



STEPPING UP

July 2011

Issue 13

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

Kindergarten Cohort graduates

Families are ready to take on kindergarten

By Abby Braithwaite

The first class of the NWDSA kindergarten cohort graduated in May. They celebrated their hard work with a party, complete with cake, camaraderie and inspirational words from Michael and Eleanor Bailey. Participants shared stories of the spring's IEP meetings, and offered tips to cohort members whose meetings hadn't happened yet. A small but crucial detail not to be forgotten - bring something sweet to the meeting!

On a more serious note, while the value of inclusion is clear for all children, there is no question that choosing an inclusive path for your child can be challenging and isolating, as you come face to face with the realities of underfunded schools and overstressed systems. For many families, the start of kindergarten is an isolating and mysterious process, and the NWDSA partnered with wonderful speakers to help demystify the process, from eligibility requirements to evaluations, from classroom supports to the nuts and bolts of the Individualized Education Programs that drive our children's education. The cohort also provided participating families the opportunity to connect with other parents, sharing stories and strategies as the series of trainings progressed. All the cohort members have agreed that the connections they made this year will be an important part of their support network as children start kindergarten in the fall, and IEP's are implemented.

Please see *Kindergarten Cohort* on page 4

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Celebration

Bike First! helps people learn to ride

By Ann Donaca-Sullivan

Our son, Cody, has an easy-going personality. He is funny and loves to laugh. Cody is good at swimming, running and making others feel loved. He enjoys hanging out with friends, being around animals, helping others and listening to music. When he graduates from high school, Cody will be a preschool teacher. He also happens to experience Down syndrome.

Since birth, we have strived to have Cody included in all areas of his life. There was no surprise when he showed interest in wanting to learn how to ride a bike. He would watch others and run beside them, trying to keep up. It was painful to see him watch other typically developing children ride their bikes around the neighborhood while he was "stuck" on a trailer bike.

Please see *Celebration* on page 7

*"A single sunbeam is
enough to drive away
many shadows."*

~ St. Francis of Assisi

NWDSA

northwest down syndrome association

Resourcefulness Center
11611 NE Ainsworth Circle,
Suite 321

Portland, OR 97220

Mailing Address

PO Box 9127

Portland, OR 97207

www.nwdsa.org

503-238-0522

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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

Annual Report Card

A look back at the work of the NWDSA this year

As parents are taking stock of kids' report cards, we thought we'd take the opportunity to recap some of what the NWDSA has been up to this year. These are just some of the highlights of what has been another busy and productive year!

COMMUNITY

Buddy Walk

The 2010 Buddy Walk was our biggest and best yet, with over 1,200 people in attendance. We are currently planning the 2011 walk, to be held on Saturday, September 24th. We are seeking sponsors and volunteers, so let us know if you are interested in helping out!

Socials

A sunny Summer Social at Blue Lake Park and a bouncy Holiday Social at JJ Jump in Clackamas each gave over 200 families a chance to get together with old friends and new. This year's Summer Social is coming up on July 31st at Lee Farms in Tualatin.

Golf tournament

On October 4th, 2010, Melanie Fallis and the Persimmon Country Club hosted the 1st annual Tee Up for Down Syndrome benefit golf tournament, in memory of Bill Fallis. This fun event provided seed money for the Kindergarten Inclusion Cohort. Registration is available for this year's tournament, to be held on October 3rd. Come out for a round of golf and support a great organization!

World DS Day

On March 21st, with the help of volunteer Kristy Hellum and the cooperation of Buddy Walk sponsor Der Rheinlander, the NWDSA celebrated World Down Syndrome Day with a night on the town. This first-time event was a great opportunity for families and friends to come together and celebrate the people in our lives who have Down syndrome.

OUTREACH

Family outreach

The NWDSA received a generous grant from the Spirit Mountain Community Fund for New Parent Outreach. We completed an update on the 3rd edition to the New Parent Guide, and have mailed out 75 copies to new families and supports since last June.

We supported dozens of families through phone support and office drop-in hours. Parents supported included those with prenatal and postnatal diagnoses, as well as adopting families. We held monthly Open Arms Playgroups in Portland and Vancouver, building community and sharing resources.

Community outreach

NWDSA board and staff members were invited to participate in a wide array of presentations, trainings and panel presentations to college classes and community organizations around the area. We enjoy these opportunities to promote inclusion and educate the community about issues that affect our community.

Please see *Report Card* on page 3

Report Card

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PARTNERSHIPS

In June we celebrated our one-year anniversary in our Resourcefulness Center in the MESD administrative building. A generous gift from the MESD will help support the next stage of the All Born “In” photo project.

Inclusion Alliance

The NWDSA is a founding member of the Portland area Inclusion Alliance, a group of organizations and individuals working together to promote inclusion in our community.

The Children’s Levy

NWDSA board and staff members enjoyed the opportunity to present a panel on inclusion to Portland Children’s Levy grantees in May. We look forward to the opportunity to build on this relationship.

INCLUSION

All Born “In”

On April 16th we held the 6th annual All Born “In” cross-disability inclusion conference. Participants enjoyed workshops on themes from preschool to employment, and were inspired by keynotes from Kathie Snow, Oregon State Representative Sara Gelser and Michael Bailey. A grant from La Salle Catholic College Preparatory School’s Community 101 class helped provide scholarships and interpretation for Spanish-speaking families attending the conference.

K-Cohort

In May, 16 hard-working parents graduated from the 1st annual Kindergarten Inclusion Cohort. Families spent a great year building person-centered portfolios for their children and building toolkits to help their little ones start off on the right foot in inclusive placements across Portland and southwest Washington. We are currently accepting applications for the 2011-2012 K-Cohort.

ADVOCACY

Educational

NWDSA Board President Steven Holland sat on the citizens’ budget review committee for Portland Public Schools. NWDSA families testified at Portland School Board meetings in defense of Special Education funding.

Legislative

In response to budget cuts in Salem, the NWDSA solicited stories about Early Intervention services from families in our community and created a booklet of stories and photos to share with lawmakers in Salem.

NWDSA board member Abby Braithwaite enjoyed the opportunity to join the Clark County Disability Coalition, an affiliation of groups advocating around issues affecting the disability community.

ORGANIZATIONAL GROWTH

The NWDSA welcomed four new board members to our community this year. We have also enjoyed the commitment of several new volunteers, who worked with us on projects including the Buddy Walk, World Down Syndrome Day and the Kindergarten Inclusion Cohort. The NWDSA mailing list now includes over 1400 parents, caregivers and professionals.



Resourcefulness Center
11611 NE Ainsworth Circle,
Suite 321
Portland, OR 97220

Mailing Address
PO Box 9127
Portland, OR 97207
503-238-0522

Angela Jarvis-Holland
Executive Director

NWDSA

Board of Directors:

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

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.

Kindergarten Cohort

Continued from page 1

As part of the final session in May, cohort members reflected on the series of trainings, and shared their thoughts about the six months they spent learning together. Here are a few reflections that participants shared:

“The cohort is a good reminder to me why I am doing this for my son and why it is so important.”

- The session on the details of Special Education law was useful and enlightening. To have grounding in the actual rights and intent of IDEA will give us the confidence to stand our ground if necessary in the future. But another vital message was to balance the legal and potentially confrontational side of things with a good dose of collaborative energy and grace.



- The most valuable part of the cohort for me was the feeling of community and support. I find this whole process very challenging, difficult and often times lonely. The cohort is a good reminder to me why I am doing this for my son and why it is so important.

The NWDSA is currently accepting applications for the 2011-2012 cohort class. If you have a child who will be starting kindergarten in the fall of 2012, who experiences a developmental disability, please consider taking advantage of this unique opportunity. The Cohort is open to families across the Portland Metro Region and Southwest Washington, and is cross-disability opportunity. Visit the NWDSA website at www.nwdsa.org or call the Resourcefulness Center at 503-238-0522 for more information. Applications are available for download on the website.

All Born In Wrap Up

Annual conference was a great success

By Joni DeRouchie

The All Born “In” conference just keeps getting better and better! Over 300 parents, educators, and students attended the 2011 All Born “In” Conference in Portland in April. It was a wonderful day of workshops, presentations, and seminars focused on inclusion and community building. We featured twenty-five sessions this year in what was our biggest conference to date, spanning a broad spectrum of topics for parents and professionals, including IEPs, social learning, advocacy, employment, sex education, independence and wellness, movement and sensory needs, and much more.

Keynote speaker Kathie Snow provided some great inspiration for parents and professionals. Kathie last keynoted for All Born “In” in 2007, and it was great to have her energy in the room once again. Other keynote speakers were Oregon State Representative Sara Gelser, and Portland’s Michael Bailey. Numerous other presenters and speakers inspired,

Please see ABI Wrap Up on page 5



The main ballroom at ABI

Buddy Walk Festival News

Register now for the walk on September 24

By Kim Jarvis

Registration for the 13th annual Portland and Southwest Washington Buddy Walk Festival on September 24, 2011 is up and running. Go to www.nwdsa.org and follow the links to sign up as a team, family or individual. This year we are hoping to attract a crowd of over 2,000 people to the Rose Quarter so plan on bringing your friends and family, your classmates and neighbors to help make the 13th annual walk the biggest one yet.

Don't miss the opportunity to mingle with old friends and new as your kids get their faces painted and play carnival-style games organized by JJ Jump. Supervisor will be providing live music and as always we have some great speakers lined up. Gustav's Pub & Grill is donating hot dogs for everyone and we'll also have Dreyer's ice cream, water from Nestle, and Kidz With Ice will be providing special treats. We have also been busy collecting a variety of excellent raffle prizes so don't forget to buy some tickets on the day.

Since last year's turn out was so phenomenal, resulting in long lines at the t-shirt table, we have made some changes to how we will hand out t-shirts and food tickets. This year we would like the team captain or one member of the family to pick up the shirts for their whole group. That way we won't have such a traffic jam at the tables.

For more information or questions please call Angela Frome at 503-238-0522 or e-mail afrome@nwdsa.org. Para comunicarse en español, llame a Maria O'Harra, 971-570-0942 o Isis Sanchez, 503-442-5817.

ABI Wrap Up

Continued from page 4

enlightened and empowered us with information and ideas to help our children and students live full, inclusive lives.

With the help of Susan Cushman from United Cerebral Palsy we expanded the self-advocate art sale. Six artists and entrepreneurs showed their work and sold prints and originals. Dylan Kuehl, a public speaker, artist and performer from Olympia led a self-advocate panel discussion on following your dreams to build a meaningful life. The conference concluded with a dance routine by Dylan and a musical performance by the NWDSA Youth Board. The laughs and smiles of the kids and parents as they danced to the music reminded what the NWDSA is all about - celebrating the diversity and abilities of our wonderful community.

We could not have brought it all together without the many volunteers and sponsors who dedicated their time and efforts to make the 2011 All Born "In" conference such a success. We look forward to working with everyone next year and the years to come, as ABI continues to grow.

All Born "In" Saturday Sessions

We are interested in hosting Saturday Sessions for parents and professionals in order to delve more deeply into topics discussed at the conference. We need your help to determine how many parents and professionals are interested in participating in Saturday Sessions. Please visit www.nwdsa.org to let us know what topics and subjects are important to you, and how you would like to be involved.



Buddy Walk fun

"My favorite thing was the diversity of the presentations: Parents, professionals, legislators, authors-knowledgeable and experienced."

-- participant at the All Born "In" conference



Dylan Kuehl struts his stuff at ABI



The 2011 Developmental Disability Awareness Poster



Daniel Jarvis-Holland, center, accepting a grant from members of La Salle's Community 101 program

Events

2011 Summer Social: Sunday, July 31 from noon to 3 PM at Lee Farms in Tualatin. Come enjoy an afternoon of socializing and fun with the NWDSA. There will be food, music, crafts, hay rides, hay maze, petting zoo, giant slide, bounce house, jumping pillow and more. RSVP to 503-238-0522 and check out Lee Farms at www.leefarmsoregon.com.

Buddy Walk 2011: This year's walk is on 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.

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. The July meeting is cancelled but the group will resume in August. For more information see contact info for Portland Open Arms listed above.

Et Cetera

... Adelina Martinez, a long-time member of the NWDSA and All Born "In" communities, was awarded a 2011 Champion Award in April from the Oregon Council on Developmental Disabilities. The award recognizes her efforts as a volunteer advocate for Latino parents of children with developmental disabilities. Adelina received the award from Gov. John Kitzhaber and State Rep. Arnie Roblan at a presentation at the state capitol in Salem. During the ceremony, the 2011 Developmental Disability Awareness Poster promoting inclusive education for all children was also unveiled.

... The NWDSA is a founding member of the new Portland area Alliance for Inclusion and Universal Design, a group of organizations and individuals working together to promote inclusion in our community. This builds on the last six years All born in conference and the best practices we have been promoting.

... The Community 101 program at La Salle Catholic College Preparatory awarded a \$1,000 grant to NWDSA. The money, given in partnership with the Oregon Community Foundation, helped provide scholarships and interpretation services for Spanish-speaking families attending the All Born "In" conference.

... NWDSA is pleased to announce that Tonia Albers will be joining the Board of Directors as Secretary. Tonia is a long-time volunteer for the NWDSA and we are fortunate she has agreed to serve on the Board. The Secretary's role is an important position for any non-profit, and Tonia's skills and her positive attitude will allow her to do a great job for NWDSA. Tonia is currently an office manager for Windermere Cronin & Caplan Realty Group.

Celebration

Continued from page 1

My husband, Shawn, came up with the idea to get Cody an adult tricycle. I believe my response was, “Over my dead body! I’ll teach him!”

Have you ever tried to teach someone how to ride a bike? As you can imagine, the disasters that followed were abundant. He was ten years old and a solid 100 pounds. Fortunately, I came upon an article on Lose the Training Wheels (LTTW). This was it! This was how my son would learn to ride!

After contacting an acquaintance, Patty Verzani, to help, we jumped on the band wagon and started organizing just how we would manage bringing LTTW to Portland, Oregon. Money, volunteers, space, the list was enormous, but we were determined. We decided to book the organization and worry about the details later. This was years ago and we are still going strong!

During our first clinic of 2006, Cody learned how to ride. There was an overwhelming sense of relief: the dream of Cody being able to ride was becoming reality. It still brings tears to my eyes. Although Cody learned to ride, he didn’t however learn how to start and stop. This meant that for the entire year, I ran behind him never knowing when he would switch pace! Fortunately, during year two, Cody learned how to start and stop!

When year three arrived, Patty and I decided we would officially name our clinic Bike First! We were here to stay and wanted to parallel the concept of People First. Each year, we register 40 people. Some of the participants have returned several years in a row; some skip a year and come back for refresh their skills. Most are new faces from ages 8 to 57!

The most noticeable benefit of Bike First! is people with disabilities learn the skills needed to ride a typical bike. There is an even larger benefit though. Each year, we have an abundance of people apply to be spotters... those who help teach, encourage, and support our participants. The effect on those volunteering, sponsors, those who read about our clinic in the papers, parents, etc. is phenomenal. It affects the way they look at ALL PEOPLE, not just those with disabilities. We see this happen year after year.

For example, kids like Cody: he has a circle of friends who understand inclusion. At least 10 of Cody’s close friends help with Bike First! each year. These children have been exposed in a different way to the value of including all people. They will be in society with a sense of compassion being part of their lives. This value becomes instilled and will stay with them forever. Our society is better because of what happens in Bike First!. In schools we teach academics, but people need to learn COMPASSION. It has taken a back seat. Our children with disabilities may learn to ride a bike, and it’s a wonderful thing. But we also need to remember the ripple effect Bike First! has. Everyone involved passes it on. The spirit of community is resilient.

For Cody, his bike riding ability has opened doors that invite independence, confidence, and friendships. He is now a freshman at Grant High School and has been a general education student with supports from the learning center since kindergarten. Cody rides his bike alone to school and back each day. Sometimes he takes a detour and gets a Diet Coke or stops at the park on the way home. On sunny days, he rides around town visiting friends. It is common for him to join block parties and call telling us to join him.

Our boy is independent. He is strong. He is friendly. He is included.



Riding outside



Getting the bikes ready for the next clinic



Cody the bicyclist



northwest down syndrome association

PO Box 9127

Portland, Oregon

97207

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, 971-570-0942 o Isis Sanchez, 503-442-5817



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this newsletter

NWDSA Newsletter Committee

Editor: Abby Braithwaite

Production & Design: Kim Jarvis



SAVE THE DATE

**2nd Annual Bill Fallis Memorial Golf Tournament
Tee UP for DOWN Syndrome**

Monday, October 3, 2011

*Persimmon Country Club
Gresham, Oregon*

Register Now @ www.nwdsa.org

Cash Rebate on foursomes for "1st Annual" participants!