



STEPPING UP

June 2009

Issue 7

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

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From NW to DC

Advocacy on the national level

By Abby Braithwaite

In February, the NWDSA Board of Directors had the opportunity to travel to Washington, DC for a conference that brought together parents and advocates from Down syndrome groups across the country. The conference involved a day and a half of sharing ideas and learning together with other groups, and a day of advocacy on Capitol Hill.

The whole trip was interesting; the highlight of our trip was the day that we spent on Capitol Hill. The day kicked off with a reception hosted by Congresswoman Cathy McMorris Rodgers of Spokane, WA and Congressman Patrick Kennedy of Rhode Island, two of the co-founders of the Congressional Down Syndrome Caucus. We shipped the All Born "In" banners across the country to bring a message of inclusion to the gathering. We also shared All Born "In" calendars with other groups interested in sharing the calendar's powerful message with their Congress people. Members of the Congressional Down Syndrome Caucus graciously welcomed us to DC, and then along with 300 other Down syndrome advocates, we fanned out in the halls of the Senate and the House to meet with our legislators and let them know about some of the issues of concern to our community.

NWDSA board members had the pleasure of meeting with Cathy McMorris Rogers and Jeff Merkeley of Oregon, and we also met with legislative aides from the offices of Congressman Brian Baird, and Senators Patty Murray and Maria Cantwell of Washington State. It was a wonderful experience to sit with these people, introduce our families, and share a bit of our stories. Our adrenaline ran high, and we walked until there were blisters on our feet, but by the end of that

Please see DC on page 6

Celebration

Happy Birthday to Eleanor

By Michael Bailey

On the morning of April 2nd, 21 years ago, I had spent the night learning the meaning of 'cervical block.' It was about 8:30 AM, my brother and I had been with Jonna for nearly 24 hours of horrid labor, which ended suddenly with an emergency C-section delivery. It was a hell of a night and we all felt relief that it was over. A relief lasted less than ten minutes, when a pediatrician we had never seen before said, "Your daughter has an extra chromosome. It's called Down syndrome and if you're interested there is some literature you can read

Please see Celebration on page 9

*"And in the end it's not
the years in your life
that count, it's the life
in your years."*

Abraham Lincoln

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To be added to our mailing list please visit www.nwdsa.org and click on the resources link, or send your mailing info to the address above. There is no subscription fee, but if you would like to make a donation, you may send a tax deductible contribution to NWDSA at the address listed above or use PayPal on our website.

Readers are welcome to submit letters and articles to the address above or e-mail editor@nwdsa.org. Please include your name, address, phone number and e-mail.

All submissions will be reviewed and edited for content and style.

The NWDSA Mission:

Create and nurture a loving and inclusive community celebrating every person with Down syndrome.

NWDSA will accomplish this mission by empowering and supporting families and individuals who have been touched by Down syndrome. We will work to increase education, promote public understanding and acceptance, and toward full inclusion of individuals with Down syndrome in our community.

Opinions published in *Stepping Up* are not necessarily those of the NWDSA

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

Letter from the Board

Introducing our Advisory Board

By *Steven Holland, NWDSA President*

An important milestone was realized earlier this year when the Executive Board of Directors of the NWDSA established our first ever Advisory Board.



Sharon Lewis and Steve with an All Born "In" banner in the Rayburn House building in DC

We are pleased to announce that Duncan Campbell, Rhidian Morgan, Paula Stanovich, Sherry Kucera, Giuseppe Lipari, Heather Durham, Robert Shook, and Gerald Hubbard have been appointed to our Advisory Board. This outstanding group of individuals bring a diverse perspective to our group. The Advisory Board members have professional backgrounds as business executives and owners, artists, educators, health care providers, government leaders, and youth advocates. Most importantly, they know us and our community, and they care deeply about the vision and values of the NWDSA.

On April 28th our Advisory Board convened its first official meeting, where we discussed the ongoing projects of the NWDSA. We outlined the mission of the Advisory Board, which includes building partnerships, leveraging relationships, providing guidance and assistance with fundraising, and assisting with our strategic planning.

The Advisory Board has committed to quarterly meetings, and a free dialogue amongst Board members and our community between official meetings. We deeply appreciate, and sincerely thank these individuals for their investment with NWDSA, and we hope you will appreciate them as much as we do.



Board Member Jen Brandse, US Senator Jeff Merkely, NWDSA President Steve Holland in the cloakroom of the U.S. Capitol Building in Washington DC

Community Voice

A message from Tony Starlight, an entertainer unlike any other

By Brett Kucera

When I was introduced to Daniel, son of NWDSA board members Steve Holland and Angela Jarvis-Holland, I wasn't sure how to interact with him, because after all, he had Down syndrome. Now, I had met their elder son Quinn before (and had similar trepidation because, after all, he was a dreaded teenager) and we got on fine, but no one had warned me his little brother had Down syndrome. Not being prepared, I was left no recourse but to treat



*Eleanor and Tony,
Quinn in background*

Daniel like I would any other kid. I told a few corny jokes and he laughed at some and rolled his eyes at most... just like any other kid. I rubbed his head and it irritated him but he knew there was affection behind it... just like any other kid. And after about two minutes I found him to be mildly annoying... just like any other kid.

The first time my brother put his infant daughter in my arms I was terrified. How do I hold her? Will she break if I'm not careful? There was a fear of the unknown. I soon relaxed and just enjoyed holding her and interacting with another human being. When I met Daniel the same fear of the unknown surfaced. I knew nothing about Down syndrome and didn't know how to interact with Daniel. After the

fear of the unknown subsided and we began interacting like two human beings everything was great.

I think the most important thing for the NWDSA to remember is that people who aren't medical professionals, or family members of someone with Down syndrome, might not really know what it is. Of course, education is the key, but how should an organization educate? I think it's very important to immediately remove any "victim" attitudes. Every person in the world has a unique set of challenges and it is important not to let any one of these challenges define the person. Daniel's challenge may be Down syndrome but it does not define him.

I am honored to be involved with any campaign for educating the general public on Down syndrome. I hope as an entertainer I can help reach people with music and humor. That we can create forums where people who want to learn aren't afraid to ask questions that may seem ignorant. Where they can see and hear someone with Down syndrome speak about their experience. The NWDSA is strong because isn't just a parents' advocacy group, it is an organization dedicated to teaching people how to treat someone with Down syndrome... just like any other person.

Editor's note: Brett Kucera, a.k.a. Tony Starlight is an entertainer and the owner of Tony Starlight's Superclub & Lounge located on NE Sandy Blvd in Portland. His wife is Advisory Board member Sherry Kucera. Please see events for information on a benefit to be held at Tony Starlight's on July 9.

After the fear of the unknown subsided and we began interacting like two human beings everything was great.



Tony Starlight at the NWDSA fundraiser event in January

Family Corner

Encouraging others to expand their vocabulary

By Jonas Hinkley



Archer, young fan of Spiderman

One of the first things I noticed upon becoming a parent of a child with a disability is that a word I'd hardly noticed in my childless life was now suddenly everywhere. I heard it on TV and in the movies, I heard it on my way home from work when I was surrounded by teenagers on the MAX train; it's all over the internet, of course, and when I actually had a spare moment to sit down and read I found it staring back at me from the written page.

It didn't help that I was often reading comics, which, while significantly more mature and well written than when I was a kid, are still primarily written with an ear towards modern slang and the relative youth of their readership. And so the words "retarded" and "retard" were thrown around without a thought.

So I started writing e-mails whenever I came across the words. My goal was not to just berate people into realizing that what they were saying or writing was WRONG and BAD and EVIL, even if that's what I thought. I'm still too cognizant of the fact that a short 19 or so months ago, while it may have been infrequent, my own ignorance might have led me to say something was retarded when I meant "stupid." And it wasn't until Archer, my son, came into my life that I realized how limiting, reductive, and offensive that was — while he may have an intellectual disability, he's in no way not smart. And so my letters would be composed in a way that I hoped was engaging and yet got the point across that the indiscriminate and thoughtless use of the r-word needed to stop.

More often than not, the response, if I got one, would be of the "I'm sorry you're offended, but I just see it differently" variety. But even in those cases, it's my hope that the perpetrators will think about the word the next time they use it.

And then there was All-Star Superman issue #11. In one of the opening pages, the villain of the piece, Lex Luthor, calls his jailers "knuckle-dragging retardards." Well, not only was this pretty horrifying to me, but as this is one of DC Comics' flagship titles, and one that is specifically promoted as being great for new readers, I couldn't quite believe that using this word was acceptable to their editorial office. And so I wrote to the publisher and editors with what I thought was a pretty reasonable request to not use that word.

A week later, I got a response from Paul Levitz, the publisher, who agreed with me that this was not acceptable use of language in their publications. He stated that he and the editors would make sure that this was changed prior to the publication of the trade paperback featuring this issue. This was much more than I expected, and I'm happy to report that DC followed through; in the most recent publication of the collection, the r-word is nowhere to be found. This means that someday Archer and I can read what was otherwise a pretty great Superman story without either of us having to cringe at the unfortunate use of the r-word. And I guess it shows that no matter how insignificant the action, it's possible that your voice will be heard and that change — even if it's slow as molasses — can occur.

...the indiscriminate and thoughtless use of the r-word needed to stop.

Buddy Walk News

Be a part of the action

From the Board of the NWDSA

It's hard to believe it's already time to start thinking about Buddy Walk. We have set the date for September 26th, and we are getting ready for our kick-off committee meeting. If you are interested in joining the group that helps put this great event together every year, we would love to have your help. We meet twice a month for dinner and strategizing, and we can use all the help we can get. Contact Kyle at 503-238-0522 for more information, and see Event section of this newsletter for more details on meetings.

If the committee isn't for you this year, then you can start thinking about building your team. Every year we seek to have a bigger crowd than the year before, and we are always excited to see new faces at the walk. Bring your friends and family, your classmates and neighbors, and help the 2009 walk be bigger than ever.

Buddy Walk is a community event, and also a fundraiser. If you know of any local business that might be interested in sponsoring the walk this year, please get in touch with Angela Frome at afrome@nwdsa.org so that we can get them a sponsor pack. We have sponsorship levels to fit all sizes of business, so be creative and think of anyone who might be in a position to help out this year.

We are excited to be moving forward, and look forward to your participation in the planning and the event!

Compassion and Solidarity

Difficult times bring us all together

From the Board of the NWDSA

While this has been a year of successes and celebration in many of our families, it has also been a year of intense sadness for some families in our community. The loss of 13-year-old Austin Sheely and 16-year-old Nathan Vredevelt hit our community hard, and the board of the NWDSA would like to send our deepest condolences to the families of these two boys. We work so hard to help our kids be successful, and the heartbreak in lives cut short is indescribable.

Austin passed away in January due to complications of leukemia treatments. Austin is survived by his parents, Wes and Sunday, and his two brothers, Wes Jr. and Blake. Austin's mom, Sunday, was instrumental in forming the Northwest Down syndrome parent support group, which went on to become the Northwest Down syndrome Association.

Nathan died after being struck by two cars outside the Rose Quarter where he was attending a Trailblazer basketball game with family and friends last March. The Trailblazers, in an effort to assist the family with medical bills, hosted a collection at one of their games that generated more than \$21,000 in cash donations. Nathan is survived by his parents, John and Pam, and a sister and brother, Jessie and Benjamin. Nathan's mom, Pam, wrote *Angel Behind the Rocking Chair*, an inspirational book about raising a child with Down syndrome.



Get your team together now

Join the Buddy Walk Committee! See the Events section and back page of this newsletter for more information.



Austin Sheely at the Buddy Walk in 2008

DC

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If you want a different vision for the future of your child, you must will the necessary means to achieve that vision.

long, invigorating day, it was clear that we experienced just a small taste of the work that goes on in DC on behalf of our community every day.

In the midst of our day on the Hill, we had the good fortune to stop and have lunch with Sharon Lewis. Many of you may remember Sharon from her days as an advocate on the state level here in Oregon. In 2007, Sharon was invited to Washington, DC on a Kennedy Fellowship, and is the Senior Disability Policy Advisor for the House Committee on Education and Labor. She has become a very well regarded advocate, and we were glad for the chance to sit with her and get some pointers on the workings of our Federal Government. It was also nice to take a few minutes to catch up with an old friend.

We also enjoyed crossing paths with Madeleine Will, director of the Policy Center at the National Down Syndrome Society. Madeleine has been working as a disability advocate for 36 years, and she recently took a few minutes to talk with me about her journey and her experiences as a mother and as an advocate. Like many of us, Madeleine began working on disability advocacy after the birth of her oldest son, John, who was born with Down syndrome. She started as a volunteer, but as someone with an interest in the world of public policy, she soon realized that she had found a career that suited her well.

Madeleine's career spans almost 40 years, and a generation's worth of changes. She was present and involved on several pieces of ground-breaking legislation that improved the lives of individuals with disabilities. She worked on the state level in Maryland to pass one of the first laws in the country legislating community-based services for adults with disabilities, and at the federal level, she has worked on IDEA, ADA and, most recently, the Kennedy-Brownback law, which requires doctors to give current information when presenting parents with a prenatal diagnosis of Down syndrome.

I could fill pages with stories from my conversation with Madeleine, but I will leave you with a few final thoughts. Madeleine said the goal in her work is to see our society reach a better understanding of the positive, affirmative contributions that individuals with disabilities make to our families and communities. This vision keeps her working tirelessly to find partners who share her focus and drive.

When asked what advice she would give to someone like me, who is just starting out in the advocacy world, she said, "If you want a different vision for the future of your child, you must will the necessary means to achieve that vision. One way to get there is through the advocacy and public policy channels... Even if you don't like it and aren't comfortable, advocacy is something you can learn to do. Nothing is more powerful than responding to an action alert or talking to an elected official."

I am grateful that the NWDSA has given me the opportunity to start to explore the world of advocacy, and I am also incredibly moved when I think of the work done by parents and self-advocates who have come before me on this path. Mostly though, I am grateful to my daughter for giving me the drive and conviction to fight for the change that I know is possible in this world.



Abby Braithwaite and Representative Patrick Kennedy (D-RI)

Growth Through Sharing Stories

Reflections from our Executive Director

By Angela Jarvis-Holland

Summer is just about upon us, and I think we are all ready for it; as the seasons change I always like to take a minute to reflect back on all the important events of the year. As a family we have enjoyed holidays, birthdays and celebrations, and the NWDSA has also had a full calendar of events, socials and conferences.

Our fourth annual All Born “In” cross-disability inclusion conference was a huge success with over 200 attendees! We had an overwhelmingly positive response with the evaluations, showing we met a lot of needs with the program and speakers we provided. Many thanks to those who supported the conference and partnered with us to make it happen. David Pitonyak, one of our keynote speakers, brought a mixture of wisdom, knowledge and stories to share about behavior. We also heard from Janice Fialka about her son’s journey to college, a story that widened our horizons for our children.

These stories are what stick with us the most, and remind us of the importance of our own family stories. I hope that the work of the NWDSA helps provide an empowering context for our stories, and a way to frame them that can reveal the strength and pride of our community.

We will be starting a second newsletter this year to reach out to the wider community with our cross-disability, community inclusion message. This will be a place where we can share powerful strength-based stories from families and staff who want a more inclusive world. This will sit under the umbrella of the NWDSA as a part of our All Born “In” awareness, advocacy and outreach work.

We are also busy working on an outreach plan for our New Parent Guide and the education work we do with hospitals about Down syndrome. Our roots are in the Down syndrome community; it is our home base and what continues to motivate all of our work. It is the love of a child with Down syndrome that brings us together, and we want social justice for all children.

Come find out more about the work at our Down syndrome community

drop-in sessions which we will be hosting each Thursday from 12:30 - 2:30 PM. We will also host monthly cross-disability All Born “In” sessions the 4th Wednesday of every month, from 5:30 - 7:30 PM. Both sessions will be at the NWDSA Resourcefulness Center at 6826 NE Glisan. Any time we can widen our circle and share more of our resources we all benefit. We would love to connect with more of you, share a tea or coffee, and hear your family stories.



The Board of the NWDSA on the steps of the capital building in Washington DC

It is the love of a child with Down syndrome that brings us together, and we want social justice for all children.



Board Members Angela Jarvis-Holland, Angela Frome, Jen Brandse and US Representative (D-WA) Cathy McMorris Rodgers

Events

Portland Open Arms Playgroup: Join other parents and their children on the 3rd Friday of every month from 10 - 11:30 AM at the Rainbow Preschool in Bethlehem Lutheran Church, 1244 NE 39th Ave. in Portland, just off I-84. A great opportunity to ask questions, share ideas, and learn from others' experience. For more information contact Jamie Burch at 503-704-3883 or Abby Braithwaite at 360-887-0684.

Vancouver Open Arms Playgroup: We are currently meeting at Church of the Good Shepherd, 805 SE Ellsworth Road, Vancouver, WA 98664. Join us every month on the 3rd Thursday from 5 - 7 PM; dinner will be provided. For more information see contact info for Portland Open Arms listed above.

James Bond Night Benefit: Fire up the Aston Martin and cruise on by for a special benefit on July 9th at Tony Starlight's Supperclub & Lounge at 3728 NE Sandy Blvd Portland, OR 97232. Dress up as your favorite 007 character, SPECTRE members welcome. Visit www.tonystarlight.com for more info.

Down syndrome community drop-in session: Join NWDSA Board Members for a casual afternoon exploring our resources and getting to know other parents. We will meet every Thursday, from 12:30 - 2:30 PM at the NWDSA Resourcefulness Center, 6826 NE Glisan Street, in Portland. Enjoy light refreshments and a chance to share stories and ideas. Please RSVP at 503-238-0522 or to Angela Jarvis-Holland at ajarvis-holland@nwdsa.org.

All Born "In" cross-disability inclusion drop-in session: Join us on the 4th Wednesday of every month from 5:30 - 7:30 PM to discuss IEP goals and inclusion, and explore our resources. For location and contact info, see DS community drop-in session listed above.

Buddy Walk Committee Meetings: Join us on the 2nd and 4th Tuesday of every month for a fun evening of planning and strategizing. The first meeting will take place at the NWDSA Resourcefulness Center on Tuesday, June 23rd, from 6:30 - 8:00 PM. Light dinner will be served. For more information contact Kyle at (503) 238-0522.

Et Cetera

... On June 5th, board members Angela Jarvis-Holland and Abby Braithwaite were invited to present at a Grand Rounds at OHSU in front of a group of Ob/Gyns on the subject of prenatal genetic testing for Down syndrome. They worked with OHSU genetic counselors Cori Feist and Gwen Fraley and self-advocate Karen Gaffney to present the most up-to-date information on the issues surrounding genetic testing, including the controversy around the launch of a new test that would offer results to pregnant women early in the first trimester. The focus of the NWDSA presentation was to provide information on Down syndrome today, and to discuss the need to provide expectant parents with all the information necessary to make an informed choice about their pregnancy when faced with a prenatal diagnosis. We enjoy these opportunities to collaborate with health care professionals to educate and inform about relevant and important issues. This work is made possible in part by a generous grant from the Walmart Foundation to support our work around awareness, health-care, and public policy. If you are interested in this work, please feel free to contact us at 503-238-0522 with questions and thoughts.



Shaken not stirred



*Chloe, Karen, Adara
(the triple threat)*

Celebration

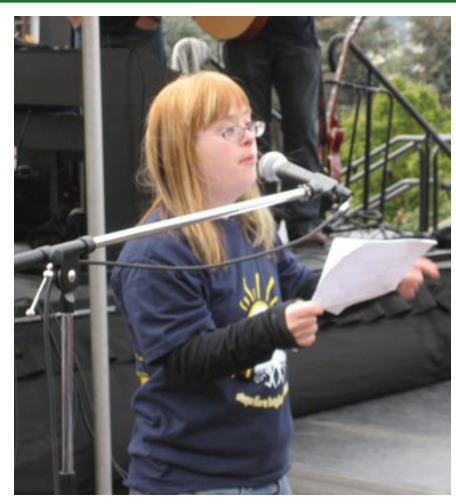
Continued from page 1



Eleanor charming Gov. Kitzhaber 16 years ago

before you leave the hospital.” And he handed the tiny swaddled bundle back to me. And with those words we felt that our world had come crashing down. And it did. But right now in the room next to me that very person – that tiny, swaddled bundle – is asleep surrounded by dozens of fresh red roses and full of happiness and excitement. It is funny how what seemed so big and scary at the time, in reality turns out just to be the path your life has taken.

On April 2nd of this year, my daughter Eleanor turned 21, a landmark in her life. And in ours. And her presence in our lives and in this world now seems completely positive and wonderful. Her mother and sister were in Tennessee for the US High School Chess Championships on her birthday, which meant that I alone – for once – was the final arbiter of what is appropriate. After her birthday fancy restaurant dinner with her now suddenly under-age boyfriend, we took him home and then went to a British Pub nearby where I had the pleasure of buying her first ever beer and watching her launch herself into the official world of being an adult. What a pleasure.



Eleanor can often be found making motivational speeches at both the local and national level. In the photo above, she is speaking at the 2007 Portland Buddy Walk.

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For more contact info
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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.



northwest down syndrome association

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A Message from the NWDSA

As proud parents to children with Down syndrome, each board member of the NWDSA has firsthand experience with the joys and the hardships of raising 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 al 971-570-0942 o Sheyla Hirshon 503-239-1509



e-version of this newsletter and past issues available at www.nwdsa.org

Please Recycle



this newsletter

[NWDSA Newsletter Committee](#)

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Nancy Korf, Kim Jarvis
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In order to make another great Buddy Walk happen, we need your help. The committee is a great chance to get more involved in the work of the NWDSA. Join us on the 2nd and 4th Tuesday of every month from 6:30 - 8:00 PM for a fun evening of planning and strategizing. We will meet at the NWDSA Resourcefulness Center. To join the committee, or discuss other Buddy Walk Volunteer options, please contact Kyle at (503) 238-0522.

