



# STEPPING UP

December 2012

Issue 18

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

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## *We All Belong* - the making of a documentary

*By Joni DeRouchie*

The *We All Belong* project started a year ago, when I was a second-year film student at Mt. Hood Community College. As part of my practicum class, I was instructed to create a project for a non-profit group. I approached Angela Jarvis-Holland at NWDSA, where I'd been a part-time staff member for a couple of years, and asked her if she'd want to be the subject of a documentary. She jumped at the chance to spread the word about the new Kindergarten Inclusion Cohort and granted me access to a Cohort session and agreed to help arrange interviews with some of the parents enrolled in the Kindergarten Cohort.

Along with two of my classmates, Emily Morris and Matt McKague, I filmed two days' worth of footage, including interview segments with NWDSA staff members, as well as Michael Bailey, President of National Disability Rights Network and Eleanor Bailey, speaker and community advocate. We discussed what segregation means in the 21st century, how it affects children in the long run, and how programs like the Kindergarten Cohort can help parents fulfill their dreams of an inclusive life for their child.

Most special to me were the interviews with the mothers enrolled in the Cohort program, who graciously shared their dreams and fears about their children as they head into kindergarten. Their testimonies struck me as so honest and powerful that I couldn't wait to share the project with others.

Please see *We All Belong* on page 3

## Celebration

Building an inclusive preschool experience for Parker

*By Molly Hulett*

My husband Chris and I have two children, Parker and Lilly. Parker loves cars, dancing, playing music, and also happens to have Down syndrome. When Parker was born three years ago our world changed. Parker was born with pulmonary hypertension on top of his Down syndrome diagnosis; we were working with a huge medical team, and were completely overwhelmed and exhausted.

Once Chris and I were able to talk with each other about Parker's diagnosis, we decided that we were going to treat Parker just like we would treat any of our other children in the future. Together we talked about our hopes and dreams for Parker, and one of those included the dream that Parker would grow up in inclusive educational settings.

Please see *Parker* on page 4





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To be added to our mailing list please visit [www.nwdsa.org](http://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](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 and other disabilities.

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 the back cover  
by Jodi Collins of  
Urban Photography  
[www.urban-photography.com](http://www.urban-photography.com)

## Dear families and friends of NWDSA

By Steve Holland, NWDSA President

Once again, the NWDSA has experienced an incredible year of growth and accomplishments. We have resumed our Reciprocal Learning Community parent trainings, and we are beginning our third class of the Kindergarten Inclusion Cohort parent training program. Open Arms playgroup and Club Upside open gym are regular offerings, as well as various social events throughout the year, and of course our All Born (In) inclusive education conference. We added several trainings throughout the year on subjects related to the All Born (In) conference and making inclusion successful. This year we introduced the *We All Belong* DVD, highlighting the Kindergarten Cohort project. We also created a new set of All Born (In) advocacy banners. NWDSA Executive Director Angela Jarvis-Holland represented our community on the Oregon Public Broadcasting "Think Out Loud" radio program, and spent many evenings volunteering on the Portland Public Schools facilities committee. Abby Braithwaite represented the NWDSA on the Clark County Disabilities Coalition and helped put together the 2012 Candidates Forum on disability issues in Clark County. At the Board level, we worked with community partners to develop an enhanced strategic plan for NWDSA. We also selected a new development chair to help take our fundraising to the next level. You can read more about her on page 6. Information about these events, others news, and links to programs can be found at [www.nwdsa.org](http://www.nwdsa.org).

Our Treasurer Tina Bartley will be moving off the Board at the end of this year. Tina has volunteered many hours over the past few years as our Treasurer, and has been a regular volunteer at social events and the Buddy Walk. Tina has made significant contributions to helping us transition to a more robust accounting system along with the regular duties of a board treasurer. We will miss her presence on the Board, but she will continue to volunteer as her time permits at various NWDSA events. We sincerely thank Tina for her contribution to NWDSA.



Although there is uncertainty as we head into 2013, we are certain of some things. Namely, we will always strive to help our family members and friends live a joyful life and help them find their true path. We will never let go of our goal to have our family members and friends fully included in school and in their community, and we will be there alongside them as they create opportunities to contribute to society and to their own well-being.

We want to thank our staff, our part time office and technical support, our many volunteers, and the many in-kind and financial contributions from so many individuals and organizations in our community. Without your support we could not work together to build a brighter future for our children!

Sincerely,  
Steven Holland

## We All Belong

*Continued from page 1*

Angela was excited about the initial 20 minute-long cut of the video and wanted to share it with attendees of the 2012 All Born (In) conference in April. It was thrilling for me to see the reactions of the participants as they viewed it for the first time, along with a few hundred other parents and educators. The reaction from ABL attendees and others who saw the video at private screenings made me think that maybe my humble class project had turned into something more meaningful than I'd ever anticipated.

I spent the summer re-editing the short; I added photos from Jodi Collins' beautiful photo awareness campaigns and other graphic elements. I was challenged by Angela to find a way to add close captioning, something I'd never done before. With the generous help of NWDSA dad Jonas Hinckley and LNS Captioning, I was able to successfully subtitle the video.

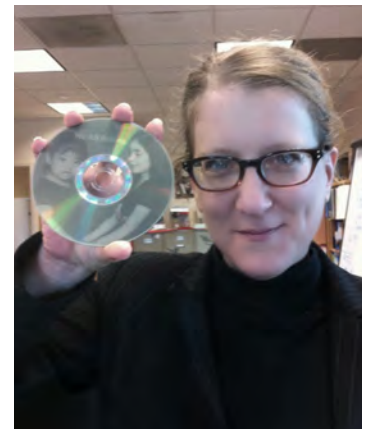
Grant money enabled us to purchase a duplication machine and the necessary equipment to create our own DVD duplication operation at the Resourcefulness Center. As a result, we have a very polished and professional video package completed almost entirely with pro-bono work contributed by talented parents and community members.

Since its release, *We All Belong* has traveled the country, being shared at educational and inclusion conferences, and the feedback has been positive and heartwarming. The DVD was a labor of love that took over eight months to complete and is a fantastic example of what a parent-driven, grassroots movement can do. I would like to extend my thanks to the families who participated and shared their thoughts and experiences with me, and to NWDSA for partnering with me on this (and hopefully future) projects.

*Editor's note: You can purchase We All Belong as part of an "Inclusion Awareness Packet." All profits from the sale of the Inclusion Awareness Pack go directly to funding the Kindergarten Inclusion Cohort. Please visit the new All Born (In) website at [www.AllBornIn.org](http://www.AllBornIn.org) to learn more and buy the DVD.*



*"Kindergarten placements are the front line of the disability rights movement. And this film proves it."  
-Michael Bailey, President, National Disability Rights Network*



The filmmaker with a newly-pressed DVD






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*"The path to inclusion is rarely easy but it is always right!"*

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## Parker

*Continued from page 1*

Fast-forward three years and here we are...the transition to preschool. I never realized how much of a rollercoaster it would be -- lots of ups but also lots of downs. As an Early Childhood Special Education Teacher I work with children with disabilities in inclusive settings, so I always took it for granted that it would be easy to find the perfect preschool for Parker. I also participated in the NWDSA's first Kindergarten Inclusion Cohort when Parker was just two. I was interested in the cohort professionally, so I could help the families I work with, and I also figured it couldn't hurt to start collecting the tools I would need for Parker's transition to kindergarten. I didn't expect to have to put them to use so soon.

Parker has a July birthday, so we started to look for preschools within our community in the spring. Parker was already attending a parent-child class with Chris one day a week at a local school, so we decided to pursue preschool there. When we applied, some teachers told us that they thought Parker should stay another year in the parent-child class because he wasn't "ready" to move to the preschool classroom.

We continued to advocate for preschool for Parker. I was so frustrated at times because I heard things like, "He can't walk up and down the stairs as fast as his peers," "He can't communicate with us," "He still puts things in his mouth."

I didn't know where to turn. I knew Parker had a right to be in that classroom, but I needed support. That's when I turned to the community of support at NWDSA. I emailed Abby and Angela and explained my situation. They were the rock I needed at the time, and they helped support us by linking us to resources and also just being there for us.

We wrote a person-centered plan for Parker that talked about his strengths, which was key in helping them understand that he really was more like the other kids than not. In the end Parker was placed in the preschool classroom. We just had an IFSP review for him and he met a few of his goals already and is talking more than I knew. I continue to be thankful for the staff and community of people that are supporting Parker, and last week I sent an email to his teacher thanking her. She sent an email back, including this line:

*Ahhh, you are so sweet but I think I'm the lucky one to have Parker and all of your family, he is a gift and I recognize that and he is teaching me.*

The path to inclusion is rarely easy but it is always right! Parker has the right to be in a school setting with the peers he will grow up with but sometimes we have to fight for that. I am thankful for the support I get from NWDSA and other parents I have connections with. I would be happy to support any other families that are on this rollercoaster ride. We all need support at times!



## Creating a resource for families facing heart surgery

By Jamie Burch

Hello, my name is Jamie Burch. I am a former NWDSA Board member, and my husband and I have two daughters. My younger daughter, Karley, is an energetic 3rd grader with Down syndrome. When Karley was four months old she had open-heart surgery. My husband and I did not feel like we had a lot of resources or information about what we were going through, and we would have loved the opportunity to connect with another family who had had a similar experience and made it through.

I am working with the NWDSA to create a book of stories for other families whose children are facing heart surgery. It will include stories from local families who have children that have had heart surgery or a cardiac procedure. The booklets will be distributed through the NWDSA, as well as in the offices of pediatricians, cardiologists, cardiac surgeons, and hospitals.

I am very passionate about this project because my family's experience would have been much better if we had met a local family who had experienced what we were going through. It would have prepared us and kept us from feeling so alone, and hearing someone else's story and seeing their child would have been very reassuring. If I had had a resource like this then maybe I could have felt more connected, ready, and reassured.

This is where we can come together to help families who will be where we have been before. If you like the sound of this project and feel your story would benefit other families I would appreciate your support. I would like to collect your story if you are willing to help.

To make this process as easy as possible I am willing to help get your story to the NWDSA in whatever way that works best for you. We could discuss possible talking points or ideas about what you might want to tell others about to get you going; I could type up your story over the phone or Skype and email it to you to edit; you could type up your own story and email it to me to review, or whatever it takes to collaborate. If you have pictures of your child before and during surgery as well as recent ones that you could share that will also be a key component of the booklet.



Even if you aren't sure if your story is worthwhile I guarantee you it will be to someone whose child is facing the same surgery or procedure yours did. Your story is incredibly valuable! I look forward to hearing from you and hope we can work together by sharing your story and pictures of your child.

*Editor's note: The NWDSA will maintain editorial supervision and oversight of this project. We welcome your contributions! Please contact Jamie Burch at 503-704-3883 or [butterflyburch@yahoo.com](mailto:butterflyburch@yahoo.com) for more information.*



*"Hearing someone else's story and seeing their child would have been very reassuring"*





## The 2012 NWDSA Winter Social

The NWDSA would like to thank Nora and her crew at JJ Jump Clackamas for hosting another great NWDSA Holiday Social. Kids of all ages had a great time at JJ Jump, and enjoyed the chance to meet Santa! Thanks, too to Nathan and Eric and EnVision Photography and their team for a great batch of Santa photos. And thank you to Santa Art and all the volunteers who made the day possible.



Thank you all for being a part of our community and our world. From my family to yours, I wish you love, peace and joy in the New Year. This year Daniel told me he wants to go to college and have a girlfriend. Typical dreams for a typical teenager who happens to have Down syndrome. I am so glad to represent an organization working to put foundations under our dreams.







## The NWDSA's new development chair

The NWDSA is excited to introduce Amy Geoffroy as our new development chair. Amy and her husband Kevin have two girls, a cat and a dog. Emily is a seventh grader at Beaumont Middle School, and Abigail, who has Down syndrome, is a third grader at Alameda Elementary School. The Geoffroys moved to Portland two years ago, taking advantage of a new job opportunity for Kevin in healthcare IT management to get away from hectic New Jersey in favor of a more sustainable lifestyle in the beautiful Pacific Northwest. They live in Northeast Portland and love the walkability and community feel of their Beaumont-Wilshire neighborhood. The entire family is happy with the move, and the girls are well ensconced in their school and neighborhood community activities. Emily plays clarinet and saxophone in jazz band, acolytes at St Michael's and All Angels, and is an avid vegan baker. Abigail is fully included in the general education third grade at Alameda, and she keeps busy and active with both ballet and cheerleading.

Amy has been involved as a leader in the Down syndrome and inclusive education communities since Abigail's birth. In New Jersey, she served as president of Network21: Supporting Families with Down Syndrome and as an advisory board member of New Jersey Coalition for Inclusive Education. She supports women with prenatal diagnoses both in person and online through Down Syndrome Pregnancy, Inc. and the BabyCenter DSP board. Amy has worked professionally in non-profit development for four years, first as development associate at Rutgers University and currently as development coordinator for the Oregon Area Jewish Committee, a social justice and human rights organization. She has also worked in event management and nonprofit administration. Amy is excited to put her energy and skills to use on behalf of NWDSA and the families we serve, and we are excited to have her with us!



*Amy is joined on the Development Board by:*

- Sherry and Brett Kucera
- Terry Costello
- Mikki Keller
- Melanie Fallis
- Kristian Burch
- Jennifer Muir
- Becky Adelman

*Together they will work on fundraising, grant writing, special events and community messaging. If you are interested in supporting this work or know of connections that may be useful, please contact Amy at the NWDSA Resourcefulness Center, 503-238-0522*



## The spirit of Portland & SW Washington Buddy Walk Festival

By Angela Frome

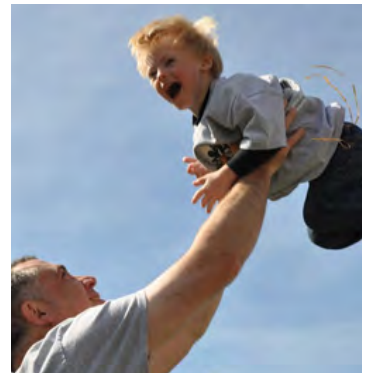
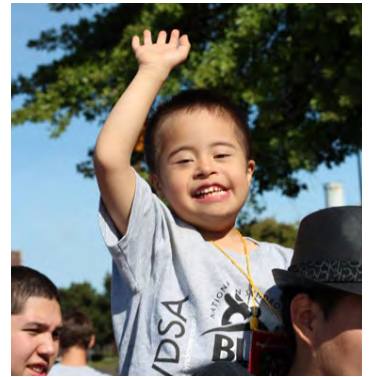
The Buddy Walk has grown into a wonderful event over the last 14 years and has blossomed into a community festival rather than just a fundraiser. Through the years many wonderful people have come along side us from all walks of life to share in the day and take in the wonderful energy that the day brings. The walk has grown from having 100 participants to over 1500 and over 125 volunteers supporting the day!

This Buddy Walk Festival happens because of in-kind donations from local businesses and community members volunteering their time, goods and themselves. This year we had Nora from JJ Jump, who hosts our Winter Social, provide prizes and coordination of games for the kids as well as jumping in to make coffee drinks for folks. Central Catholic High School had over 80 cheerleaders kicking off a great cheer at the start line and working the game booths having fun with the kids.

Brett From Tony Starlight's Supper Club and Lounge was our wonderful emcee and his wife Sherry ran our Silent Auction and Raffle tent of donated items. We had local food vendors including Gustav's, Portland Prime, Cliff Bar and Widmer Brewing Company who give their products and services and who all have employees who love someone with Down syndrome.

The spirit of the day is to celebrate community, have fun and bring joy by inviting more people into our circle whether you know someone with Down syndrome or not. We had a mom, Isis, who brought her salsa dancing group with her; Mikki and her children from Kidz with Ice donated their coffee, snow cone and cotton candy truck to bring us some sweet treats; Lee Farms, where we hold our Summer Social, donated and served fruit from their local business; the 501st Star Wars Legion brought smiles to everyone's faces, a local magician came and entertained us, and several large Buddy Walk teams showed great spirit and pride and helped raise money to support the work.

Another great theme of the day is relationships and the caring and keeping of one another. I always feel great pride, joy and gratitude when I look around the Rose Quarter Commons on Buddy Walk day and recognize that every tent, table, booth, entertainer, volunteer, business leader and family member is here because someone cares about building a community that recognizes the value of every person!





Leo Award winner Paul Carson - Photo courtesy of *The Standard*



Film producer Arthur Bradford and NWDSA members at a benefit screening of *How's Your News & We All Belong*



Open Arms Playgroups are a great way for kids and grown-ups alike to get a little social interaction

## Et Cetera

... Congratulations to Paul Carson!

At The Standard's President's Forum on Wednesday, Oct. 24, Greg Ness presented Paul Carson, IDI training consultant, with the third Leo Award in 2012. Paul was recognized for his volunteer work with nonprofit Northwest Down Syndrome Association in support of the organization's mission.

Being a part of a group making a more positive future for a traditionally marginalized and often undervalued group continues to inspire Paul. "NWDSA is helping us all create an environment in Oregon that leads the way to a brighter and more inclusive future," said Paul. "Not just for our kids, but for all kids."

*Ed. Note: This is an excerpt from a piece originally published by The Standard, where Paul works. The photo is also courtesy of The Standard.*

... Announcing the new All Born (In) website!

We are excited to announce the birth of a new website, designed by Joni DeRouchie as the home-base for the NWDSA's cross-disability inclusion work. We invite you to take a few minutes to visit [www.allbornin.org](http://www.allbornin.org) and let us know what you think. We are thrilled to begin building a resource repository for inclusion in our area and beyond!

... NWDSA Receives Grant from the Spirit Mountain Community Fund

The NWDSA Board would like to thank the Spirit Mountain Community fund for awarding the organization a grant to support media outreach, including work on upgrading the website and the continued publication of this newsletter.

## Events

**Community Drop-In:** Explore our resources, enjoy light refreshments, meet and share with other parents. Every Wednesday, 12 - 2 PM at NWDSA Resourcefulness Center, 11611 NE Ainsworth Circle, Ste 321, Portland, OR 97220

**All Born (In) Drop-In:** Discuss IEP goals and inclusion, and explore our resources. Fourth Wednesday of every month, 5:30 - 7:30 PM at NWDSA Resourcefulness Center

**Open Arms Playgroups:** Join other parents and their children for an opportunity to ask questions, share ideas, and learn from others' experience.

**Portland:** the second Tuesday of every month from 5:30 - 7:30 PM at Resurrection Lutheran Church, 1700 NE 132nd Avenue, Portland OR 97230

**Vancouver:** the third 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.

**Club Upside Vancouver:** All ages event where adults can share day to day life, challenges and triumphs; children can play and develop life-long friendships; and siblings can share their feelings and know they are not alone on this journey. Play equipment and baby toys included, snacks provided and there is no cost to families. Join us on the second Saturday of every month, 2:00 - 4:00 PM, St. Andrew Lutheran Church, 5607 NE Gher Road, Vancouver WA 98662.

## Visibility! More role models with DS are taking the spotlight

By Paul Carson

Recently people with Down syndrome have been taking on much more visible roles in popular media. As the dad of a three-year-old with Down syndrome, it's inspiring to see this increase in visibility. From TV to advertising circulars to the local comic book scene, the faces of people with Down syndrome are becoming more and more common in the media.

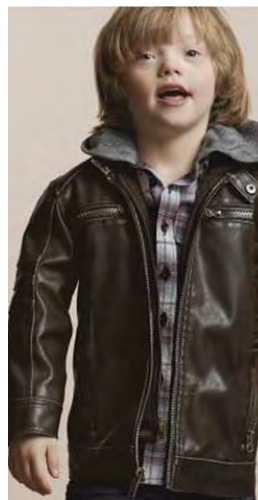
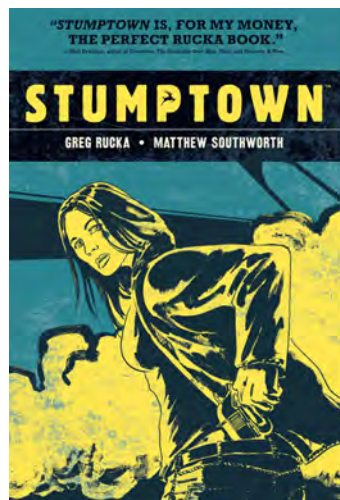
Lauren Potter is the 21-year-old actress who plays Becky on the Fox high school hit *Glee*. Potter grew up loving Disney princesses and staging plays for her family - now she speaks to people all over the country. Series creator Ryan Murphy explains, "*Glee* is about inclusion. It's about a lot of different types of kids who for whatever reason don't fit in."

Luke Zimmerman plays Tom on *The Secret Life of an American Teenager*, a character who holds a fulltime job as an HR manager, charged with firing people because he's the only one strong enough to do what's necessary. With less than 10% of citizens with intellectual disabilities active in the workforce, characters like Tom serve as phenomenal role models.

In Portland comic book sensation Greg Rucka's detective series *Stumptown*, the lead character lives with her brother Ansel - who has Down syndrome, holds a steady job and is definitely the more responsible of the two. Rucka and artist Matthew Southworth did several versions of the character, taking care to get his voice right and depict Ansel in a realistic, matter of fact way. When producers interested in developing *Stumptown* into a TV series suggested changing Ansel into someone who "just stuttered," Rucka realized they didn't respect the character, refusing to consider the change. "He's the moral compass."

Perhaps one of the most visible new role models is a young six-year-old model named Ryan, who's appeared in ads for Target and Nordstrom. Impressively, Target doesn't single Ryan out at all - he's just another ordinary, happy kid, helping redefine what normal is.

By being visible - by being seen -- Ryan and these other wonderful performers and characters are helping expand the stage of opportunities for the next generation of young people as they consider their place in the world. If you look for examples of inclusion - and inspiration - there are more possibilities every day!



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or [www.allbornin.org](http://www.allbornin.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 who experience 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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& Joni DeRouchie

A PDF of this newsletter and past issues are available for download at [www.nwdsa.org](http://www.nwdsa.org)



## Save the Date! all born (in)

2013 Cross-Disability  
Inclusion Conference  
April 13, 2013.

New location! Holiday Inn Airport

Tools, Networking & Inspiration for  
Parents & Professionals

More information & registration coming soon to the brand new website at [www.AllBornIn.org](http://www.AllBornIn.org)