Both in-kind and monetary donations are always appreciated.

... Over 50 people attended The Reciprocal Learning Community (RLC) on Saturday November 7th. The session focused on the first five years, including healthcare guidelines and incorporating therapy into daily routines. Heather Durham, pediatric audiologist, discussed the importance of regular screenings for hearing, and Ted Curtis, pediatric ophthalmologist, explained how a young child's vision is checked. Mary Williams shared concrete ideas of how parents can provide opportunities for physical therapy at home, while Lisa Rhodes and Jen Brandse covered oral motor skills and how they relate to feeding and communication. Two parents from our community started and ended the session by sharing their story, providing a glimpse into what life is like raising a child with Down syndrome. The evaluations for the session were overwhelmingly positive and indicate a need for more of this type of information. Look for upcoming drop-in sessions that will delve into these topics with more depth.



Childcare at the RLC allows both parents to attend the workshop

Celebration

Continued from page 1

“Why?” I asked. “They are adorable.”

“Because the younger one has Down syndrome,” she replied. Her response astonished me; with a background of volunteering, working and living with those with disabilities, it seemed unbelievable to me that her diagnosis could so drastically affect the likelihood of her adoption. All I saw was a sweet pair of sisters that needed a home. My adoption worker encouraged me to submit my application to adopt the girls. I did so, but I was afraid to get my hopes up. Two wee ones were my dream, could it come true?

Four days later I learned I was one of three families being considered to adopt the two sisters. Three months later I got the call that blew my mind: I had been chosen and was going to be the mom of these two sweet girls. Overjoyed, excited, ecstatic cannot begin to explain how I felt.

One week later I met Leah and Eden. At first Leah, almost two, seemed to be avoiding me, but she ended the visit in my lap reading a book. Her foster mom said that she did not warm up to strangers easily and to consider myself blessed; I already did. Leah’s little sister Eden was all smiles and rolling all over the place. She was turning one the next week and had just begun to prop herself up on her elbows.

I was in love. We got to know each other and bonded during our regular transitional visits over the next few months, and they moved home on July 18, 2008. I knew there would be difficulties along the way; having an infant with special needs and a toddler enter my home all at once was bound to create the need for adjustment. But I was in heaven.

Fast forward to today. The adoption has been finalized and we are officially a family. Both girls are loved by grandparents, aunts and uncles, cousins and friends. Leah is an awesome big sister and loves helping Eden. Eden is blossoming faster than her momma can keep up with, learning to walk, talk and keep up with her big sister. We have been through an emergency hospitalization, heart surgery, a multitude of doctor visits, and a few sleepless nights. She has been welcomed by friends and family and has opened people’s eyes to what someone with Down syndrome can accomplish.

I have been blessed with an overabundance of kisses, giggles, hugs, the awe of hearing Eden say “Maaaa,” watching her feisty personality blossom, seeing a sister bond like none other, and the tears of her first steps. I am so blessed to be her mother.



Emily, Eden and Leah at the pumpkin patch

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Angela Jarvis-Holland
Executive Director

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Steven Holland
Jen Brandse
Abigail Braithwaite
Angela Jarvis-Holland
Angela Frome

For more contact info
please visit
www.nwdsa.org

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.



northwest down syndrome association

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Portland, Oregon

97207

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 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 make a donation, please visit our website at www.nwdsa.org or call 503-238-0522.

Para comunicarse en español, llame a Maria O’Harra al 971-570-0942 o Sheyla Hirshon 503-239-1509



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this newsletter

[NWDSA Newsletter Committee](#)

Editors: Abby Braithwaite,
Nancy Korf, Kim Jarvis

Production & Design: Jen Brandse

Save The Date!!! all born (in)

2010 Cross-Disability
Inclusion Conference

April 17, 2010

8:30 AM – 5:30 PM

Ambridge Event Center

1333 NE MLK Blvd

Portland, Oregon 97232

Tools, Networking & Inspiration for
Parents and Professionals.

information will soon be available at
www.nwdsa.org