



STEPPING UP

June 2008

Volume 12 / Issue 2

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

INSIDE THIS ISSUE

- 1 The Power of Partnership
- 1 Celebration
- 2 Letter from the Board
- 3 Community Voice
- 4 Family Corner
- 5 Special Insert
- 9 Buddy Walk
- 10 Events
- 10 Et Cetera

The Power of Partnership

Perspectives of a PSU Professor of Special Education

By Paula Stanovich

On April 26th I had the opportunity to be a part of the 3rd annual All Born “In” conference. It was a wonderful day, a day on which I learned much, taught a little, and met many amazing people. There was a great buzz in the air that day, a positive energy that is feeding me still.

If I had written my reflections on All Born “In” immediately after the conference I think they would have been quite different from what they are now. The passage of time changes our memories, perhaps not always for the better, but also provides some needed distance and can allow us to know what is important by what remains.

What remains for me is the sense that all of the people in those meeting rooms could become a powerful force for change. The uniqueness of All Born “In” is in its goal of bringing together a seemingly disparate collection of individuals to unify around a common purpose. In attendance this year there were parents, grandparents, guardians, siblings, friends, self-advocates, teachers, paraprofessionals, administrators, therapists, teachers-in-training, and teacher educators. Those of us who attend All Born “In” generally represent two groups that are often portrayed as being at loggerheads with each other (and, truthfully, sometimes are). And, yet... it is in partnership that power lies. And partnership begins with commonalities, not differences.

Please see *Partnership* on page 9

Celebration

Recognizing a Local Trailblazer

By Abby Braithwaite

I turned 33 earlier this spring. A birthday is usually a time for self-reflection, but this year I was able to deflect the focus away from myself, onto 33 years in the life of another family. I spent the morning of my birthday chatting with Judy Marick, the mother of six children, and a founder of Pride for Kids in Vancouver. Judy’s fourth child was born with Down syndrome. At 33, Jason is active in the PHAME drama program, and has a steady job. Judy recently retired from Pride, but she continues to work as an advocate for children with disabilities and their families.

Judy and I met on March 5th to talk about the history of Pride. Thirty-three years ago, the world was a very different place for parents of babies with Down

Please see *Celebration* on page 11

*“You see things;
and you say Why?
But I dream things
that never were;
and I say Why not?”*
George Bernard Shaw



Resourcefulness Center
6826 NE Glisan St.
Portland, OR 97213

Mailing Address
PO Box 9127
Portland, OR 97207

www.nwdsa.org
503-238-0522

Stepping Up 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 *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

A Season of Growth

By Steven Holland, NWDSA President

Cause Change & Lead
Accept Change & Survive
Resist Change & Die
- Ray Norda, Chairman, Novell

That quote says a lot. Most of us recognize that change is inevitable, but change that we influence and control is best. Growth is change too - and the NWDSA is indeed growing.

We are pleased to announce that Angela Frome will be joining our Board. Angela is a mother of three, and is passionate about working to improve the lives of individuals with Down syndrome. She is a graduate of Portland State, and has completed the Partners in Policymaking program in Salem. Angela served on our board a few years ago, but took some time away following the birth of her son Ben. She served with us when we developed our mission, vision, and values, and led our first Buddy Walk after we transitioned from the NW Parent Support Group to the Northwest Down Syndrome Association (NWDSA).

May has been one amazing month for the NWDSA! The seeds we have sown and cultivated are bearing fruit, sprouting like a springtime garden.

At the ARC of Multnomah-Clackamas Annual Meeting and Dinner, the NWDSA was the proud recipient of the Organization of the Year Award. In addition, board member Angela Jarvis-Holland was also recognized for her outstanding work and commitment to our community, and received the Person of the Year Award. At the Oregon Mega Conference in Bend, the NWDSA received the Media Award for the All Born "In" photo awareness gallery. We want you to know that we are not motivated by awards - but this recognition does validate our work and efforts on behalf of our children and community. In reality, everyone reading this newsletter, and everyone who believes in bettering the lives of people with Down syndrome, has a share in these awards.

In addition to the recognition we received, we are celebrating the expansion of the Open Arms play group to Vancouver, Washington. We also held our first Resource Night with a focus on IEP (Individual Education Program) information. A number of families took advantage of the opportunity to visit our Resourcefulness Center at 6826 N.E. Glisan Street in Portland to gather information, and make friends with other families. During May we also met to plan and brainstorm ideas for the 10th Annual Buddy Walk - to be held October 4th at the Rose Quarter.

Capping off the month for Angela and me was the completion of our son Daniel's IEP. As many of you know, the IEP process is a stressful but integral part of achieving a successful inclusive education experience. The progress Daniel has achieved is incredible, and we helped him and his team build a solid IEP so he can grow next year as a third grader.

Wishing you all a happy summer!

Community Voice

Open Arms on Both Sides of the River

By Jamie Burch

This has been an exciting year for Open Arms. In March we celebrated the one-year anniversary of Portland Open Arms. A great group of families came together, with kids ranging in age from six weeks to six years old. We shared great snacks and mini cupcakes, as we laughed together and shared stories and information. The highlight of the day was an awareness speech by self-advocate Eleanor Bailey. Thanks to Abby Braithwaite, Rochelle Ghose and all the families who attend for making this group such a success.

Recently, a handful of families have come together and shown interest in starting an Open Arms in Vancouver, Washington. Parents Lisa and John Rhodes wrote a proposal to the NWDSA board of directors for a mini grant, which was approved, to fund this new playgroup. It is my pleasure to announce Open Arms Vancouver launched their first get together last month on May 15. The families decided evenings would work best and a dozen families shared a few hours of networking, playtime, and the beginning of new supportive friendships within their community. Thank you to Pride for Kids in Vancouver for hosting this event and to Adina and Greg Williams who donated pizza for the kick-off night!

I started Open Arms with Sydney Shook in 2004. We had our first play group at a park in Beaverton, Oregon, just her kids and mine. Each month, more and more families joined us and we gained so much from each other's companionship, ideas, and experiences. Open Arms gave me the opportunity to see other children with Down syndrome growing, playing and learning, and gave me access to many parents and their perspectives. This invaluable resource helped shape my feeling of normalcy in life and strengthened my confidence as the expert on my child.

When my daughters were younger, Open Arms was my look into the future. Now this play group is a special time for me to reminisce, hold babies, hear and see those first sounds and signs, watch new milestones as they are achieved, be proud of how far we all have come and remember how pleased I am to be part of a community of parents who love their children so much. For more information, please visit our website or contact myself or Abby Braithwaite.



Adara and Evan at the Vancouver planning meeting

The new Vancouver Open Arms meets the third Thursday of every month. See Events on page 10 for more details.



Eleanor speaking at Portland Open Arms



Karen holding Caroline, Colleen holding Lilly

Family Corner

A Poem for Lilly

By Colleen Roscoe

Sing

Bright and graceful our daughter appeared
Whispering a new sound
An unfamiliar cadence
In a world of memorable songs

We released the melody of our dreams
Exhaled it through our hearts
And let it slip through our palms
To discover a new and perfect rhythm

Her song echoes in our hearts
In a pitch that hums sweetness and peace
We breathe in the notes of new hope
And dance to her powerful beat



Matt, Lilly, and Colleen Roscoe

all born(in)

The NWDSA is happy to present a special insert in this edition of *Stepping Up*. It gives us a chance to update our community on all that has happened with the All Born "In" Photo Gallery and Cross-Disability Inclusion Conference.

On the following pages, you will see photographs of the conference which were taken by professional photographer Clara Link. Clara is a young woman with Down syndrome who did a phenomenal job of capturing many inspirational moments at the conference. For more information on Clara's work, visit p2ppower.org/clara/index.htm. As parents, NWDSA board members hope that our children will find productive work in our society. It is inspiring to be able to employ someone who shows us this dream can be a reality.

This year's conference was our 3rd annual gathering of parents and professionals passionate about inclusion. There were over 200 conference attendees, learning and sharing in 15 different sessions throughout the day. All the information presented was based on current best-practices, and the speakers made up a diverse and dynamic group. The conference was made possible by hundreds of volunteer hours, as well as the generous help of over a dozen sponsors. We received broad community support, without which the day would not have been possible.

We are also proud of the exposure the photo gallery has been receiving. The article below describes in more detail the various locations where the banners have been displayed. Many of you have already seen the series of inspiring and beautiful images. However, if you still haven't experienced this exhibit, keep your eyes peeled. The banners will continue to travel around the area for the next several months.

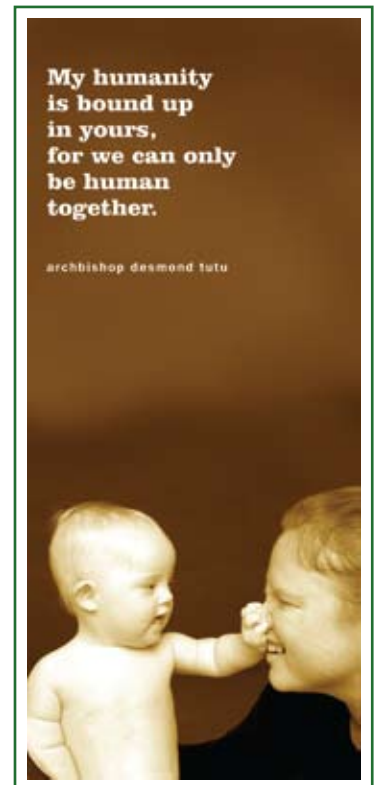
Photo Gallery Tour 2008

Expanding Our Community

By Abby Braithwaite

The All Born "In" photo gallery has had quite a tour around the area since the January debut at OHSU. The banners have spent three days at the Legislative Building in Olympia, WA, working to build awareness around some important bills in their winter legislative session. The images also made a trip to the capitol in Salem to kick off the Developmental Disability Awareness Month activities. They spent a day at Lloyd Center at a Multnomah County event promoting child and family health, and they have appeared at multiple conferences around the area. At our All Born "In" conference in April they helped set the tone for the more than 200 conference attendees, and over the weekend of May 29th they traveled to Bend for the state-wide developmental disabilities Mega-Conference. We have more plans in store for them, and we are in the process of expanding the gallery with another five or six banners. We are also starting to pull the funding and sponsorship together to put out a 2009 All Born "In" calendar using these gorgeous images.

Please see *Photo Gallery* on page 8



One of 14 banner images that make up the All Born "In" photo gallery

At the All Born "In" conference in April, the banners helped set the tone for the more than 200 conference attendees.



Randy Hicks, Dean of Portland State University College of Education



Keynote Speakers Emma Van der Klift and Norm Kunc



Keynote Speaker Steve Hanamura



Connecting with others committed to change



Community Advocate Eleanor Bailey



Roberta Dunn, Alicia Delashmutt, Steve Holland, Molly Cermak parents presenting on the Kindergarten Transition Panel



Paula Stanovich The driving force



A crowd with a passion for inclusion



Parents at Steve Hanamura community session



An attentive crowd gains valuable information



Ruth Falco presenting on Early Literacy



Professionals at Steve Hanamura community session



Angela Jarvis-Holland speaking at the All Born "In" conference



Jordan Ackerson, Self-Advocate



Steve Holland, President of the NWDSA



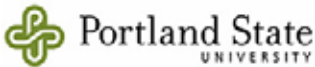
Corinne Thomas-Kersing, Matt Perrault and Patti McVay presenting on Planning for Student Centered Transitions



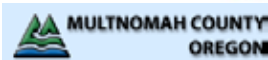
Full House at PSU University Place

all born(in)

2008 Photo Gallery and Cross-Disability Inclusion Conference was made possible by the help of partners listed below. We are proud to share a vision of a world that celebrates human diversity.



Multnomah Early Childhood Program



Multnomah Developmental Disabilities Services



Clark County Developmental Disabilities Program



Inclusive Child Care Program

& the generous contributions and in-kind support of numerous others

Photo Gallery

Continued from page 5

The photo project provided us with a chance to meet many new people, and is an excellent example of how we can bring the larger community into our work. The project started several years ago, when parent Tacee Webb approached us with the idea of making a calendar. Tacee introduced us to photographer Jodi Collins, of Urban Photography. Jodi generously donated her time and artistry to the original DS Now calendar of 2005, and was eager to work with us again in the spring of 2007, when we began shooting for the ABI exhibit. In December of 2007 we met graphic designer Alex Harris, who in turn introduced us to Bryan Dalton. These two young graphic designers dedicated an incredible amount of time and energy to turn Jodi's beautiful photos into the larger-than-life banners that make up our awareness photo gallery.

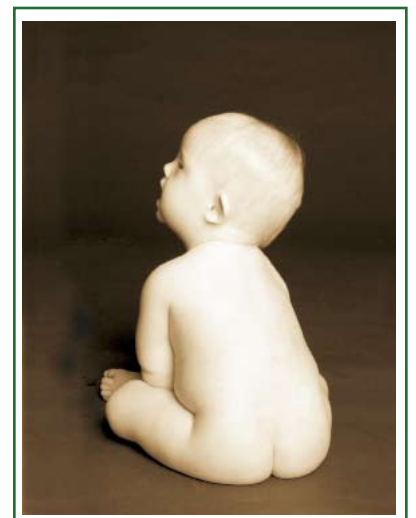
When Jodi became a mom of two beautiful little babies in January of this year (congrats, Jodi!) we decided to give her a bit of a break, and were connected with Joshua Dommermuth of Quixotic Images, and he, together with graphic designer Giuseppe Lipari, is helping us expand our gallery with more images.

Additionally, the connections we made with project sponsors illustrate the expansion of our community. The project started with a seed grant from Hanna Anderson, which was matched by OHSU, TigerStop, and the MESD. Without the trust and generosity of these businesses and organizations, we never could have gotten off the ground.

As the banners travel around Oregon and Washington, they serve as a powerful introduction to our group and the work that we do to promote greater awareness of the value of all individuals. Our community continues to grow as more people have the opportunity to view the photo gallery. And now, as you read in the Letter From the Board, we are receiving some exciting recognition from some area agencies for the work.

We are also beginning work on a 2009 calendar, featuring the beautiful images from the photo gallery. It is our hope that we can raise enough money through sponsorship to produce the calendar. Through the calendar sales we will both raise money for next year's conference, and continue to grow the reach of these images, allowing them to influence and inspire an ever-broadening audience.

It is very exciting to be moving forward with this exciting awareness work, and to be recognized for our efforts, but without the help and support of our entire and ever-expanding community, the photo exhibit could not have happened. So, from all of the Board of the NWDSA, and all of our families, we send a heartfelt thank you to those who helped us with this exciting work. Thank you for joining our community.



Buddy Walk News

10 Years and Going Strong

An Invitation from the Board of the NWDSA

It's been a busy and dynamic year for the NWDSA, and now we are getting ready for one of the highlights the year. Every fall, Buddy Walk gives us the chance to connect and celebrate together, while at the same time raising funds for the year's work. On October 4th, we will celebrate the 10th anniversary of Portland and southwest Washington's original Buddy Walk. Over the past decade we have connected with many families and made great friends; we have shared coffee and hot cocoa, painted faces, learned magic, grooved to funky tunes and strengthened our relationship with the Jedi Forces. This year is sure to be the best yet, you won't want to miss it.

The Buddy Walk would not be successful without the help we receive from our community. This year we are proud to say that we have had two great examples of leadership, determination and friendship from the younger generation. Quinten Melius, a junior at Clackamas High, has a brother with Down Syndrome. He organized a fashion show fundraiser for the NWDSA at his school which raised over \$600 and provided some great Down syndrome awareness. Kevin Nickerson, an eighth-grader at Rachel Carson Middle School, did a school project on Down syndrome. The project included volunteer time, so he decided to form a Buddy Walk team. Kevin chose Down syndrome for his project to honor a friend with Down syndrome. We can all make a difference, young or not so young.

Our Buddy Walk Committee is up and running, we would love to have you join us as we prepare for this year's celebration. Be a part of an amazing team of volunteers and experience first hand all that is possible with the ideas and energy generated by a passionate group of people. Call 503-238-0522 if you are interested.

This year's walk will be at the Rose Quarter Commons from 10 AM to 1 PM on Saturday, October 4th. You can register at the walk as you arrive or if you prefer the hi-tech route, register online at buddywalk.kintera.org/nwdsa. Make a commitment, make a difference and more importantly, make a friend.

Partnership

Continued from page 1

What commonalities brought us together that day?

- Our belief in the value of each human being,
- Our passion and commitment to building an inclusive society that starts first with building inclusive schools,
- Our knowledge that the "other side" has something to offer, and
- Our understanding that, without those others, we are not whole ourselves and cannot possibly succeed in achieving our goals.

This is where the power is, inside us, in our hopes and dreams. My hope is that each day each of us will try to unlock a little of that potential power: lend a hand, ask a question, provide a service, advocate for ourselves. Be both a giver and a taker. Give help and take responsibility. Push a little, but don't forget to pull as well. In these joint efforts, perhaps we can begin to see the change we want to happen and keep the dream of All Born "In" alive. The question that remains for me a month after the conference is "What will I do today to advance the cause of inclusive education?" The question for you is the same: "What will you do today?"



*Volunteers at last year's
Buddy Walk*

*We need your help!
Call 503-238-0522 if
you want to be a part
making this the best
Buddy Walk yet.*

The 2008 Buddy Walk will take place on Saturday, October 4 at the Portland Rose Quarter Commons. Bring your friends, neighbors, and family to have some fun and raise awareness

Events

Portland 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 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 Jamie Burch at 503-704-3883 or Abby Braithwaite at 360-887-0684.

Vancouver Open Arms Playgroup: The newest Open Arms playgroup meets the third Thursday of every month from 5 - 7 PM. We are currently meeting at Pride for Kids, 6511 NE 18th St., Vancouver. Pride is generously letting us use their space until we find a permanent location. If you or your child is involved with a location that has a preschool setting in Vancouver and might be willing to offer their space to us on a monthly basis, please contact Jamie Burch at 503-704-3883 or Abby Braithwaite at 360-887-0684.

Buddy Walk 2008: Note the new date! Celebrate the 10th annual NWDSA Buddy Walk on October 4 at 10 AM at the Rose Garden Arena. If you would like to volunteer, please contact the NWDSA at 503-238-0522.

All Born "In" Photo Gallery: As part of First Thursday festivities, the banners will be displayed at City Hall, 1211 SW Fourth Ave. in downtown Portland, on July 3, 2008 from 5:30 - 7 PM. Join us for refreshments and a chance to see this beautiful gallery.

Et Cetera

... Eleanor Bailey, an intern at NWDSA, graduated from Grant High School on June 3. While at Grant, she was a member of the Choralateers choir and Friend's First. She was also a Commissioner of the Metropolitan Human Rights Commission as well as Kids As Self Advocates, a national self advocacy advisory group of teenagers. In April she presented at the Pacific Rim Conference on Disabilities in Honolulu and the following week was a co-keynote speaker for the Parent Training Centers Regional training in Tacoma. She will participate in a transition program at PSU beginning in September. This summer she will continue her work at NWDSA, attend Mt. Hood Kiwanis Camp, visit her grandparents in the Midwest and generally "hang out." We are proud of you Eleanor, keep up the good work!

... We are excited to announce a new option for sponsorship of our work. If you look on the back cover of this issue, you will notice a couple of new logos. Co-Bella Design, an architecture firm in northeast Portland, and Polliwog Toys, a toy store in Southeast Portland, stepped up to help with publication costs for this issue of the newsletter. This is an exciting opportunity for us to reach out to local business owners, introducing ourselves and our work to an ever-widening group. It is also a chance to introduce these businesses to you, and let you know that they are supporters. If you know of a business that may be interested in sponsoring a future issue, please let us know by sending an e-mail to editor@nwdsa.org.

... The rummage sale was a great success! Thank you Eleanor Bailey for the wonderful fundraising idea, Bethlehem Lutheran Church for the use of their fellowship hall, everyone who donated items, and all the people who came to support the event. Leftover items were donated to Goodwill, the Arc and Helping Hands. Now it is time to plan a summer social for August. Please look for more details soon!



Time to Celebrate!

Celebration

Continued from page 1

syndrome. The only infant services readily available were drop-off respite programs, designed to give moms a break. For Judy, this wasn't enough. She believed that it was possible to raise Jason at home just like her other kids, and for him to learn and thrive, so she began to look for supports to give him the extra help he needed. The Experimental Education Program at the University of Washington was doing research at the time on early childhood education for babies with Down syndrome. IDEA had just passed to provide special education for school-aged kids, but there was not yet an equivalent for kids from birth to five. The UW program was working to change this, and Judy and her family got involved right away.

Soon after Jason was born, Judy met Kay Parkes, another mom of a new baby with Down syndrome, and the two of them soon began to dream together. When Jason was 9 months old, Judy and Kay approached UW about starting a therapy center. Their vision was to incorporate strategies and therapies from the UW program into a parent-centered model. Kay and Judy wanted to create a venue where parents with high expectations for their kids could come to learn and share, and where the professionals working with them believed in the children's ability to learn and grow.

Within a year the first Pride class was formed. The early days at Pride were heady and exciting, with lots of work, innovation and even some fun field trips. The parents in that first group were learning to be therapists and researchers, tracking the progress of their kids and providing data instrumental to the work being done at the University of Washington.

Talk about parents in the driver's seat! These folks went up against the medical and educational establishments of their day to prove that their kids could learn. Judy met doctors when Jason was a baby who encouraged her to be "realistic" about Jason's life, and told her expectations were too high. But she didn't let the doctors' warnings discourage her, and just kept pushing ahead.

I am grateful to parents like Judy for helping create the world my daughter was born into. I am also grateful for the example she sets for me. There is still a lot of work to be done to create a truly open and accepting world for our kids



Judy Marick

to grow up in. As a mom just starting out on my journey as a parent and advocate, it was incredibly empowering to sit and chat with Judy. Through the force of her love for her son, and her belief in herself and her family, she paved the way for countless other kids and parents over these past 33 years. There's been a lot of change in my short lifetime, and it is exciting to think how much more progress we can make over the next generation.



Resourcefulness Center
6826 NE Glisan St.
Portland, OR 97213

Mailing Address
PO Box 9127
Portland, OR 97207
www.nwdsa.org
503-238-0522

NWDSA Board of Directors:

Steven Holland
President

Jamie Burch
Secretary

Christy Reese
Treasurer

Jen Brandse
Whitnie Trost

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.



PO Box 9127
 Portland, Oregon
 97207

A Message from the NWDSA

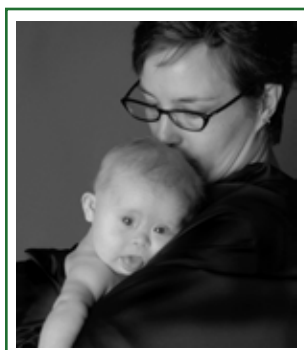
As proud parents to children with Down syndrome, each board member of the NWDSA has firsthand experience with the joys and the hardships of raising a child with individual needs. We understand the importance of connecting with other families and how much we rely on these relationships when we encounter the inevitable challenges. We also celebrate each others victories, making the journey so much richer. The 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 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 971-570-9942 o Sheyla Hirshon 503-239-1509

NWDSA would like to thank
 The following companies for donating part
 of the printing costs of this newsletter



Phone: 503-617-4919
 Fax: 503-617-4939
 21440 NW Nicholas Ct #C
 Hillsboro, OR 97124
inquiries@advantagepress.net



Please Recycle



this newsletter

e-version available
 at www.nwdsa.org



2900 SE Belmont Street
 Portland, OR 97214



NWDSA Newsletter Committee

Editors: Abby Braithwaite,
 Nancy Korf, Kim Jarvis
 Production & Design: Jen Brandse