



# STEPPING UP

December 2011

Issue 15

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

## Brunch brings families together

Reintroducing the Reciprocal Learning Community

By Abby Braithwaite

On November 5th, the NWDSA hosted a brunch for families with young children with Down syndrome. The childcare rooms were full of little ones and a great group of volunteers of all ages, and the MESD cafeteria was packed to capacity with 40 parents eager to connect and learn together. NWDSA Board members shared the NWDSA mission, history and projects, and long-time advisory board member and partner Mary Williams, an Occupational Therapist, shared some information on how to incorporate therapies into the daily life of a family. Mary travels with a huge bag of tricks, and parents enjoyed passing her “therapy tools” around the room. These tools ranged from poker chips to pipe cleaners, cookbook holders to toilet paper tubes, and everyone went home with a few new tricks they could try without spending a penny on special equipment.

Kristy Knight, an audiologist from Oregon Health & Science University, presented on the medical guidelines for children with Down syndrome, and then went into detail on the anatomy of the ear and the importance of frequent hearing screenings for children with Down syndrome. Kristy works closely with NWDSA advisory board member and fellow OHSU audiologist Heather Durham, and they are a great resource for this community.

Time passed quickly at the brunch, but it was a great chance to meet new families and reconnect with some old friends, as well as reintroduce families

Please see *Brunch* on page 3

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## Celebration

Breaking through and having a BLAST!

By Jodi Collins

I had a great time earlier this fall working with the NWDSA to take photos celebrating graduates of the first NWDSA Kindergarten Inclusion Cohort. As a professional photographer I am fortunate to make my living doing what I love, and I also enjoy a chance to give back to the community when I can. I have worked with the NWDSA twice in the past, and I was excited when they got in touch wanting to launch another project. It’s a lot of work and a bit of a logistical juggle getting so many families in and out of the studio, but shooting the sessions for this project makes my heart and soul feel so alive and full of joy! In one of the sessions, the little girl I was photographing had such a good time in the studio that she ran right through the backdrop, her big brother hot on her heels!

Please see *Celebration* on page 7



Ellie is breaking through



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Readers are welcome to submit letters and articles to the address above or e-mail [editor@nwdsa.org](mailto: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](http://www.urban-photography.com)

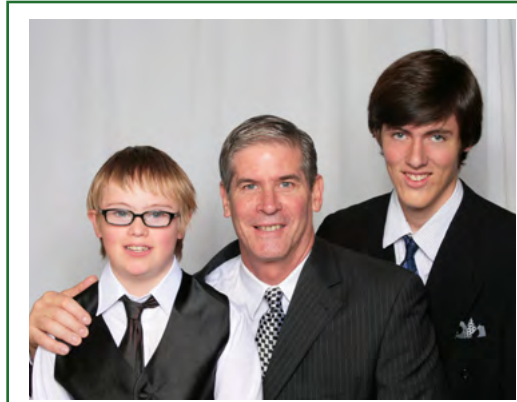
## Letter from the President

By Steven Holland, NWDSA President

As my family and I gear up for the holidays every year, I take a few minutes to take stock in the incredible community of friends and family that support us. These are tough times for many families, and the struggles are not unique to families in the Down syndrome community. I have two great sons, Quinn and Daniel. Quinn is 17 and Daniel is 12, and has Down syndrome. My boys each have a unique personality and way of looking at the world. It takes a real commitment by my wife Angela and me to do the best job we can of raising Quinn and Daniel. Thankfully my family has a great support network as we navigate sometimes-challenging waters.

Watching my boys grow I am reminded of my own childhood, and the job my parents had in raising my siblings and me. We grew up in Southern California in the 1960s and 70s, and my brother Joe and sister Sue had serious heart abnormalities requiring open-heart surgery. In the 60s open-heart surgery was extremely risky and required extensive recuperation. I remember many nights of my mom nursing my brother, then my sister, at home while they recuperated. My dad worked a night job and did not get home until midnight. He also worked a job on the weekends. Our neighbors the Ruedas had ten children of their own, but when my parents stayed at the hospital with my brother, the Ruedas cared for the rest of us. They welcomed us into their home and their kids were like cousins to us. I remember my time with the Ruedas as calming in a scary time for our family. We moved away to the suburbs, and lost touch with the Ruedas, but I think about them now and again. I think about how family is there to love and support each other, even when things are tough, and how important friends are. When the going gets tough having a community built around family and friends is pretty important.

Being a part of the NWDSA has helped our family build a community. An important part of this community is connecting with other parents. Over the years I have appreciated sharing my experiences, and hearing stories from other parents about their own journey. I have especially enjoyed connecting with other dads at RLCs, the All Born "In" conference and at NWDSA socials. At the recent New Parent Brunch held at the NWDSA Resourcefulness Center it was great to see so many families coming out and stepping up to join this community. Elsewhere in this issue you will find an article from Paul, a father of a 2-½ year-old, who is looking to connect with other dads. Paul and his wife Susan are some of the newest parent volunteers in the NWDSA community, and we are excited to get to know them. Volunteering at an NWDSA



is event is one of the best ways to get involved in the community. Let us know if you'd like to be more involved!

Enjoy the holiday season. All the best to you.

*Interested in meeting other Dads? Let's get together, have some fun and learn from each other. Contact Steven Holland at [sholland@nwdsa.org](mailto:sholland@nwdsa.org).*

## Brunch

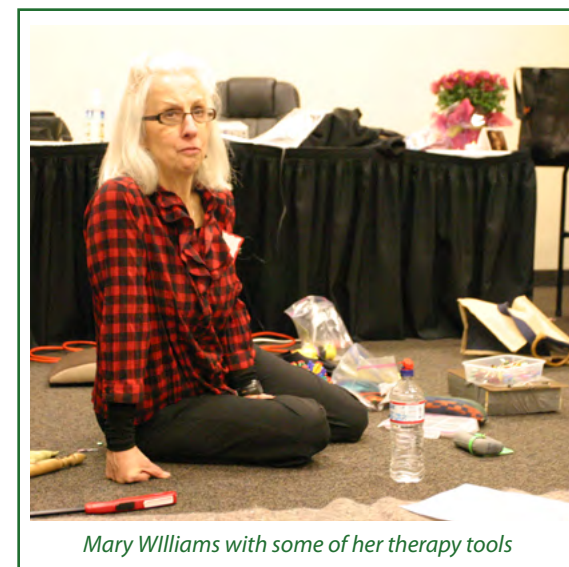
Continued from page 1

to the Reciprocal Learning Community (RLC). The RLC was founded in 2002 by Angela Jarvis-Holland, the Board of the NWDSA and a steering committee of volunteers, in response to severe cuts made at the state level to Early Intervention services in Oregon. When Angela's son Daniel, now 12, received Early Intervention services, there was a lot offered to parents, including playgroups, trainings and great resources. When these programs faced a cut of nearly 70%, Angela and her husband Steven, with the support of the NWDSA, decided to tackle the problem head on by creating another forum for parents to come by the information and support that the Jarvis-Holland family received through Early Intervention.

Designed to inform and empower parents, the RLC looked to present research-based, best practices information relevant to the needs of families with children aged 0-5 with Down syndrome. At its peak, the RLC presented free quarterly sessions on topics such as nutrition and wellness, speech and literacy and motor development. To create each session, a group of parents and professionals came together to form an ongoing reciprocal learning community. NWDSA staff worked with a steering committee that included other parents to decide the focus of each session and maintain editorial controls. We have a strong team of professional advisors to draw on as we craft the sessions, as well as a large catalogue of best practices materials. Professionals acted as advisors and session presenters, but parents remained in the driving seat throughout the planning process. We also look to parents to help find funding and volunteers for childcare and food.

There are a lot of new families in the area right now and many demands on our limited resources. With your support, it's time to bring the RLC back to the front burner. Workshops take place on Saturday mornings, in hopes of bringing in as many working parents as possible. Childcare is provided by volunteer childcare professionals, and the morning begins with coffee and pastries and a chance for conversation while kids get settled. There is always a parent story to start the session and an inspiring speaker to introduce ideas for empowered lives. To welcome our non-English speaking families we also provide translation as needed. The day concludes with a community lunch that provides vital time to connect with other families.

The RLC has always been a vital way for families to connect, and we are excited by the possibility to bring this opportunity back. If you have expressed an interest in volunteering to help with the planning of the next session, thank you and we will follow up. If not, please contact the NWDSA Resourcefulness Center at 503-238-0522.



Mary Williams with some of her therapy tools



Happy Holidays from  
the NWDSA





### Buddy Walk Festival News

Sunshine and good times had by all

The 13th annual Buddy Walk in September was a great success with more than 1,500 people showing their pride. It was so exciting to see so many hundreds of people joining together to celebrate our community.

We had live music from Newel Briggs and indie band Supervisor. JJ Jump organized games for the kids and Hooperville USA provided a lot of hula hoop action. Gustav's Pub & Grill donated hot dogs for everyone and Dreyer's ice cream provided sweet treats on the hot and sunny day. We also had water from Nestle and Kidz With Ice provided coffee drinks, cotton candy and more. The Buddy Walk has really evolved into a day-long family festival with something for everyone.

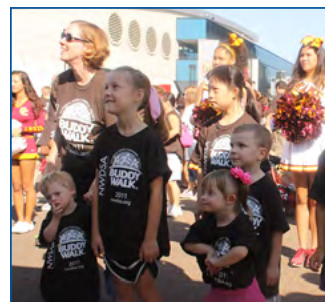
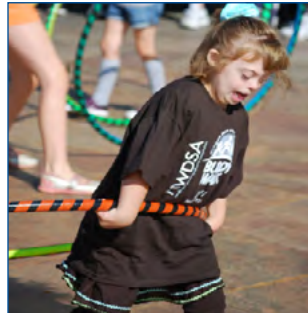
The NWDSA would like to thank all of the individuals and companies that gave generous donations of their time and/or products to bring you this year's entertainment, refreshments and donations for our raffle prizes, silent auction and goodie bags. And a special thank you goes out to Sue Dobrunick from Cliff Bar for all of her help getting donations and sponsors. We could not have pulled this event off without the support of over 30 volunteers. 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. Be sure to save the date for next year's walk on September 29, 2012.

The NWDSA would like to thank all of the teams who came together to support the Buddy Walk. We had more teams this year than ever before.

Thank You!



Thank you Team Bullwinkles for being our biggest team this year



### You're a hero to somebody - clown shoes optional

By Paul Carson

If you're a new father, congratulations - you just landed the best job in the world! Fathers are looked at as heroes, as protectors, as clowns and sometimes as jungle-gyms. Fathers are endlessly comparing their children's accomplishments - and being guys, sometimes doing so competitively. Sometimes it may be hard for us to hear these comparisons, particularly if our kids are behind on a milestone or struggling to learn an important skill. It may sting to hear about your friend's son taking his first steps when your boy or girl isn't quite there yet.

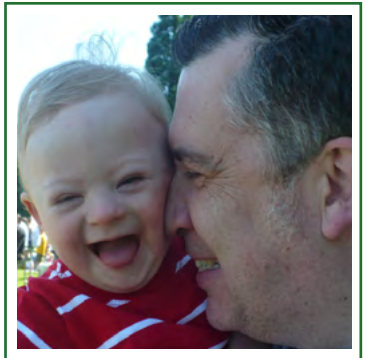
Our son Anthony is two-and-a-half and is still working on his first words. He points very enthusiastically and sometimes he yells, because he doesn't have a vocabulary yet. We go to speech therapy and work with just about every speech-learning tool there is. But what I like to focus on is how much Anthony understands. While his speech may be delayed, he listens to and understands a lot - we've learned never to underestimate what words he may have picked up!

Anthony still needs help walking independently. He's got orthotics and has had all kinds of therapies, but he still needs help from us to balance and go any kind of distance. But he loves walking! While he still needs a copilot, he loves trying and we can tell he's got the heart of an explorer. He loves to climb and has a reserve of energy I truly envy. He's also got an uncanny aim. His pitching arm is a little scary!

The point is, dads, for every delay and struggle, if you look for it, you will find an amazing strength and ability in return. Our children are astonishing!



They may take some time getting there, but we should never diminish their potential. Our children look to us to see what's possible. As dads, we have to remember that every child is different and it's our job to help our kids believe they're capable of anything. That's what sons and daughters look to their fathers for - and that goes beyond any diagnosis. That's universal for anyone who's lucky enough to be a dad. So take heart - our kids may need some extra help sometimes. How wonderful that when they look for it, we're there to let them know that that's okay - and that's an amazing feeling.



Anthony and Paul

"The point is, dads, for every delay and struggle, if you look for it, you will find an amazing strength and ability in return. Our children are astonishing

-- Paul Carson



Open Arms Playgroup

## Events

**OTAC Positive Behavior Supports Workshop:** Free workshop features educator Stephanie Hunter. This training will provide information about behavior, communication and effective simple proactive strategies that can help to decrease challenging behavior and increase independence. Saturday, December 10th, 9:00am - 12:00pm, Multnomah Education Service District (MESD), 11611 NE Ainsworth Circle, Portland, OR 97220. To RSVP, please call 503-238-0522.

**OTAP Accessible Instructional Materials Workshops:** Free workshops focus on Accessible Instructional Materials (AIM) and how they can help parents and professionals enhance learning experiences for students. These two workshops will present similar material. February 17th, 10:30am - 1:30pm, and February 18th, 9:00am - 12:00pm at MESD, see address and phone number above.

**OTAP iPad Workshop:** Learn about iPad and tablet applications that support learning and communication at home and in the classroom. Spend 3 hours with experts getting tips on the best apps available and how to use them. March 3rd, 9:00am - 12:00, MESD, see address and phone number above.

**Open Arms Playgroups:** Join other parents and their children for an opportunity to ask questions, share ideas, and learn from others' experience. **Portland:** the 2<sup>nd</sup> Tuesday of every month from 5:30 - 7:30 PM in Bethlehem Lutheran Church, 1244 NE 39<sup>th</sup> Ave., just off I-84. **Vancouver:** the 3<sup>rd</sup> Thursday of each month from 5 - 7 PM at Church of the Good Shepherd, 805 SE Ellsworth Road, Vancouver, WA 98664. Contact Abby at 971-998-8744.

## Et Cetera

... The Achieving A Better Life Experience Act (ABLE) of 2011 was introduced last month as S. 1872 in the Senate and H.R. 3423 in the House. The ABLE Act will give individuals with disabilities and their families the ability to save for their child's future just like every other American family, and help people with disabilities live full, productive lives in their communities without losing benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary's employment, and other sources. Write your members of congress and ask them to cosponsor this act. Please visit [www.ndss.org](http://www.ndss.org) for more information, and links to your Senator and Representatives' offices.

... In early November the company Sequenom introduced MaternaT21, a prenatal genetic screening tool that will allow pregnant mothers to take a simple blood test as early as 10 weeks gestation to screen for a fetus with Down syndrome. This test, while not as accurate as amniocentesis or CVS, and not yet FDA approved, will likely bring with it an increase in the number of families who receive a prenatal diagnosis of Down syndrome. The NWDSA is currently working with area genetic counselors and national-level groups to put together a position statement and a set of best-practices guidelines for healthcare providers to use when offering a prenatal diagnosis to patients. If you would like to learn more about the work happening locally or on the national level, please contact Angela or Abby at 971-998-8744. Visit [www.ndss.org](http://www.ndss.org) and look for their "Position Statements" under the Newsroom tab for more information. We are also collecting your stories to use in our presentations and advocacy. If you would like to share the story of how you received your pre- or post-natal diagnosis, please pass it on to [abraithwaite@nwdsa.org](mailto:abraithwaite@nwdsa.org).



The NWDSA would like to thank der Rheinlander for their continued support. A \$2 portion of the door fee from everyone who attended their Oktoberfest in September funded this year's Winter Social. Plans are already underway for a family day on Sept. 22nd during next year's Oktoberfest. Check out their website, [rheinlander.com](http://rheinlander.com), if you want to dine out and support one of our partners.

## Celebration

*Continued from page 1*

It's appropriate, in a way, that Ellie busted through the backdrop in her photo shoot, because these photos celebrate families who are busting through stereotypes and the norm of segregation of children with disabilities in our schools. As NWDSA Executive Director Angela Jarvis-Holland framed the project for me, "We grow together, we play together, we learn together." When our children grow up together, play alongside one another at recess and learn side-by-side at their desks in school, they are working to create a world where all children, regardless of ability, will have room to thrive.

I remember when a friend in school was pulled out of our classroom and put in a special classroom for a couple of hours every day. He wanted to learn in his own way in the regular classroom and those years of not having that choice were hard for him. As the mom of 3-year-old twins, I dream big for my kids. Part of that dream is that they will never know exclusion or loneliness. My work with the NWDSA has helped open my eyes to sharing that dream with all children, regardless of their learning style or label.

*The Kindergarten Inclusion Cohort is a cross-disability program designed to give parents the skills and tools to advocate for their children with developmental disabilities to be fully included in school. For more information, contact the NWDSA Resourcefulness Center at 503-238-0522. Jodi Collins' website is [www.urban-photography.com](http://www.urban-photography.com).*



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Angela Jarvis-Holland  
Executive Director

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Angela Jarvis-Holland  
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Guiseppe Lipari  
Tonia Albers

For more contact info  
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[www.nwdsa.org](http://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.



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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](http://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

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## Save the Date! **all born (in)**

2012 Cross-Disability  
 Inclusion Conference

April 28, 2012

8:30 AM – 5:30 PM  
 Ambridge Event Center  
 1333 NE MLK Blvd  
 Portland, Oregon 97232

Tools, Networking & Inspiration for  
 Parents and Professionals.  
 information and registration available at  
[www.nwdsa.org](http://www.nwdsa.org)