

STEPPING UP

Winter 2014

Issue 22



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

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College-Bound: Making higher education a reality for all students

By Abby Braithwaite

Katie Bartlett is 13 and a 7th grader at Family House Academy, a small private K-8 school in Kelso, Washington. When she was just 11, Katie said to her mom over breakfast one morning, “Mom, I want to go to high school, then college, get a job, and have a wedding.” Her mom, Sally, knew that the next steps on her daughter’s journey were clear, and that they were in this together. From Katie’s earliest days, her mom has been looking toward the future. Sally, Community Liaison for the Arc of Cowlitz County, reflects, “When we received Katie’s diagnosis of Down syndrome prenatally, one of my first thoughts—fears—waves of grief was around college. When Katie was three months old, I learned of the Bellevue Community College post-secondary options. I made a trip up to one of their open houses; thank goodness, because that began to open my eyes to the possibilities...Now, we need more options in Washington State! And we have about seven years to get something going.”

The week before Thanksgiving, Sally and three other local advocates attended the *State of the Art Conference on Postsecondary Education and Individuals with Intellectual Disabilities* at George Mason University in Washington D.C.

Please see *College* on page 5

Celebration: We were hers—thoughts on fatherhood

By Diego Conde-Orama

At last we were making it. After two failed attempts, we were oh so close to clear the risk zone of the first 12 weeks and breeze through an easy pregnancy. At last we could relax a little, paint the room, buy baby clothing and break the news to the family.

Then the dream died. I use these harsh words because political correctness is absent in the cold geneticist’s office where they break the diagnosis; because at that time it is normal to feel that the baseball dream, the homecoming dream, the walking-down-the-aisle dream were all slain by a single extra microscopic chromosome. Family members mourn with you the loss of that dream. They cry with you. They give you what they understand is good advice, and you grieve... as you should.

But then there was a shift in the room. Maybe it was the rapid flickering in the monitor, and my heart, for some reason, wanting to catch up to it. Maybe it was my wife’s smile while looking at that monitor: unchanged, still fresh, and still jolly even after weeks of learning about good ol’ 47th chrome (our little nickname for the extra chromosome). I really don’t know why, but the air wasn’t as heavy, the waters calmed down and I was going to be a father.

Please see *Celebration* on page 10



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

The last few months have been busy times. So many passionate and committed people work with us to achieve our mission of acceptance and inclusion. This newsletter will highlight some of the incredible projects and work underway in support of our families. In this spirit, we wanted to highlight a couple of recent key issues we have been involved with.

Recently NWDSA board, staff, and parents attended a number of events and advocacy meetings in support Portland Parent Union (PPU) in their work to end the push-out of students that exhibit behaviors that schools may struggle to understand. PPU sponsored their Week of Action October 4-11 that brought community focus to the Dignity in Schools Campaign (DSC) which challenges the systemic problem of “push-outs” in our nation’s schools and advocates



for the human right of every child to a quality education and to be treated with dignity. The DSC unites parents, youth, educators and advocates in a campaign to promote local and national alternatives to a culture of zero-tolerance, punishment and removal. NWDSA supports the work of Sheila Warren and PPU on this crucial issue!

On November 3, a number of NWDSA board members, staff, and volunteers met with Senator Ron Wyden and his staff to discuss our support for the ABLÉ Act. Senator Wyden has become a strong voice in support of getting this bill passed in the Senate. The ABLÉ Act would allow families to save money for their children with a disability, and it would remove the \$2,000 limit on

assets that disqualifies a person from receiving certain Social Security and Medicaid benefits if they qualify for those benefits. The ABLÉ Act would help make the American Dream a reality for people with disabilities. The concept is modeled after the popular 529 College Savings Plan, but is less legally and administratively complex, and less costly than a Special Needs Trust. The passage of this bill would help create a bridge to a brighter future for people with disabilities. We ask that you write your Senators and Representatives in Washington and ask them to support this bill. You can go on their webpage, and fill out the contact form to express your support for the legislation!

For families and students, we hope your fall is going well, and that your schools are working with you to help your student accomplish their education goals for the year. We look forward to seeing you all at the Holiday Social, and as always we hope everyone has a great Holiday season!

Best regards,
Steven Holland
Board President

'Brokerage 101' workshop helps families unpack complex changes to supports

On October 22nd, the Northwest Down Syndrome Association and All Born (In) hosted a dynamic "Brokerage 101" workshop at the MESD Building. This interactive session featured parent perspectives and real-life experiences from Michael Bailey, Sheyla Hirschon, Eveyln Lowry, and Susan Cushman who shared what works and what doesn't. Thank you to Beth McHough-Peccia at MCDSS, Larry Deal from Independence Northwest, and Dan Peccia from SDRI who shared about the K Plan, brokerage services and many critical changes that impact resources to families experiencing DD. We will be following up with additional resources and opportunities for learning more.

Keep an eye on our event calendar at www.nwdsa.org/events and follow us on Facebook at www.facebook.com/nwdsa to stay informed about upcoming K Plan sessions.



Kiddos are (mostly) all smiles as they begin the new school year



2014 Buddy Walk Speakers



My friends give me a lot of support. When I have a problem or I just need to talk to someone that I know, they can help.

That's why we have friends, because they can be there for you if you need help.

And isn't that what this Buddy Walk is all about?!

Rachel Esteve



We are all different races, sizes and ages but a community is one big family.

I have a lot of dreams for my future. I will need more people on my team to make this happen.

When we are all part of a team we can take care of each other and be stronger.

Daniel Jarvis-Holland

A beautiful, sunny Buddy Walk brings record numbers

Our 2014 Portland Metro and SW Washington Buddy Walk Festival was NWDSA's largest walk yet, with 2,000 participants showing up to build community with friends, family, and colleagues in support of our loved ones with Down syndrome. Self-advocates Rachel Esteve and Daniel Jarvis-Holland spoke eloquently and movingly about their dreams and goals. Live music, salsa dancing, balloon art, bounce house, slides, games, good eats, auctions and raffles and fun all around made this sunny, warm day in Portland unforgettable.

A big thank you for the support of our amazing donors and Buddy Walk teams—your efforts helped us meet our online giving target of \$50,000.

We are so grateful to all of our sponsors who helped underwrite many of the event costs, and especially for our Diamond Sponsors: Regence BCBS of Oregon and Latitudes, Inc. The Buddy Walk is a model of community effort, and we thank everyone who helped make the day possible: sponsors, auction donors, teams, volunteers, and YOU!

Mark your calendar for next year's walk: Saturday, September 19, 2015!



College

Continued from page 1

These four moms have one thing in common with many other parents across the region—they each have a child who wants to go to college. What sets them apart is that post-secondary options for their children are extremely limited in the area. There is a call to action on a larger scale: Oregon’s 40/40/20 plan states a goal that by 2025, 40 percent of adult Oregonians will have earned a bachelor’s degree or higher; 40 percent will have earned an associate’s degree or postsecondary; and 20 percent will have earned at least a high school diploma or the equivalent. That’s a lofty goal, and if it is include ALL children, there needs to be real change in expectations and programs for children with disabilities.

Also on the trip to D.C. were Ann Donaca-Sullivan, a professor of education at Concordia University, Maureen Higgins, who works at the Multnomah County Library and is mom to Eddie, a 13-year-old 7th grader at Beaumont Middle School, and NWDSA/ABI Executive Director Angela Jarvis-Holland. These women have known each other for many years, and came together most recently as participants (and in the case of Ann, facilitator) of the Dreambuilders transition cohort that NWDSA and Community Vision, Inc. created and partnered on last year. The cohort was designed to help families begin preparing for the transition out of high school several years in advance. It became clear that while many students in the program have dreams of college, and their parents are supportive, there are just a handful of post-secondary options available around Oregon and Washington. There are several initiatives in the works around the country, and many of the people working on the issue came together at the *State of the Art* conference this month.

When it came time for Cody Donaca-Sullivan to graduate from high school, his parents knew that they would have to create something for him. Today, he is the first person with Down syndrome to attend an Oregon university. A freshman at Concordia this year, Cody says, “I love Concordia. I love everything about it!” He also works in a preschool and volunteers at Faubion School. Says his mom, “Cody wanted to go to college because his friends were going to college. Concordia University found a way to make this happen. I am going to the conference in order to help implement inclusive programs in Oregon at the university level for people with intellectual disabilities.”

Please see *College* on page 9



California Pizza Kitchen and Bent Brick held fundraisers to benefit NWDSA/ABI programs. Don't miss the upcoming fundraiser at: La Bonita Restaurant, Thurs. Nov. 6th 2710 N Killingsworth St., Portland OR (Killingsworth location only) 15% of the day's proceeds will benefit NWDSA/ABI



all born (in)

2015 Cross-Disability Inclusion Conference
 May 2nd, 2015 - **SAVE THE DATE!**
 Airport Holiday Inn
 Portland, OR

Learn more at www.allbornin.org



GIVE THE GIFT OF...

INCLUSIVE EDUCATION is at the front line of the disability rights movement, and critical to our mission of creating an inclusive civil society.



“ Since attending our first ABI Conference, Isaac has had doors opening for him I never imagined. Learning our rights and responsibilities was imperative for an inclusive education. Now in 7th grade, Isaac enjoys everything with his non-disabled peers as one of them. This would not have been possible without ABI.

Isaac's Mom

VIBRANT COMMUNITY is vital for families to celebrate and find strength in unity. Our socials and playgroups have enabled strong bonds within the community.

“ It's such a relief to have somebody that is going through the same thing we're going through. We're there for each other and that's the best thing ever. Our social calendar fills up with different activities we do through the NWDSA. As my son Michael puts it, these are our people!

Sean's Mom



EMPOWERED FAMILIES and self-advocates are educated, equipped, and supported to create inclusive communities where everyone belongs.



“ With the support of the NWDSA, I'm able to step out of my comfort zone and advocate directly with lawmakers to help create a supportive and inclusive educational experience for my daughter. I would not have the resources or guidance to advocate for my child as effectively without this community.

Jasmine's Mom

A HOPEFUL FUTURE is the greatest gift you can give, by supporting a community in which people of all abilities can contribute and thrive.

“ NWDSA / ABI has been our hub of support since our daughter was born. The wealth of knowledge, connection, and experience has been invaluable in our journey. I look to the friendships and connections that I have made with them to support our family and our daughter well into the future.

Neva's Mom



NWDSA/ABI creates and nurtures a loving, inclusive community celebrating every person with a disability, including Down syndrome. We thank each and every person, foundation or business who donated time, talent or treasure to NWDSA/ABI this year, and we ask for your continued support in 2015.

NWDSA/ABI is connected to over 1,600 families as well as hundreds of professionals and policymakers. We engage families early and often through various social, learning, and sharing opportunities. We provide new parent outreach and family support across the arc of childhood; while our home base is our community of families experiencing Down syndrome, our work extends to support families experiencing a wide range of developmental disabilities. We host a web of highly successful and innovative educational programs and cohorts that help families presume competence, develop advocacy skills for themselves and their children, and build a path to inclusion and success in schools and in the greater community. Our multi-media photo and video awareness work includes banners and images celebrating our common humanity, along with many others and a video series including *We All Belong*, about the civil rights frontier of inclusive education, which has had over 6,500 views on YouTube. Our newest resource *Healing Hearts* presents 15 stories of families' experiences with heart surgery.



Give the gift of community by mailing your donation

You can also donate online at www.nwdsa.org/donate

Name _____

Address _____

Phone _____ Email _____

My donation is for:

- NWDSA - Creating & Nurturing an inclusive community
- All Born (In) Cross-Disability Support

My donation is in memory of / in honor of:

Name _____

Donation Amount: _____ **I am paying by:** Check (please enclose) Credit card (please fill out info below)

Credit card # _____ **Type of card (Visa/MC/Disc/Amex)** _____

Exp. date _____ **CVV #** _____

Send this form with your check made out to NWDSA to: NWDSA, 11611 NE Ainsworth Cir, Portland OR 97220



NWDSA's Bike First! is proud to promote inclusion by teaching individuals with disabilities the skills needed to ride typical bicycles. www.nwdsa.org/bikefirst



“So proud of [my child] on her bike. Thanks NWDSA Bike First! for giving her the skill and confidence to ride.”



“[My child] learned how to ride in this summer's clinic. We can't thank you enough for this incredible gift you have given to our family!”



Greetings from our New Parent Outreach Coordinator

By Pamela Dye

I am excited and honored to start my new role as coordinator of New Parent Outreach/Educational Programs here at NWDSA. We launched this fall with a great RLC session in October entitled “Making Sense of Assistive Technology for Your Young Child to Help Them Thrive” with Samuel Sennott, Ph.D and Eric Sanders, Ph.D CCC-SLP. Sam is an Assistant Professor and Assistive Technology Specialist at Portland State University and Eric is an Assistant Professor and AAC Specialist at Pacific University. They shared great information on the ways that technology can help support learning and communication. After the session we had a wonderful lunch together where families were able to connect with each other and get questions answered by Sam and Eric. We're hoping to have future workshops with this pair, so stay tuned!

I am also working to make connections with new families so that we can be there for friendship and support, and weave a strong community for all of us. I am enjoying meeting with genetic counselors and nursing staff to create ways that we can let new families know of this great organization and make those family-to-family connections, and ensure that all new families in our area have access to current resources and information.

Being in the office and working with the staff and volunteers here is a great way to spend each day. The office is always filled with great energy and laughter as we work to make a difference in the community and in the lives of families and individuals that experience disabilities. The love, friendship, and kindness that are spread here make a difference to me and everyone that steps into these doors; the NWDSA Resourcefulness Center is proof that a small group of hard-working individuals can make big differences in the world.

Upcoming RLC Session “Shared Reading” scheduled for Feb.28th
More details coming soon to www.nwdsa.org/events

NWDSA/ABI receives Grassroots Grant from Meyer Memorial Trust

NWDSA/ABI is the proud recipient of a \$40,000 grassroots grant from Meyer Memorial Trust. This two-year grant supports our All Born (In) cross-disability inclusion work. For the past ten years, the All Born (In) Movement, rooted in educational best practices, equity and social justice for all, has worked to increase awareness and pursue a more inclusive civil society.



Meyer Memorial Trust

“Meyer Memorial Trust is proud to support the cross-disability work of the Northwest Down Syndrome Association, which pursues an inclusive civil society by defending the civil rights of individuals with disabilities, increasing skills to support diverse learners, empowering families and self-advocates, and promoting public understanding,” said Doug Stamm, MMT's chief executive officer. “We are pleased to partner with NWDSA in moving this important work forward.”

College

Continued from page 5

Daniel Jarvis-Holland recently got a chance to share his hopes and dreams with Oregon Senator Ron Wyden. As Daniel pounded his fist on the table and declared, “I want to go to college!” it was clear that Senator Wyden understood the urgency that Daniel feels about his future. A freshman at Benson Polytechnic High School, Daniel has some very clear dreams, from comic book artist to café owner. His brother Quinn is a student at Portland Community College, and Daniel sees no reason he shouldn’t be able to follow in his brother’s footsteps. At *Beauty in Diversity*, a recent event at PCC’s new SE Campus, Daniel and Quinn both spoke eloquently about the need to work together to make college more accessible for all students. On the refrigerator door in the Jarvis-Holland home is a magnet that reads “Benson High School Class of 2018,” a reminder every day that the future will be here before we know it.



“Beauty in Diversity” art reception at the new Portland Community College SE Campus, Sept 2014. Sponsored by All Born (In) and featuring images celebrating our common humanity by Jodi Collins Photography, and remarks from OEIB Chair Dr. Nancy Colden and PCC board member Courtney Wilton. The event was Funded in part by the Oregon Council on Developmental Disabilities.



His mom, Angela, recently reflected on why Daniel might have such clear goals for himself. For one thing, he and his family have grown up with the All Born (In) conference. The first year of the conference Daniel was just 5 years old, and Angela remembers the power of having adults with disabilities at the conference, talking about their lives, goals, and work in the community. As Angela says, “Daniel never heard that he couldn’t go to college. He’s heard that he might have to fight for the opportunity, but the opportunity has always been there. In the beginning we were careful to dream big dreams for Daniel, but over the years his own interests have developed, and his dreams have become his own.”

Please see *College* on page 11





This year's Summer Social was held at Camp Angelos, a new location with fishing and lots of fun games and activities enjoyed by families in our community



Celebration

Continued from page 1

Not a special father, not a father of a baby with Down syndrome, just...a father. Granted: a father that had weekly high risk pregnancy appointments, and who wondered why the growth chart of our baby had the incline of the national employment rate, but a father nonetheless.

She was born carrying 6 lbs. and a mild cry; more like a meh. Of course, those were anxious moments, but she was here and she was ours; and we were hers. We've had our share of surgeries that sound eerie and dreadful but which are actually quite common and routine. We have seen our baby champ check in at 5 months old for open heart surgery on a Monday and be home giggling by Friday. It's scary, it's uncertain...it's parenthood.

From that point on, we have not done one thing that an ordinary parent would not do for their children. Yes, her development is a bit delayed, which only gives us more time to enjoy each and every stage, and each and every accomplishment. Yes, bottle-feeding is a pain in the rear. Yes, there are more medical expenses. Yes, there are concerns about bullying when she gets to school. But, what parent these days does not share the same worries and or experiences the same fears.

Yes, there are support groups and specialized care programs for people with Down syndrome. They are great and immensely helpful to allow your child to more fully develop into an independent adult. However, we have found these support groups to support parents more than kids; and that's a good thing. It is us who need to remove some of those uneducated fears and learn to adjust our parenting paradigms. It's not that we have more challenges as parents, we just have different ones. Educating yourself to better understand them will take you a long way.

In the end, Down syndrome doesn't define our daughter nor does it define us as parents. We are an up family, with two rookie parents trying to do their best and a girl that rocks that extra chromosome and is blossoming as an amazing individual. We all should be as lucky.

New parent-driven resource for families facing heart surgery

Healing Hearts: Families' Experiences with Down Syndrome and Heart Surgery is a parent-driven booklet chronicling the first-hand stories of 15 families and their experiences with heart surgery. It also contains information, resources, and a glossary which was medically reviewed by Dr. Mark Reller at OHSU. This booklet has already become a tremendous resource and support for new families of babies and young children with Down syndrome facing heart surgery. Thank you to Jamie Lesley Burch for working tirelessly to make this booklet a reality.



College

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A big concern on the minds of the group who attended the conference from this area is that post-secondary options need to be as diverse as the students who access them. Cody wants to work with kids; Daniel wants to be an artist and business owner; Katie wants to work in the medical field; Eddie is a performer and a musician, and his mom could see him pursuing a degree in theater or communications, but cautions, "It will be his dream to pursue. It's exciting that he has so much potential and I want to be part of the team that helps ensure there are opportunities for all of our kids."

Angela, Sally, Ann and Maureen are excited for the opportunity to join the national conversation on this subject. Stay tuned for a community meeting when they return, where they will share what they learned and work to build more community momentum to make real college opportunities available to anyone who shares the dream of going to college.

Events • Full calendar & details at www.nwdsa.org/events

DEC 5, All day - Winter Holiday Craft Bazaar: MESD Building • 11611 NE Ainsworth Circle • Portland, OR • Learn more www.nwdsa.org/events

DEC 6, All day - La Bonita Fundraiser: La Bonita • 2710 N Killingsworth St. (this location only) • Portland OR • 15% of the day's proceeds will benefit NWDSA / ABI • Learn more www.nwdsa.org/events

DEC 14, Noon-2 PM - Winter Social: JJ Jump • 9057 SE Jannsen Rd • Clackamas, OR • RSVP www.nwdsa.org/events or (503) 238-0522

DEC 15, 6-10 PM - Toast for Inclusion: Bad Habit Room • Proceeds benefit the Kindergarten Inclusion Cohort • 5433 N Michigan Ave • Portland, OR • \$5/door, \$5 pints • Learn more at www.nwdsa.org/events

FEB 28 - RLC Workshop: Shared Reading • For parents of children age 0-5 with Down syndrome • More info on this session coming soon

MAY 2 - ABI Conference **SAVE THE DATE!** • Holiday Inn Airport, Portland • Learn more www.allbornin.org

JUN 28-JUL 2 - Bike First! Bike Camp • Teaching individuals with disabilities the skills to ride typical bicycles • Learn more www.nwdsa.org/bikefirst

Drop-In Hours: **NEW DAY!** Every Thurs., noon - 2:00 PM, Get answers to your questions about IEPs, school, home, development, and more • NWDSA Resourcefulness Center • 11611 NE Ainsworth Circle, Suite 321 • Portland, OR

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 space to be announced! Stay tuned!**

Vancouver: 1st Sunday of every month • 3:30 - 5:30 PM • Central Park Childcare, 2115 East McLoughlin Blvd, Vancouver WA

Club Upside Vancouver: Where parents can share and children of all ages and abilities can play • 2nd Saturday of every month • 2:00 - 4:00 PM • St. Andrew Lutheran Church, 5607 NE Gher Road, Vancouver WA • **Dec 13 is Club Upside's annual holiday celebration, featuring a visit from a sensory sensitive Santa**

NWDSA
northwest down syndrome association

Angela Jarvis-Holland
Executive Director

NWDSA Board of Directors:

Steven Holland
Abigail Braithwaite
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Ruth Falco
Isis Sanchez

For more info please visit
www.nwdsa.org
or www.allbornin.org

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.

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 (503) 239-1509 o Isis Sanchez (503) 442-5817



winter
social

SUN. DEC. 14th NOON - 2 PM

JJ JUMP IN CLACKAMAS
9057 SE Jannsen Road
just off I-205 at exit 13

RSVP at
www.nwdsa.org/events

The poster features a light blue background with stylized blue evergreen trees and white snowflakes. The text is arranged in a clean, modern layout with varying colors for emphasis.

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