



STEPPING UP

December 2010

Issue 11

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

Kindergarten Inclusion Cohort

Building skills, building community

By Abigail Braithwaite

Beginning this month, a group of parents and caregivers will meet monthly for an intensive training series on the nuts and bolts of preparing for an inclusive kindergarten placement for our children. The NWDSA is excited to offer this project to empower families to advocate for children with disabilities to be educated in general education classrooms. Seed money for this year's pilot project was provided by the generous donation from the Tee Up for Down Syndrome golf tournament, held on October 11, 2010, in memory of Bill Fallis.

The idea for the Kindergarten Inclusion Cohort grew out of the All Born "In" cross-disability inclusion conference, and the need to offer parents more resources, trainings and opportunities to connect the other 364 days of the year. There is a lot of work that goes into the process of kindergarten transition, writing IEP goals, and supporting schools in the implementation of those goals. While it is true that schools are required to provide a quality education in the least restrictive environment to all students, it is also true that there is a lot that a parent can and must do to ensure that their child's needs are being met. All parents need to be active participants in the process, picking up their responsibility to work with the teachers to ensure the most success for their children.

Please see *Kindergarten Cohort* on page 3

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Celebration

Tee UP for DOWN Syndrome builds community bridges

By Melanie Fallis

In July's "Stepping Up" issue, you met me as a new NWDSA advisory board member and chairperson for a new NWDSA event, Tee UP for DOWN Syndrome. This golf tournament, held on October 11, 2010 at Persimmon Country Club in Gresham, was a way to honor my late husband Bill's love of golf and his endearing affection for five-year-old Riley, a grandson with Down syndrome. Held on the first anniversary of Bill's death, and on the course where he had played the day before, this "First Annual" tournament fielded 56 golfers. With about 80 attending the following live auction, we returned over \$17,000 in profit to NWDSA.

The July newsletter also introduced my daughter Jennifer, Riley's mommy,

Please see *Celebration* on page 11

*Blessed is the season
which engages the
whole world in a
conspiracy of love.*

*-- Hamilton Wright
Mabie*

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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

Another exciting year comes to an end

By Steven Holland, NWDSA President

It is a little shocking that the year is almost behind us. Before we know it the holiday season will be in full swing! In some ways we may be glad to say goodbye to 2010, but in many other ways we are sad to see it go.

2010 has been a tremendous year of growth and achievement for NWDSA. We experienced significant growth in the All Born In Conference, which is rapidly becoming the standard for cross-disability inclusive education. Our Resourcefulness Center moved in to new space in the Multnomah Education Service District main office near Airport Way. The space is more comfortable, offers great resources, and allows us to work on expanding our collaborations in the community. The NWDSA worked hard during the summer on behalf of school-age families, by analyzing and protesting the cuts to Special Education by the Portland Public School District. The NWDSA Youth Group hosted a summer book sale to raise money for the Sri Arunodayam home in India that serves abandoned children with disabilities. Our 12th Annual Buddy Walk was a phenomenal success in terms of turnout and “fun” -raising. The Open Arms program for new families continues to grow and expand, bringing parents and their children together as they start their journey. In October we launched our latest project, the Kindergarten Inclusion Cohort. This project will provide crucial support and training for parents as they prepare their children for school.

On the legislative front, our community is applauding Congress for passing legislation that eliminates the term “mental retardation” from federal laws. The measure replaces that derogatory term with “intellectual disability” in existing health, education and labor law. “Rosa’s Law,” is named after a Maryland girl with Down syndrome. The legislation is a step in the right direction, - although we ultimately want language like “individual with different abilities” rather than using the term disability.

We also want to announce a new board member of NWDSA, Giuseppe Lipari. Giuseppe is creative director of Studio Lipari, a design studio in Portland, working on print, web, illustration, advertising and marketing projects for a variety of clients. Originally from New York City, Giuseppe honed his skills at Parsons School of Design, and has worked on nationally recognized campaigns from movie posters to packaging. Giuseppe became a part of our family through his outstanding contributions to our ABI photo project.

“I’m proud to be a part of this energetic, ambitious team, and I believe in its progressive message. With a great mission, and lots of active and caring people behind the organization, there are many opportunities we can explore to drive the NWDSA forward. My experience with NWDSA has been inspiring on a personal level, and I look forward to help spread the message of inclusion to a wider audience in creative and resourceful ways,” he said

We are looking forward to seeing everyone at the Holiday party on December 12th and until then, take care and enjoy the fall!

Steven Holland
NWDSA President

Kindergarten Cohort

Continued from page 1

In addition to providing skills and resources to individual families, the goal of the cohort is to provide participating families with a community of people to support them throughout the process of the transition to kindergarten and beyond. Through sharing experiences, successes and struggles, attending each other's IEP meetings, and traveling alongside one another on the journey, each participant will have the opportunity to forge strong relationships with other committed advocates. We are standing on the shoulders of parents and advocates who have come before us as we do this work; by sharing history and building community, we can help to combat the isolation that often hits families of children with disabilities particularly hard.

Inclusion is not just an education issue. It is a philosophy of life that extends into all areas of life, and at its heart it is about the civil rights of all citizens to access our community fully, and to give back as contributing members of society.

In the spring of 2007 David and I attended our first All Born "In" conference with Adara in tow. She was just nine months old, and I have to confess that we were not exactly sure what we were doing there. We had heard the term "inclusion" tossed around since we started attending NWDSA events, but it seemed like a far-off school thing, and we weren't sure how it pertained to being the parents of a sweet and tiny baby. But we made it through the conference day, and learned a lot despite our initial misgivings.

It turns out that for parents of a tiny baby, inclusion was the way we lived our daily life. Inclusion was a family meal, a library story hour or a trip to the grocery store. Inclusion was a crowd of cousins swooning over the newest inductee into the mischief squad at a family wedding, or calling a babysitter so we could go out to dinner as grown-ups once in a while. Inclusion was easy, and it came quite naturally to our little family.

As Adara grew up, she became ready for life outside the family nest, and we found a place for her in a local Montessori school where inclusion was learning to walk so that she could play on the big hill at recess, learning to share toys and lessons in the classroom and participating in field trips and classroom parties. Inclusion became a little more complicated as we left the cozy confines of Early Intervention and wrote our first IEP when she was not quite three. But it was still natural and right, and we felt strong in our commitment to help Adara build an inclusive resume for herself as we moved toward the big day when it was time to help her transition into kindergarten.

And that day always seemed so far away that I find it more than a little surprising that we have arrived at the point where kindergarten is on the horizon. As a volunteer for the NWDSA for the past three years, I have been fortunate to receive an informal immersion into inclusion. But as we ready ourselves for the transition to full time school, I know that we have a lot left to learn, and David and I are tremendously excited for the opportunity to participate in the first K-inclusion cohort. We started dreaming about this moment four years ago, when we embraced the concept that our daughter has the right to full inclusion in her world. And now we are preparing ourselves for the hard work necessary to bring that dream into a reality.

For information about future kindergarten cohorts, call 503-238-0522.

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Adara is ready for school

Community Voice

Self Advocate speaks at Eugene Buddy Walk

By Amelia Abel

Editor's Note: Below is the text of a speech given by self-advocate Amelia Abel at the Buddy Walk held recently in Eugene, Oregon.

"Imagine a world where everyday was one great big Buddy Walk."

Hello everyone. My name is Amelia Abel. I am 20 years old. The theme for today is, "Imagine the Possibilities." Let us imagine together what is possible.

FIRST: Imagine a world where everyone who has a different ability is accepted for who they are, is included in all activities, and is appreciated for their differences. Now people with disabilities are not always included or accepted. We can be isolated and feel lonely.

But today, we see that people can forget their differences. We can be comfortable and happy together. Imagine a world where every day was one great big Buddy Walk.

SECOND: Imagine the possibilities in a world where everyone with disabilities gets the support they need to overcome life's challenges. Children with Down's syndrome do better if they get early intervention services. Students with Down's syndrome need extra help to succeed in schools. We know what to do.

Thanks for coming out today and helping to raise money to support services for kids with Down's syndrome.

I am learning to live on my own. It is not easy. I know the bus routes around Eugene. I can cook chicken enchiladas. I am living in an apartment and working in daycare through the community living program.

Someday I will have my own apartment and I will have a job working with children with disabilities.

Everyone should be given the chance to develop his or her full potential. I hope you all have a dream for yourself. I hope we all reach our dreams. And I hope we all offer a hand to help others reach their dreams.



"Let's imagine a world where everyone is living on the inside".

People with disabilities often feel like they are living on the outside of the world and that everyone else is living on the inside.

Let's imagine a world where everyone is living on the inside.

Now, we can only imagine this world.

People with disabilities try to figure out how to get inside. But it is hard. Regular people do not know that they keep us on the outside: they think the world is fair and open to all people.

We can all help create a world where everyone lives on the inside. Where everyone is included.

Imagine the possibilities.

Buddy Walk Festival News

2010 breaks all the records

By Kim Jarvis

The 12th annual Buddy Walk in September was a roaring success with more than 1,200 people attending. It was so exciting to see so many hundreds of people joining together to celebrate our community.

Luckily the sun was shining as a huge crowd gathered in anticipation of the day's events. Registration took a bit longer than we would've liked and we were in the surprising position of running out of t-shirts due to the overwhelming number of people. As someone on the NWDSA Board of Directors said, "This is a good problem to have!"

The Screening Room donated their time and provided musical entertainment while participants were waiting to register and the kids had games and face painting to enjoy. One of the big hits were the hula hoopers from Hooperville USA. They brought lots of extra hoops so everyone had a chance to join in on the hip-swiveling action. A ladder truck from the Portland Fire Department and cheerleaders were also on hand to provide some fun.

We had a special guest speaker as Pam Vredevelt, who lost her son Nathan in March, 2009 after an accident on I-5 near the Rose Garden, talked about her family's story. She also presented the NWDSA with a check for \$2,000 in memory of her son and a special painting of her son. We were also pleased that Team Nathan brought over 120 participants to our walk. Community advocate Eleanor Bailey and members of the NWDSA Board rounded out our speakers.

The number of teams that registered for the walk this year was also at an all-time high. We had approximately 50 teams sign-up, consisting of hundreds of walkers. Without their support the Buddy Walk would not have been the success it was. We would like to thank each and every team member for their contributions to the day.

We enjoyed increased support from our sponsor Gustav's this year. In addition to providing hot dogs for all of the walkers, they also made the NWDSA the recipient of funds from their annual Oktoberfest held on Oct. 24-25. Members of the board were at Gustav's both nights collecting entrance money and enjoying the festive atmosphere and we look forward to continuing and strengthening this partnership in the coming year.

This year we gave away a Wii game console, three bikes, a big screen TV and some skateboards and snowboards in the raffle and the auction featured



Pam Vredevelt was our featured speaker this year

1200 people joined the NWDSA for the 12th Annual Buddy Walk, making it our biggest walk to date.



The Screening Room provided the music during registration

Please see *Buddy Walk* on page 7

BUDDY WALK™

2010 Sponsors

Thank you for your support!



NWDSA Executive Director
Angela Jarvis-Holland



There was something for
everyone at this year's
walk



The NWDSA would like to thank all of the individuals and companies that gave generous donations of their time and/or products to bring you this year's entertainment and refreshments, donations for our raffle prizes, silent auction and goodie bags: Widmer Brothers Brewing • 'D' Sands Condominium Motel • Haggen Food and Pharmacy • Missing Link Bike Shop • Whole Foods • Irene Sandler • Dave's Killer Bread • Brenda Harvey at US Bank • New Seasons • Hooperville USA • City of Portland • Doctor Reed Hall

We would like to give a special thank you to Mindy Parker's family and Craft Brewers for help with our raffle and silent auction. We'd also like to welcome them to our community and congratulate them on the arrival of their daughter.

Kidz With Ice has been a long-time supporter of the NWDSA and has provided food and treats at our socials and Buddy Walks for years. This year they donated their time and services to bring us cotton candy, mochas, Italian sodas, shaved ice and popcorn. This generated hundreds of smiles.



We would also like to thank 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. The money you helped raise will go directly to helping local families by funding Reciprocal Learning Communities, an updated New Parent Guide, summer and winter social events, advocacy and much more throughout the year.

Buddy Walk

Continued from page 5

electronics, a keg party, baskets from New Seasons, Baskin Robbins, Dreyers and Whole Foods, as well as a stay at the D Sands Condominium in Lincoln City.

After the walk, Bev and The Boys rocked the plaza with tunes old and new. And since it was such a warm, sunny day, the fountains came on giving kids and adults alike the chance to cool off. It was a bustling, exciting day filled with love and support. Watching brothers and sisters, parents and grandparents, aunts and uncles, friends and neighbors all celebrating our community was an emotional and wonderful experience. The Buddy Walk has really evolved into a day-long family festival with something for everyone.

We could not have pulled this event off without everyone's help and support. And we are always looking for more volunteers and sponsors. If you would like to get involved, or know of a business that would like to help us out with sponsorship, we would love to hear from you. Call our Resourcefulness Center at 503-238-0522. And be sure to save the date for next year's walk on September 24, 2011.

These two pages feature pictures from this year's walk, but we would love to have more. Please send them to afrome@nwdsa.org.



*Buddy Walk Coordinator
Angela Frome*



*A group of volunteers stuffed
goodie bags before the walk*



NWDSA Celebrates New Home

Open House is a great success

The Northwest Down Syndrome Association rocked the house during its Open House celebration in September at our new headquarters in the Multnomah Education Service District building.

Staff from MESD joined friends and family from the NWDSA community to celebrate the new partnership, enjoying light refreshments, guest speakers and live music from Tony Starlight, owner of Tony Starlight's Supper Club and Lounge in the Hollywood District. Tony brought along Barbara and Beau Ayers, who helped him regale the audience with several numbers by Neil Diamond. By the end of the evening everyone had their hands in the air and their "heartlights" shining.

MESD superintendent Ron Hitchcock spoke about how the NWDSA found its new home at the MESD building, NWDSA Executive Director Angela Jarvis-Holland spoke about the importance of partnerships, and NWDSA staff member and self-advocate Eleanor Bailey and Youth Board Member Quinn Jarvis-Holland also spoke. We also held a raffle for a Flip video camera that was won by MESD staffer Patty Campbell from School Health Services.

The Resourcefulness Center is open for weekly drop-in sessions and we are always looking for volunteers, so we hope to see you here soon.





Save The Date!!! 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

Over 20 different sessions to
choose from

For more information contact
Angela Frome
503-238-0522
information will soon be
available at www.nwdsa.org

HAVE YOU BEEN NAUGHTY OR NICE?



*The Northwest
Down Syndrome
Association
invites you to
our Annual
Winter Social*

Yummy Treats
Photos with Santa
Activities for All Ages

Sunday, December 12
12 to 3 PM

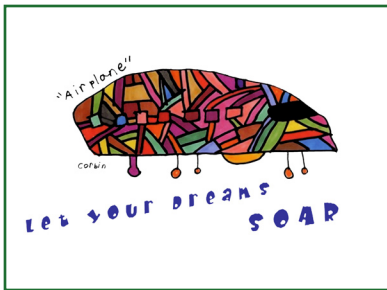
at the Clackamas JJ Jump
9057 SE Jannsen Road
just off I-205 at exit 13



Space is limited
Please RSVP ASAP
503-238-0522



This year's holiday social will be held at JJ's Jump in Clackamas. RSVP by Dec. 3.



Inspirational artwork by self-advocate Corbin Chanter. Visit www.corbin-smiles.com to see more.



Carol Topaz sent in these adorable handmade baby hats, created by her mother-in-law Esther Pherrin, that will be sent out with every New Parent Guide

Events

2010 Winter Social: Sunday, Dec. 12 from 12:00 PM to 3 PM at the Clackamas JJ's Jump. Come enjoy an afternoon of socializing and fun with the Northwest Down Syndrome Association. In addition to the bouncy fun there will be air hockey, photos with Santa and pizza. RSVP ASAP to 503-238-0522.

Portland Open Arms Playgroup: Join other parents and their children on the 2nd Tuesday of every month from 5:30 - 7:30 PM 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 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. 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.

2011 All Born "In" cross-disability inclusion conference: April 16th 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.

Buddy Walk 2011: Save the date for next year's walk, September 24, 2011 at the Rose Quarter Commons. A volunteer meeting is set for Jan. 12, 2011.

Et Cetera

... The NWDSA is pleased to announce that our website, nwdsa.org, has been updated and is now full of new information and links. If you are looking for information on our upcoming events, the kindergarten inclusion cohort or want to know more about us, please check out nwdsa.org.

...Parents of Special Education Students Ages 18–21: Is Your Child receiving Less than a Full School Day of Services? If your services were cut to less than a full school day after turning 18, Disability Rights Oregon would like to hear from you. DRO is concerned that a new state policy may encourage districts to provide less than a full school day of services for students 18 to 21. Please call 503-243-2081 to discuss the details of your situation or fill out an on-line intake form at the link below. DRO is committed to taking appropriate action if student rights are being violated. <http://www.disabilityrightsoregon.org/need-help/intake-form>

... The NWDSA is looking for two volunteers to help out two hours a week in the Resourcefulness Center. Call 503-238-0522.

Celebration

Continued from page 1

who brought together a group of friends from her social circle outside the DS community to organize this event. Along with Steve Holland from NWDSA's Board, we had Nicole, a graphic designer and photographer; Laurie, who owns Charisma! Communications; Marilyn, a non-profit development manager; Jennifer, the creative ideas person; and me, Riley's retired grandmother.



The weather turned out perfect for the day

Lots of talent and creative energy at the (kitchen) table, but none of us is a golfer! Nevertheless, we designed a logo, contracted with Persimmon, authored publicity materials, invited golfers, chose on-course contests, and asked for donations and sponsorships from everyone in the community. On the day, perfect weather, terrific on-course volunteers, and Graham, our incredible professional auctioneer (who worked his magic pro bono) surpassed expectations.



Bidding at the auction was fast and furious

Our modest goal for the tournament was clearing \$10,000 for NWDSA and reaching 10 new families with a positive awareness of individuals with Down syndrome. "It sounds like a disease, instead of just having an extra chromosome," I

wrote in our press release. "Our family is not seeking a cure, but rather inclusion; this tournament is about celebrating diversity." During the live auction, Angela Jarvis-Holland, NWDSA's Executive Director, remarked that she was thrilled to see so many strangers interested in and supportive of NWDSA. The over 100 individuals and businesses who donated prizes, cash, or in-kind gifts, and the overwhelmingly positive feedback from those who attended have inspired me to go for a Second Annual. Watch this space to save a date for 2011 soon!



Tournament organizers, from left: Laurie Halter, Jennifer Johnson, Brenda Trosvig, Nicole Ishida, Steven Holland, Melanie Fallis

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Jen Brandse
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Angela Frome
Tina Albers
Becky Adelman

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.

NWDSA

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Portland, Oregon

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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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this newsletter

[NWDSA Newsletter Committee](#)

Editors: Abby Braithwaite,
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Save The Date!!!
all born (in)

2011 Cross-Disability
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