



PUBLISHED BY THE NORTHWEST DOWN SYNDROME ASSOCIATION
CELEBRATING EVERY PERSON WITH A DISABILITY, INCLUDING DOWN SYNDROME

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 Sheyla Hirshon at (503) 239-1509 o Isis Sanchez, (503) 442-5817



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A PDF of this newsletter and past issues are available for download at www.nwdsa.org



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It Was a Dark and Stormy Walk

By Abby Braithwaite

Buddy Walk 2013 was a stormy one, with wild winds and rains and plenty that could have gone wrong. But thanks to an incredible amount of good will and creativity, it will go down in memory as a day of community in its truest and deepest sense. From the strength and grace of Buddy Walk Chair Angela Frome and vice-Chair Michelle Wallace to the helpfulness of Shawni Sullivan and her crew at the Rose Garden, from the hearty families who joined us to the friends who supported us from afar, from the incredible volunteers who went above and beyond to the sponsors and donors who made the day possible - everyone stepped up to make our annual day of pride and celebration an incredible success.

Please see *Buddy Walk* on page 4

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Celebration: Isaac's IEP Journey

By Carrie Hutchinson

I'd been obsessively checking my mailbox since our IEP meeting. The big manila envelope with the return label from the school district finally arrived and I ripped it open. After a quick scan of the front, I flipped to the last page, the placement page. And there it was in black and white: General Education with Special Education Support/Selected. I breathed a sigh of relief.

Eight months earlier, at the first Kindergarten Cohort meeting, I was unsure what would be the best option for my son. But as he spent the year fully included in preschool, he made great progress on his goals and I realized that the vibrant environment at Trillium, the public charter school where his brothers and sister attend, was exactly where he belonged. But would the school district agree?

Each month as I gathered with the Cohort, I became more determined to advocate for the placement Isaac deserved. We had sessions on person-centered planning, our rights under IDEA, behavior as communication, IEP planning and goal writing. My thinking about Isaac's full inclusion was solidified. He has every right to be a full member of his school community, and the other children have the right to an inclusive class as well, where they can benefit from the gifts Isaac has to bring.

I was confident we had the support of the teachers, staff, and administration at Trillium, so now we just needed to convince the school district.

I arrived at the District office building with copies of Isaac's portfolio outlining his skills and interests, what works and doesn't work for him, our family mission statement, and comments from his teachers. We also brought a friend who knows Isaac well, and cookies. We went in with a hopeful attitude, but were prepared to use the skills and knowledge we'd gained in the cohort to advocate as strongly as was necessary.

Please see *Isaac's IEP Journey* on page 3



NWDSA

northwest down syndrome association

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To be added to our mailing list visit www.nwdsa.org 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 the 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 abraithwaite@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 a disability, including Down syndrome.

The 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

Dear families and friends of the NWDSA

By Steve Holland, NWDSA President

October is national Down Syndrome Awareness month and while we parents know that this work is really a 365 day effort, highlighting this special month allows us more opportunities to spread the word. In the spirit of the month, on the NWDSA website, we have posted amazing photos of young people and their families celebrating life. As the saying goes, a picture is worth a thousand words, and those photos certainly live up to that.

But as we know, there are many days of joy and laughter, and some days of trial and tribulation. From those electric moments of pure adoration, to those minutes of lost patience and slammed doors – and real worries about the future. We confront serious medical conditions, but medical miracles rescue us most times – and friends and family stand strong and offer much needed support. Some weeks school is going well, other weeks not so good. The odor of prejudice and old time ignorance stays with us despite our best efforts.

But we always can and do feel proud of our children, we believe in their intrinsic worth as human beings, and we preserve in our hearts and mind those big dreams for their future. Do you know that research shows that families who believed their child could get a meaningful job were 3.5 times more likely to succeed at getting that job? Your pride has to show strength and have some muscle, because the world we live in, and our society, have not caught up with us yet.

And we are getting reinforcements in our work. There is a growing feeling in our community that the next generation, our sons and daughters, some with a disability and some without who have grown up “in the movement,” are beginning to take on the fight. They understand the need to advocate for the civil rights for people with disabilities, for equity, and for the opportunities that all young people expect.

We had two amazing young adults speak at the Buddy Walk, who were articulate and had their own strong voice calling for respect, tolerance, but also, recognition – recognition that they expect that things are going to be different for them and for their generation. Their parents in particular, and we as a community, should be proud of them.

I would like to share some lyrics from the song “I Am Singing” off Stevie Wonder’s 1976 double album *Songs in the Key of Life*, which a few years ago was voted the top album of all time on Yahoo’s Blog List. If you have never heard the album (you poor young people) you should download it and put on the headphones. It might make raking the leaves a little more tolerable.

There’s songs to make you smile

There’s songs to make you sad

But with a happy song to sing It never seems so bad

To me came this melody

So I’ve tried to put in words how I feel

Tomorrow will be for you and me

Happy fall to all.

Steven Holland and the NWDSA Board of Directors

Et Cetera

... October is National Down Syndrome Month and we celebrated all month long with inspirational images and quotes. Download and print these images at www.nwdsa.org/events/national_down_syndrome_awareness_month.html



Events • full calendar & details at www.nwdsa.org

Drop-In Hours: Every Wed., noon - 2:00 PM, Get answers to your questions about IEPs, school, home, development, and more at the NWDSA Resourcefulness Center

Open Arms Playgroups: Join other parents and their children with Down syndrome age 0 - 5 to ask questions, share ideas, learn, and have fun!

Portland: NEW TIME! Second Thurs. of every month from 9:30 - 11:30 AM at Resurrection Lutheran Church, 1700 NE 132nd Ave., Portland OR

Vancouver: MOVING TO NEW LOCATION! Vancouver families please come to the Portland Open Arms in November (see above). New Vancouver location to be announced in January.

Please note: No Open Arms in December (come to the Winter Social!)

Club Upside Vancouver: A place where parents can share and children of all ages and abilities can play. Second Sat. of every month, 2:00 - 4:00 PM, St. Andrew Lutheran Church, 5607 NE Gher Road, Vancouver WA

Stronger Together Workshop - Language: Nov. 5th, 6:00 - 8:00 PM, Cross-disability workshop for parents of children age 0 - 5 at Clackamas ESD Building, 13455 SE 97th Ave., Clackamas, OR. RSVP at www.nwdsa.org or (503) 238-0522

RLC Workshop - Behavior: Nov. 9th, 8:45 AM - 1:00 PM, Training session for parents of children with Down syndrome age 0 - 5 at Resurrection Lutheran Church, 1700 NE 132nd Ave., Portland OR. RSVP at www.nwdsa.org or (503) 238-0522

Successful Collaboration Between Parents, Teachers & Paraeducators: Nov. 18th, 6:30 - 8:30 PM Cross-disability training session for parents & educators of school-age children, MESD, 11611 NE Ainsworth Cir., Portland OR. RSVP at www.nwdsa.org or (503) 238-0522

“Toast for Inclusion” Kindergarten Cohort Benefit: Dec 5th, 5:00 - 10:00 PM, Come join us in a toast to the pursuit of an inclusive civil society at The Bad Habit Room, 1004 N Killingsworth, Portland OR. Suggested donation \$5-\$15

Winter Social for our Down Syndrome Families: Dec. 8th, noon - 2:00 PM, Clackamas JJ Jump, 9057 SE Jannsen Road, RSVP (503) 238-0522 by 12/6

Stronger Together Workshop - Routines: Dec. 11th, 6:00 - 8:00 PM, Cross-disability workshop for parents of children age 0 - 5 at Clackamas ESD Building, 13455 SE 97th Ave., Clackamas, OR. RSVP at www.nwdsa.org or (503) 238-0522

NWDSA

northwest down syndrome association

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

The 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 691 live births. The chance of having a baby with Down syndrome is not affected by where you live, social class or race. Having a baby with Down syndrome does not mean you did anything wrong: nothing done before or during pregnancy causes Down syndrome. In recent years, our community has seen incredible success in school, community and employment that would have been hard to imagine a generation ago. High expectations, coupled with appropriate supports, allow our children to live full, rich lives as contributing community members.



*Zumbathon™ fundraiser
with Nancy Korf
Photos by Jennifer J-d*



*Red Light Clothing raised
\$800 dollars for NWDSA at
their sidewalk sale*

Promotores

The Promotores Leadership Training program for Spanish-speaking families is off to a great start. The first meeting in August was a fun and interactive session where we shared ideas and set goals for the year-long program. Pablo Lopez led a series of ice-breaker activities, Rosa Flores laid out the parameters and expectations of participants, and Sheyla Hirshon led the “tree” activity, in which participants shared what they can contribute and what they hope to learn.

The group met again on October 26th to explore “Down syndrome 101”, and how Promotores members can support new parents and other family members coming to term with a diagnosis. We have a great series of trainings planned for the months to come, including a health seminar by Dr. Joe Pinter of OHSU and an inclusion movie matinee in March. We are grateful to Rosa, Sheyla and Pablo for stepping up to make this opportunity available, and to the Clark County Parent Coalition for partnering to cover costs.



Make Your Contributions Go Further

Thank you for what YOU have given to NWDSA this year. Thank you to the 1,500 walkers who came out on a blustery, wet Saturday for the 2013 Metro Portland and SW Washington Buddy Walk. Thank you to our sponsors and in-kind donors who underwrote our expenses for the Buddy Walk, paving the way for our teams to net over \$38,000 for the NWDSA's family support and community outreach programs. Thank you to the hundreds of volunteers who commit thousands of hours every year to make our work possible. Thank you for sharing your gifts with us.

If you have not yet made a gift in 2013, please consider making one before the end of the year. There are many ways to do so, from making a cash donation online to donating your old clunker of a car to offering accounting services or an in-kind service. Another way to help is creating a gift basket of goodies and gift certificates for silent auction or raffle at events.

See http://www.nwdsa.org/get_involved/donate.html for more information.

Looking to maximize your investment in NWDSA? Please check if your company offers a corporate match program and/or an employee giving program. Matching funds, payable volunteer hours, automatic payments and more are some of the ways corporations encourage their employees to give back to nonprofits with which they are involved. NWDSA is already “in the system” at Microsoft, Nike, PGE, The Campbell Group, Moda Health, National Instruments, Bill & Melinda Gates Foundation and United Way. We'd love to talk with you about your company's giving program.

The NWDSA is looking to revitalize its development board. Many companies encourage their employees to get involved on nonprofit boards, and corporate grants and sponsorships are often tied to employee volunteering. We need your help to build those partnerships.

If you would like more information about ways to get involved, contact Amy Geoffroy, Development/Asset Director at ageoffroy@nwdsa.org.

Isaac's IEP Journey

Continued from page 1

There were nine of us around the table: My husband, my friend and I, the kindy teacher, the LRC teacher, the transition specialist, a special education teacher, a speech language pathologist, and the program administrator. We began to talk through the draft IEP document together.

The administrator jumped ahead to placement, commenting that it was the “elephant in the room.” She stated that in her opinion, Isaac did not have the academic skill readiness to be successful in the general education classroom. She believed he needed intensive, discrete skill building that simply couldn't happen without a segregated classroom. She agreed that inclusion is important, but felt that having Isaac attend ‘specials’ like music or recess and lunch would serve that purpose adequately.

I thanked her for her opinion, and (mostly) politely explained why I completely disagreed. I expressed my assurance that, given the appropriate support, Isaac would be able to make meaningful progress towards his goals. My friend added that Isaac's goals would fit into the wider curriculum, seeing as her (typically developing) incoming kindergartner didn't know his alphabet either.

The administrator re-stated her opinion that he would be better served in a segregated classroom. “I'm only one member of the team, though,” she said, and then asked about concerns from the other members present. The teachers were primarily concerned about Isaac's safety but felt that with a paraeducator's support, that concern was alleviated. I particularly appreciated the LRC teacher's comment, “I really believe that his parents know Isaac best, and know best what will work for him.”

After a while it became apparent to everyone that we were not moving from our position. The administrator finally agreed to his placement in the gen ed classroom with the support of a paraeducator, with the caveat that we would have a review in December. We left the meeting in a celebratory mood, though I still held a bit of an “I'll believe it when I see it in writing” attitude.

Twelve days later I had it in writing, and a wave of relief washed over me. In addition came a wave of gratitude for the Kindergarten Cohort for preparing me to be the effective, knowledgeable advocate that my son needs and deserves. Had it not been for the Cohort, I may not have understood the importance of inclusion in kindergarten, much less been prepared to fight for it.

EDITOR'S NOTE: While each IEP process is unique, there are deliberate measures in place to protect a child's right to a Free and Appropriate Public Education (FAPE). Some of what is described in this article does not follow the intent of the law as described in the Individuals with Disabilities & Education Act. To learn more about your child's rights, and how an IEP meeting is intended to proceed, visit www.allbornin.org or come to drop-in hours at NWDSA every Wednesday, noon to 2 pm.

The Kindergarten Cross-Disability Inclusion Cohort is in its fourth year. On average, 9 out of 10 families get the kindergarten placements that they want for thier children with the help and encouragement of the Cohort.

Help empower the important work done by the Kindergarten Inclusion Cohort by attending the family-friendly Toast for Inclusion Benefit at the Bad Habit Room, Thurs. Dec. 5th, suggested donation of \$5-\$15. All donations and proceeds from the raffle and auction will go to support the Kindergarten Inclusion Cohort.



*NWDSA & Kindergarten
Cohort kiddos enjoy the first
day back to school!*



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Hooperville

Save the date!

Next year's Buddy Walk will take place on Sept. 20, 2014

Buddy Walk

Continued from page 1

"With all the people who jumped in to help, it felt very seamless to change venues with only an hour and a half notice," remarked Angela Frome.

Not being much of a crowd person, I have sometimes been a little bit uncomfortable at Buddy Walk. But the past 7 years have been a journey into community, from our first walk in 2006, when Adara was just 3 months old and we knew two people, to this year, when I barely saw the kid as she found her friends in the crowd, romped on the bouncy castle, and apprenticed with Olive Rootbeer, the veteran Buddy Walk balloon lady.

Little fills me up more than community, and I couldn't stop smiling from my vantage point at the resource table as I chatted with new families and old friends, and watched the crowd move through the Memorial Coliseum. I loved watching the teams distribute shirts to aunts and uncles, grandparents and cousins, classmates and neighbors. I loved watching first-time walkers and volunteers soak up the energy and vitality of the community. I loved seeing our veteran performers taking their places in the flow of the day, and watching the faces of young parents while speakers Eliza Schaff and Jacob Lattanzi inspired us all with dreams of full, rich futures for our children.



Angela Frome observed, "This is a day of great pride and celebration and a true labor of love." We are grateful to everyone who participated as a donor, sponsor or walker. We want to send a special thanks to Don Antonucci of Regence, our Diamond level sponsor who supported us for the second year running and came to offer some inspiring words of welcome.

Thank you and congratulations to our top three fundraising teams: The Bullwinkles, Book Buddies & Pen Pals, and Archer's Team.

In the end, Buddy Walk 2013 was, as NWDSA Executive Director Angela Jarvis-Holland says, the day we turned lemons into lemonade.



Families came out for fun in the sun at our annual Summer Social at Lee Farms in Tualatin!



The ADA: Moving Forward event at Portland City Hall on July 26, 2013 celebrated the 23rd anniversary of the signing of the Americans with Disabilities Act. The event was hosted by the Portland Commission on Disability and Connecting Communities Coalition.



City Commissioner Amanda Fritz spoke to the attendees about the work that she and the Commission had accomplished with the City.

Photo courtesy of Portland Commission on Disability and Connecting Communities Coalition