



STEPPING UP

March 2011

Issue 12

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

All Born “In” Just Around the Corner

“The right to belong doesn’t go away when budgets are tight.”

By Angela Jarvis-Holland

My son Daniel is a busy member of a vibrant fifth-grade class at Sunnyside Environmental School, embraced by a creative and gifted teacher. Recently we covered his science project in a big garbage sack to protect it from the inevitable February rain and splashed through the puddles to deliver it to the gymnasium. His two cousins attend the same school and my brother has been joking about having two projects to work on this weekend to my one.

All parents work hard to help our kids succeed, and as parents of kids who have disabilities, we have some extra duties to help them do their best. We are experts on our children and know what works for them to learn, and have dreams and a vision for their futures. As the weather warms to spring, schools start working with us on our children’s individual education plans, which will drive their education and placement in the following school year.

2011 marks the sixth year of the All Born “In” conference. For six years now we have been creating a conference to support staff and parents in creating the best outcomes for children to learn together and have their educational needs met. We connect professionals and parent leaders who are willing to share their expertise and knowledge of best practices. Six years ago, it became clear that there was a real need for this information to be made available, and positive re-

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*If you’ve never been
thrilled to the very edges
of your soul by a flower
in spring bloom, maybe
your soul has never
been in bloom.*

~Terri Guillemets

Advocacy in Action

NWDSA works to support our mission

By Abby Braithwaite

The editors of *Stepping Up* are excited to announce a new occasional column for this newsletter. Much of the work of the NWDSA is not visible through our drop-in hours, playgroups, conferences and other events. We decided to dedicate some space to talking about the advocacy work that our board and staff do on a regular basis, as well as take the opportunity to highlight the successes of parents and other community members who are working so hard every day to make this world a better place not just for their own children, but for everyone.

The mission of the NWDSA – to create and nurture a loving and inclusive community celebrating every person with Down syndrome – is an action, it’s a process, it’s a movement. In order to accomplish this mission, we need to

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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

Latest News from the NWDSA Board

By Steven Holland, NWDSA President

We are excited to announce that the NWDSA will be the recipient of a grant from the Spirit Mountain Community Fund. Members of the NWDSA Board will visit with Foundation leaders in Grand Ronde in March to accept the grant. We are also working on additional grants to further support the mission and work of the NWDSA. Although these periodic grants are important, we mostly rely on individual, family and corporate donations, as well as NWDSA fundraisers, to provide the majority of financial support for our organization.

At the end of 2010, Jennifer Brandse, longtime NWDSA Board member and Chair of the Reciprocal Learning Community (“RLC”) project decided to leave the Board to focus on her family commitments. Jen has been a Board member since 2004, and has led many RLC Saturday sessions over the years. In addition to leading the RLC, she has played key roles in editing our NWDSA New Parent Guide, developing the Newsletter, creating our Brochure, working with the Board in developing our mission and values, and serving as Treasurer in 2009 and 2010. Jen has presented at the All Born “In” Conference, supported families in the community with their IEPs, and has presented at Pacific University and other university programs in the area. She has advocated on behalf of the rights of individuals with disabilities both locally and in Washington, D.C. We greatly appreciate Jen’s work for our community, value her continued friendship, and wish the best for her and her daughter Chloe.

NWDSA continues to follow the developments around genetic testing. While NWDSA supports medical advances and safer alternatives to current genetic testing methods for Down syndrome, current developments may be ahead of the medical community’s ability to address the educational issues associated with these changes. On February 10th, San Diego-based Sequenom’s experimental pre-natal genetic test for Down syndrome received a boost when researchers said the genetic sequencing that underlies the product performed well in a recent study. In December, the company launched a large clinical trial of the new version of their test, known as the SensiGene T21, which relies on DNA sequencing. Sequenom’s goal is to begin selling the test by the end of 2011. The concern we have is that the product will likely not be accompanied with fair and accurate information about Down syndrome, that new parents may be pressured into having a test, and that the current standards for genetic counseling have not kept pace with these developments.

Our planning work for the April 16th All Born “In” Conference is in full swing, and we look forward to seeing many of you there. The conference is an important part of our work and mission around inclusive education, and given the cuts to school budgets, is crucial in establishing the importance of sharing proven educational methods for people with disabilities. We have enjoyed the launch of the first Kindergarten Inclusion Cohort, a group of about a dozen families whose children will be starting kindergarten in September of 2011. These families are committed to seeking inclusive placements for their children, and the Cohort is giving them the ability to gain access to resources and a community of support as they take on this serious commitment. The idea for the Cohort grew out of the All Born “In” conference.

Please see *Letter* on page 3

All Born “In”

Continued from page 1

views and evaluations from the conference tell us that, while the conference is an incredible resource, the need is still present, as parents and staff alike continue to work toward more inclusive schools and communities.

Parents need information and support to become empowered advocates in what can be complex negotiations. We help build partnerships at the conference that bridge the divide between parents and staff, and focus on the possibilities of inclusive education. We are learning together that when we seek more inclusive education more kids will succeed, and that universal design of instruction and differentiation will make better teachers and more successful students.

Budgets are tight this year and resources are stressed, but the civil and human rights of our community do not go away in hard times. We have sessions planned that will give concrete information, share ideas that work and help us keep our eye on the prize. The conference thrives because we know to lean on each other for support and share what we can. Current best practices in education guide the development of the conference, and our partners from PSU, OHSU and other organizations help us focus on what will create results.

We want to make a special invitation to any of you that have never been to the conference before, as well as those of you that come each year, to join us and reach out to staff and community beyond our own to come learn with us for a day. The keynote speakers this year are our old friend and colleague Kathie Snow of “Disability is Natural” and Sara Gelser, an Oregon State Representative who is also the parent of a child with a disability. We have 25 great workshops planned, aimed at professionals and families with children from birth to early adulthood. We will have sessions on assistive technology (including hot new applications for the iPad), IEP writing, employment, advocacy and more. Members of the NWDSA’s first Inclusive Kindergarten Cohort will share what they have learned as they attend monthly sessions to help prepare for inclusive placements for their children.

Come join us on April 16 and celebrate that we are all born into this world naked, new and full of potential and with some intent and creativity can continue to embrace diverse learners and be stronger for it.

Letter

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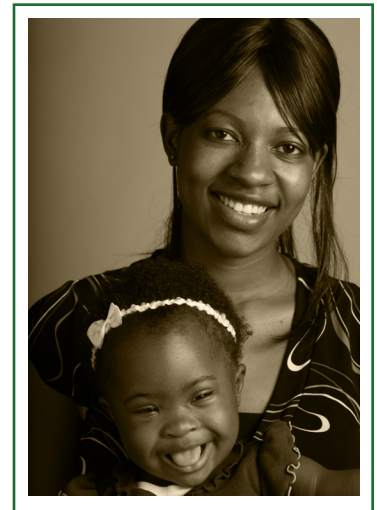
Lastly, we are pleased to have been recently asked to provide some of our NWDSA “All Born In’ cross-disability photo banners to Congresswoman Cathy McMorris Rodgers, for display in her office in Washington, D.C. Congresswoman McMorris Rodgers is Co-Chair of the bi-partisan Congressional Down Syndrome Caucus, and is an active advocate for individuals with developmental disabilities.

Best regards to everyone in our community. We appreciate the opportunity to work together with you to support our loved ones who have disabilities.

Steven Holland

President of the Board

Budgets are tight this year and resources are stressed, but the civil and human rights of our community do not go away in hard times.



all born(in)

2011 Cross-Disability
Inclusion Conference

April 16, 2011

8:30 AM – 5:30 PM

Ambridge Event Center

1333 NE MLK Blvd

Portland, Oregon 97232

Registration fee \$50

A limited number of
scholarships are available.

Contact the NWDSA by phone
or e-mail by April 1, 2011.

Community Voice

Family prevails in struggle to get health care

By Jonas Hinckley

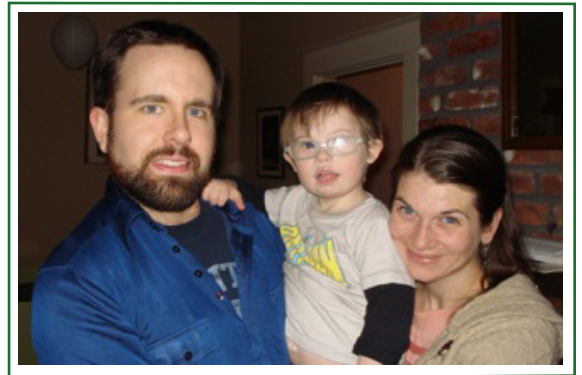
“Our family has had a great journey since Archer was born three years ago, but we have had an ongoing struggle with the quest for adequate health care.”

Our family has had a great journey since Archer was born three years ago, but we have had an ongoing struggle with the quest for adequate health care. Uninsured through our work, we’d applied for the Oregon Health Plan when Archer was a baby, but didn’t qualify because of our income level. So for the first two years of Archer’s life, we paid for a policy with a huge deductible that paid for doctor visits, although it didn’t cover any types of therapies until after the deductible was met. Then, in January of 2010, the new Healthy Kids initiative in Oregon raised the income restriction to a level at which we thought we’d qualify if we applied for Archer alone.

We applied, and were rejected once again based on income level ...and the fact that Archer currently had insurance. Healthy Kids is restricted to uninsured children, though they do indicate that some exceptions are made due to “serious medical need”.

After consulting with someone at the Healthy Kids office, we reapplied, being sure to mark the “medical need” box, and were once again rejected. About this time, I started to see billboards all over town about how Healthy Kids covered all of Oregon’s children, and I got a bit upset about the whole thing. I again spoke to someone at Healthy Kids and was told that she’d see what she could do to get our case reviewed.

I didn’t hear anything for about six weeks, when we got a letter saying that Archer had been accepted to Healthy Kids. A few days later we got a preliminary packet welcoming us to the program and describing our benefits, as well as laying out our premiums. The details were better than we had hoped, and neither my wife nor myself could really believe it.



We assumed that Archer’s Down syndrome was considered as a “serious medical need,” allowing them to waive the regular requirement that new enrollees be uninsured for two months before becoming eligible.

When we got a follow-up call the next week, we thought it was no big deal. But in fact we were then told that Archer was not eligible because our family had insurance; his disability was not a factor in the process at all and the paperwork we had received was a mistake.

This is when I just got mad. I made a number of phone calls in the following days trying to get more information and maybe get the decision reversed, only to run into a brick wall. I then wrote letters to the Governor’s Advocacy Office as well as to my local and state representatives, including my congressman and both federal senators, and some senior

Please see *Community Voice* on page 5

“...it’s disappointing to us that the private insurance companies that contract with the state are allowed to discriminate against people with developmental disabilities.”

Buddy Walk Festival News

Planning for 2011 walk is underway

By Kim Jarvis

The date for the 13th annual Portland and Southwest Washington Buddy Walk Festival has been set for September 24, 2011 and this year we are hoping to attract a crowd of over 2,000 people to the Rose Quarter. Put the date on your calendar now and plan on bringing your friends and family, your classmates and neighbors to help make the 13th annual walk the biggest one yet.

Even though the walk is still a few months away, Buddy Walk Coordinator Angela Frome is busy securing sponsorships and donations in order to make this year's walk better than ever. She is also looking for a few volunteers to help with the planning of the event as well as a crew of people who can also help out on the day. The committee meets once a month and if you are interested in volunteering, we can use all the help we can get.

The Buddy Walk Festival is a great community-building event, but it is also a fundraiser. If you know of any local business that might be interested in sponsoring the walk this year or making a donation, please get in touch with Angela at afrome@nwdsa.org or 503-238-0522 so that we can get them a sponsor pack. We have sponsorship levels to fit all sizes of business, so be creative and think of anyone who might be in a position to help out this year. We also need donations of goodie bag items, raffle prizes and silent auction items. And a big thank you goes out to those businesses who have already stepped up to support the walk.

Community Voice

Continued from page 4

people at the Department of Human Services. In a very short period of time, I got a number of responses back.

Less than a week later, not only was Archer re-accepted to Healthy Kids – based on his medical need – and the process for reviewing cases like ours was changed. I learned later that this was due in at least some part to a State Representative holding a sit-down meeting to find out how this had happened to us – and to make sure it didn't happen to families like ours in the future.

While the coverage offered by Healthy Kids is leagues better than what we had on our own – and even includes dental! – it's disappointing to us that the private insurance companies that contract with the state are allowed to discriminate against people with developmental disabilities. They specifically exclude speech and other therapies for people with "developmental language disorders" or "learning disorders" while offering it as a rehab service if someone of a typically developed nature is injured and needs that kind of help.

That probably means I need to write a new set of letters and make some more phone calls.

Editor's Note - If you are interested in working with Jonas and the NWDSA to advocate around this or other issues, please contact us at 503-238-0522.



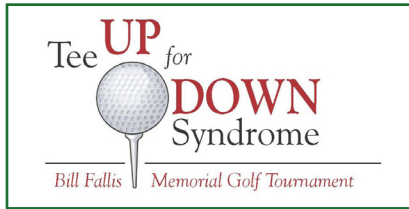
We need donations for:

- *Goodie Bags*
- *Raffle Prizes*
- *Silent Auction Items*

Can You Help?

Let's Make the 13th Annual Buddy Walk, our biggest walk to date. Save the date for Sept. 24, 2011





The second annual golf tournament in support of NWDSA is set for Oct. 3, 2011

Events

Portland Open Arms Playgroup: Join other parents and their children on the 2nd Tuesday of every month from 5:30 - 7:30 PM 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 to share resources and support. We meet every Thursday, from 12:00 - 2:00 PM at the NWDSA Resourcefulness Center, 11611 NE Ainsworth Circle, Suite 321 in the Multnomah Education Service District building, Portland. Come work on IEP goals with us. 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.

Buddy Walk 2011: Next year's walk has been scheduled for September 24, 2011 at the Rose Quarter Commons. Sponsorships and donations for goodie bags and the silent auction are needed as well as volunteers to help out on the day. See page 5 of this newsletter for more details.

Tee UP for DOWN Syndrome 2011: Second Annual golf tournament in memory of Bill Fallis to benefit the NWDSA. Save the date for October 3rd, 2011, at the Persimmon Golf Club, 500 SE Butler Road, Gresham, OR. Golfer Registration: \$140 per person; \$500 per foursome. Registration is now available at www.nwdsa.org. For more information contact melaniefallis@gmail.com.

Et Cetera

... The Oregon Developmental Disabilities Coalition and Grassroots Oregon (GO! Project) provide a weekly update on legislative activities related to people with developmental disabilities. For more information on the latest news in Oregon advocacy visit oregonddcoalition.org. The Arc of Washington State also has a Legislative Action Center on their website at www.arcwa.org. On both sites you can subscribe to an email action alert that will keep you up to date on the latest issues affecting our community. If you would like to discuss any legislative issues or want to get more involved, please contact us at the NWDSA Resourcefulness Center, 503-238-0522.

... The NWDSA would like to thank Nora Wilson from JJ Jump in Clackamas for helping make our Winter Social such a huge success in December. More than 125 guests enjoyed the bouncy inflatable playground, Wii games, a rock climbing wall and the many other delights available at the facility as well as a special visit from Santa Claus. We would also like to thank Bellagios Pizza for donating the pizza. The money to support the Winter Social came from the donations the NWDSA received from the Oktoberfest at Gustav's last September. Great community support from sponsors such as these allows the NWDSA to continue to provide social events for our members.



Santa Claus made a special visit to the Winter Social at JJ Jump

Advocacy In Action

Continued from page 1

be out in the community, working to change the public's perception of individuals with disabilities. We need to partner with other organizations with similar goals, and we need to share our stories. Here at the NWDSA we strongly believe that when the world is more welcoming to people with Down syndrome and other disabilities, it will truly be a better world for all of us. We see inclusion as a civil rights and social justice issue, and we work every day for the change that we want to see in this world.

A big part of our work is to empower parents and other community advocates to step up and be advocates for their children and communities, but we are also hard at work behind the scenes, working alongside other advocates to work for change. NWDSA board members and staff regularly attend school board meetings, and are active in conversations with the Portland Public School District, Multnomah ESD, and other school districts and ESDs in the area, advocating around special education services. For the past four years we have been working to educate health professionals and the general public on the issues surrounding prenatal genetic testing and informed decision making. We track local, state and federal legislative issues, and we have traveled to Salem and Olympia for advocacy on the state level, as well as Washington, DC, where we enjoy a strong relationship with the National Down Syndrome Society Policy Center. For more information on the latest news in Oregon advocacy visit oregonddcoalition.org. The Arc of Washington State also has a Legislative Action Center on their website at www.arcwa.org. On both sites you can subscribe to an email action alert that will keep you up to date on the latest issues affecting our community.

The NWDSA has had the great pleasure of working this year with the Clark County Disability Coalition (CCDC), a loosely knit group of advocacy organizations from around Southwest Washington working to create inclusive communities and educate citizens and legislators about the issues affecting individuals who experience disabilities. You can read more on our website about the work of the CCDC, and the NWDSA's involvement there.

If you have a success story to share, or if you are interested in becoming more involved in our advocacy work, please contact the NWDSA at 503-238-0522 or drop in on a Thursday afternoon. We would be glad to think with you.

Youth Group Receives Thank You

Founder of Home in India sends message

The founder of Sri Arunodayam, a home in India for abandoned children with disabilities, recently wrote to the members of the NWDSA Youth Group to thank them for resources the group donated to the home. The Youth Group held a book sale last June and raised over \$1,300 for the home. The donation included an expanded version of the Boardmaker software program, materials from DownsEd Trust, copies of NWDSA's New Parent Guide, DVDs, t-shirts and other educational resources.

Iyyappan Subramanian, the founder of the home, wrote this message to the group: "Thank you so much for your books and resource materials. I just received your parcel and have been looking at it one by one. I am sure all these materials will help our staff to enrich their knowledge and provide better services to the kids."

NWDSA
northwest down syndrome association

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Angela Jarvis-Holland
Executive Director

**NWDSA
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Steven Holland
Abigail Braithwaite
Angela Jarvis-Holland
Angela Frome
Tina Albers
Becky Adelman
Guiseppe Lipari

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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A Message from the NWDSA

Each board member of the NWDSA has firsthand experience with the joys and the hardships of caring for 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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[NWDSA Newsletter Committee](#)

Editor: Abby Braithwaite
Production & Design: Kim Jarvis

Register Now!!!
all born (in)

2011 Cross-Disability
Inclusion Conference

April 16, 2011

8:30 AM – 5:30 PM

Ambridge Event Center

1333 NE MLK Blvd

Portland, Oregon 97232

Tools, Networking & Inspiration for
Parents and Professionals.

information and registration available at
www.nwdsa.org