



STEPPING UP

April 2012

Issue 16

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

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Gearing up for All Born "In"

Annual conference set for April 28

Parents, caregivers and professionals register now to attend the seventh annual Educational Best Practices and Cross-Disability Inclusion Conference at the Ambridge Events Center on April 28.

This year's first keynote speaker is Madeleine Will, Director of the National Policy Center of the National Down Syndrome Society. NWDSA Board members Angela Jarvis-Holland and Abby Braithwaite had the opportunity to work with Madeleine during the National Buddy Walk on Washington in late February in Washington, D.C. By making these types of trips it allows the NWDSA to keep up to speed on national policy and make connections with our national representatives as well as continue to provide the latest in best practices information at conferences such as All Born "In."

The other main keynote speaker this year is Robi Kronberg, an experienced consultant, trainer and educator for more than 27 years. She has developed highly effective training materials and has co-authored many articles and book chapters on the topics of differentiated instruction, inclusion and co-teaching.

There are more than 26 different sessions to choose from this year, with topics ranging from iPad applications to how to write an IEP to loving literacy. For more details about the day and to register online visit nwdsa.org. There are limited scholarships available, please call 503-238-0522 to find out more.

World Down Syndrome Day Celebrations

March 21 honors those with 3 copies of chromosome 21

And what a day it was! The day started with a morning appearance on OPB's Think Out Loud radio program, followed by lunch at Laughing Planet's PSU store hosted by store manager and mom Molly Cermak, and wrapped up with a great family celebration at the Old Spaghetti Factory. Big thank yous are owed to Molly and Franz and the rest of the Laughing Planet crew for putting together a great fundraiser. The store was full of beautiful images of our kiddos and a whole community of folks supporting the NWDSA. Thank you also to Dave Miller and Allison Frost of OPB for taking the time to put a great show together, and to Karen Gaffney and Brian Skotko for joining Angela Jarvis-Holland on air. Thank you as well to everyone who called or commented on the show. It was great to celebrate World Down Syndrome Day with such a great message on the radio. And finally, thanks to Elizabeth, Kristy and Michelle for putting together the event at the Old Spaghetti Factory, to Tony Starlight for entertaining the crowd, and to all the families who came out to represent. It is wonderful to have such a vibrant community to celebrate with!

HELP US RAISE \$\$\$ FOR



Northwest Down Syndrome Association
& Celebrate World Down Syndrome Day

20% OF ENTIRE DAY'S SALES
GO TO NWDSA

Wednesday, March 21th • 11am - 9pm
@ Laughing Planet Cafe - PSU

PHONE - IN ORDERS FOR PICK-UP
(503)224-Bean (2326)



Flyer celebrating World Down Syndrome Day at Laughing Planet



Molly Cermak and her father at the Laughing Planet celebration

NWDSA

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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 the front and back cover by Jodi Collins of Urban Photography
www.urban-photography.com

Letter from the Board

By Steven Holland, NWDSA President

The Northwest Down Syndrome Association represents an extremely diverse community. We have all been struck by the news of the recent court decision that awarded a local family who are an ongoing part of our community, \$2.8 million for “wrongful birth” in a lawsuit against the Legacy hospital system.

The NWDSA’s work is fundamentally about civil and human rights. In our work fighting for the rights and dignity of individuals with disabilities it is hard to reconcile our mission with the idea that any person could be deemed “wrongfully born.” We are working on the local and national level with a coalition of groups looking to provide other options to families in this position.

The NWDSA has been working proactively for years in the area of prenatal genetic testing, tackling the issue of how to help the medical community provide accurate, up-to-date information to families faced with a prenatal diagnosis. As a community we need to ensure that more people have current, positive information about our real lives and our children’s potential. We have worked with genetic counselors and other medical providers to provide listening sessions, grand rounds presentations and information sessions on these issues. Genetic testing is a huge growth industry, with new tests for Down syndrome and other genetic conditions in development. We must help ensure that the ethical considerations and relevant resources around informed decision-making keep pace with the advances in medical technology.

Since the news of the lawsuit we have had an upwelling of interest from within our community and outside of it. We have had calls from many people interested in volunteering, and enjoyed the opportunity to work with OPB to create a great Think Out Loud hour-long radio program on living with Down syndrome. You can go to the OPB website under Think Out Loud to hear the broadcast. We have also collected over 30 stories from families about their experience with receiving a diagnosis of Down syndrome. We are working on putting together an event to bring our stories to local hospitals. We, with the help of Madeleine Will from NDSS and other partners, are working to create a dynamic conversation with those involved in genetic testing. We will share latest testing information, research and our knowledge to build on what works and best practices and resources needed for informed decision making.

In every challenge there is an opportunity, and we hope that we can take what has been a difficult moment for our community and work to turn it into change for the good.

Helping NWDSA

Creativity and fundraising go hand in hand

By Abby Braithwaite

Do you ever wonder what you could do to make a difference for the NWDSA? Let me tell you about a family who wondered just that, and stepped up to make amazing things happen.

In the fall of 2009, Bill Fallis, beloved grandpa of Riley and an avid golfer, died unexpectedly. His family decided that they wanted to pay tribute to his life, and his love for Riley, and so the Tee Up for Down Syndrome Golf Tournament was born. For two years in a row Melanie Fallis, together with

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Fundraising

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her daughter Jennifer Johnson (Riley's mom) worked tirelessly to build a wonderful event. They brought together friends, co-workers, and a host of local businesses and were able to raise critical funds that provided the seed money for NWDSA's innovative Kindergarten Inclusion Cohort. Thanks to their work and commitment to inclusion we were able help two dozen families become strong advocates for their children entering school. We are forever grateful to the Fallis and Johnson families for their energy effort and creativity, and it was impressive to watch this motivated group of people bring their web of support together to support the NWDSA and the Kindergarten Cohort. Their work was a clear illustration of the concept that a few committed people can, if fact, change the world.

Unfortunately Melanie and Jennifer need to step away from the tournament this year to focus on urgent needs in their family. If you have participated in the past as a golfer, a sponsor or a cohort member and would like to send a testimony or a thank you, please feel free to mail something to the NWDSA and we will pass it on to Melanie and Jennifer. You can email abraithwaite@nwdsa.org or mail to PO Box 9127, Portland, OR 97207.

The NWDSA is looking for ways to fill the hole that this will leave in our funding for next year's cohort. We will be hosting a meeting here at the Resourcefulness Center on Monday, April 16th, for anyone who wants to get more involved in this vital area of work. If you have ideas or connections that you would like to share, we would like to hear them! If you are worried that you don't have the experience or expertise necessary to put something together, let me share a little secret with you - Melanie Fallis is not a golfer, and she had never created an event like this before. But she was passionate about supporting inclusion, wanted to honor her husband in a way that would have mattered to him, and worked within her network of friends and family to pull off an incredible event. You could do the same thing! Please feel free to call 503-238-0522 for more information.

Events

Buddy Walk 2012: This year's walk is on September 29, 2012 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. Contact Angela Frome at 503-238-0522.

Open Arms Playgroups: Join other parents and their children for an opportunity to ask questions, share ideas, and learn from others' experience. **Portland:** the 2nd Tuesday of every month from 5:30 - 7:30 PM in Bethlehem Lutheran Church, 1244 NE 39th Ave., just off I-84. **Vancouver:** the 3rd 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.

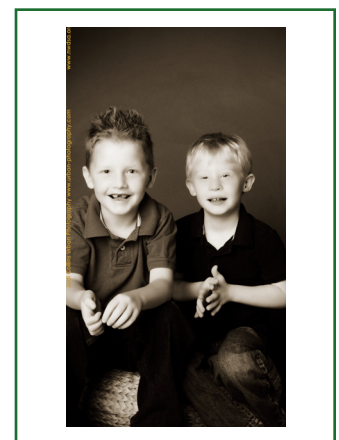
Club Upside Vancouver: All ages event where adults can share day to day life, challenges and triumphs; children can play and develop life long friendships; and siblings can share their feelings and know they are not alone on this journey. Play equipment and baby toys are included, snacks are provided 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.



Bill and Melanie Fallis with Riley at the 2009 Buddy Walk

“The entire program had a clear objective: to get the entire family- parents and children- educated and prepared for the processes and emotions involved with the transition to Kindergarten.”

-- 2011 Kindergarten Cohort graduate



Riley and a friend



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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[NWDSA Newsletter Committee](#)

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Save the Date!



September 29, 2012

Give us a call at 503-238-0522
if you would like to help out in some way