STEPPING UP

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PUBLISHED BY THE NORTHWEST DOWN SYNDROME ASSOCIATION

CELEBRATING EVERY PERSON WITH DOWN SYNDROME

INSIDE THIS ISSUE

Taking our Message to Washington

Listening Session with Representative McMorris Rodgers

By Abby Braithwaite

On August 18th, five NWDSA representatives joined U.S. Representative Cathy McMorris Rodgers of Eastern Washington for a conversation on prenatal testing. The NWDSA led a diverse group in a dynamic discussion of the medical, ethical and financial implications of prenatal testing for Down syndrome and other genetic conditions.

Congresswoman McMorris Rodgers and her husband Brian are the parents of 17-month-old Cole, who has Down syndrome. In May of 2008, Rep. McMorris Rodgers joined with three other members of Congress to form the bi-partisan Congressional Down Syndrome Caucus to bring attention to issues affecting individuals with Down syndrome and their families.

The NWDSA's relationship with the Congresswoman began when Jamie Burch sent her a New Parent Guide just after her son was born. When the All Born "In" photo gallery was in Olympia in March, I met Jamie Herrera, my representative in the Washington State House of Representatives, who is a former aide for Rep. McMorris Rodgers. Rep. Herrera offered to help connect us with the office of the Congresswoman. After phone and e-mail correspondence with staff in Washington, D.C., Angela Jarvis-Holland met with Rep. McMorris Rodgers

Please see *Message* on page 7

Celebration

Portland Buddy Walk Past to Present

By Angela Frome

As summer moves into fall, Buddy Walk preparations are moving into high gear. It's a lot of work, but it's a labor of love, and it is exciting for me to work on this year's Buddy Walk committee, planning our 10th anniversary celebration. I participated in the first Buddy Walk, and it is incredible to reflect on how far we have come since our first gathering in 1999.

The Portland Buddy Walk began when a small group of parents, led by Sunday Sheeley, launched a tradition to bring families in Portland and Southwest Washington together every fall to celebrate and create Down syndrome awareness. While there was not an organized group supporting individuals with Down Syndrome in the area at that time, these parents decided to put their heads and hearts together to create the first Buddy Walk. Sunday Sheeley's passion and commitment were instrumental in making that first walk possible.

Please see *Celebration* on page 5

> *"The first principal of nonviolent action is that of noncooperation with everything humiliating."*
>
> *Cesar Chavez*

NWDSA
northwest down syndrome association
Resourcefulness Center
6826 NE Glisan St.
Portland, OR 97213

Mailing Address
PO Box 9127
Portland, OR 97207

www.nwdsa.org
503-238-0522

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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

Wrapping up the Summer

By Steven Holland, NWDSA President

As we get our kids off to school and the days draw shorter, it's a good time to take a moment to reflect on the events of the summer. Eleanor Bailey and Jamie Burch organized a huge rummage sale that funded the amazing Barnyard Social hosted by this dynamic duo. Many families braved one of the hottest days of the year and had a great time. In July, the All Born "In" photo gallery was featured at a First Thursday event at Portland City Hall and remained on display for the entire month. Mayor-elect Sam Adams, Commissioner Dan Saltzman and other City Hall staff joined a rowdy group of flag-waving revelers who celebrated these beautiful images. In August we traveled to Spokane to share our concerns regarding genetic testing with Washington 5th District Representative Cathy McMorris Rodgers.

We are proud to create these opportunities, from fun socials, to awareness work, to reaching out to our government in Washington, D.C. As we look toward the fall, there are many exciting projects in the works. We thank you, our community, for your steadfast support, and always welcome you to join hands with us and work alongside us on this journey!

As the seasons change, the board of the NWDSA has been changing too. We are sorry to say goodbye to two of our board members who resigned over the summer. Christy Reese served as Treasurer for the past year, and Whitnie Trost has been our Buddy Walk Chair since 2005. We are thankful for the time they contributed to the mission of the NWDSA and wish them and their families the very best. Fortunately board member and RLC Chair Jen Brandse has stepped in on an interim basis to serve as Treasurer.

Beginning in September, the NWDSA Board is proud to announce the appointment of Angela Jarvis-Holland as Executive Director of the NWDSA. Angela's success in establishing the Reciprocal Learning Community, co-founding the All Born "In" Conference, her results in fundraising, and her unsurpassed ability to create partnerships, make her the natural choice for this position. She also has many years of professional experience and advanced education directly related to her role as ED. She has a degree in nursing, a double major in sociolgy and psychology, and a vocational master's degree in youth and community studies and nonprofit management. We are excited to work with Angela in this new capacity.

Last but not least, we eagerly await our 10th Annual Buddy Walk. Jamie Burch is our BW Coordinator this year, and we have a great group of volunteers who are pitching in so we can really get down and boogie! Volunteers have been signing up musicians and entertainers, creating flyers, running ads in magazines, recruiting big name sponsors, and canvassing for goodie bag donations. It's not too late to join in the fun! Each of these volunteers is not only helping out the NWDSA, they are also building meaningful friendships. If you would like to be a part of this work, please contact us.

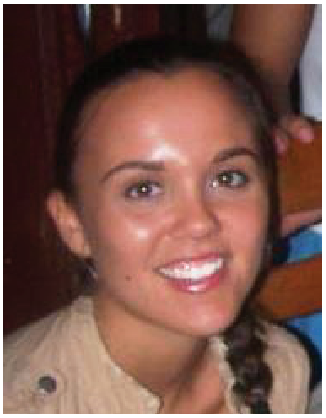
One last note – we want to raise the ante this year around Down syndrome awareness at this year's Buddy Walk. If you have connections in the media please help us get connected immediately so we can get the word out. Call us at 503-238-0522. See you at the Buddy Walk!

Voz de la Comunidad

La Vida está Llena de Sorpresas

By Jessica Montás

Editor's note: The NWDSA is very excited to have the help of Jessica Montás for this year's Buddy Walk. Among other talents, Jessica brings a strong connection to Portland's Hispanic community. We will be running occasional bilingual articles in Stepping Up in an effort to provide greater outreach to the Hispanic families in our community.



Jessica Montás, one of the members of this year's Buddy Walk committee

Cuando yo tenía 13 años, mi mamá me asignó para ser una consejera en el campamento Ky-O-Wa. Campamento Ky-O-Wa es el único campamento local que incluye a todos los ninos, a pesar de su nivel de capacidad. Mi mamá pensó que esto seria una buena experiencia para mí.

Como consejera, yo tenía la responsabilidad de ayudar a los niños en actividades como natación, artesanía, y otros juegos. Todos los niños fueron buenos, pero una en particular se destacó entre el resto. Su nombre era Eleanor Bailey, una niña de once años que tenía síndrome Down. No quería solamente ser su consejera, quería ser su amiga. Por eso siempre traté de estar cerca de ella. Como todas las vacaciones del verano, terminó tan pronto como empezó. Nunca vi a Eleanor después de ese verano pero nunca la olvidé.

Después que me gradué de la escuela secundaria en el 2004, yo fuí a la Universidad de Western Oregon en un pueblo pequeño que se llama Monmouth. Aunque adoro esta Universidad, siempre me siento aislada, con pocas oportunidades a tener experiencia con diversas poblaciones. Cuando regresé a Portland este año para las vacaciones, yo decidí a buscar oportunidades de ser voluntaria con personas de necesidades especiales. Yo estaba muy contenta cuando encontré a la Asociación Noroeste de Síndrome Down por el Internet. Un poco después, aprendí acerca del comité de la Caminata de Amigos y yo sabía que esto era exactamente lo que buscaba.

Yo estaba un poco nerviosa cuando visité la oficina de NWDSA la primera vez, pero todos me saludaron con una sonrisa y eran muy amables. Antes que empezó la reunión para la Caminiata de Amigos, entró una joven muy linda que reconocí inmediatamente, era Eleanor Bailey. Cuando ella se dió cuenta de que yo era una nueva participante, ella se presentó a mi. Yo le dije que nos habíamos conocidos casi diez anos antes en el campamento Ky-O-Wa. Ella no me reconoció pero estaba emocionada al conocerme otra vez. Estoy agradecida que me he reunificado con una amiga que pensé había perdido. Hemos trabajado juntas en planear la Caminata de Amigos y estoy segura que estoy exactamente donde debo estar.

A group of happy campers at camp Ky-O-Wa

Community Voice

Life is Full of Surprises

By Jessica Montás

When I was thirteen, my mother signed me up to be a junior counselor at Camp Ky-O-Wa. Camp Ky-O-Wa is the only local inclusive day camp, welcoming all children, regardless of their level of ability. I guess my mother thought that this would be a wonderful experience for me, and she was right.

As a junior counselor, I had the responsibility of engaging campers in activities such as swimming, arts & crafts, and outdoor games. I liked every camper, but one stood out among the rest. Her name was Eleanor Bailey; a fun-loving 11-year-old girl with Down syndrome, whose smile truly warmed my heart. I didn't just want to be her counselor; I wanted to be her friend, and therefore made extra efforts to be around her. Just like every summer vacation, it was over just as quickly as it began. I never saw Eleanor again after that summer, but I never forgot her.

For more information on camp Ky-O-Wa, check out the Portland Parks & Rec website. Interested in volunteering for the Buddy Walk? Call us at 503-238-0522

After graduating from high school in 2004, I went off to Western Oregon University, in a small town called Monmouth. Although I love the school, I often feel isolated, with limited opportunities to experience diverse populations. Knowing I would be back in Portland for the summer, I decided to search for volunteer opportunities that focused on people with special needs. I went onto Google and typed in "down syndrome Portland, OR," and quickly found the Northwest Down Syndrome Association. I was ecstatic about my finding and immediately requested to be on the mailing list. Soon after, I learned about the Buddy Walk committee and knew this was exactly what I was looking for.

I was a little apprehensive about my first visit to the NWDSA office, but was greeted with smiling faces and a warm welcome. Just before the meeting began, in walked a beautiful young woman who I recognized right away; it was Eleanor Bailey. Noticing that I was a newcomer, she introduced herself. I told her that we had actually met before, almost ten years ago at camp Ky-O-Wa. Although she didn't remember me, she was excited to have me join the committee and insisted that we had some serious bonding to do. I am truly grateful to have been reunited with a friend I thought I had lost. After a summer of hard work on the Buddy Walk committee, and a couple ice cream dates with Eleanor, I know I'm exactly where I am supposed to be.


Emma & Grace, two of our young volunteers, were in charge of selling cookies at the rummage sale.

Family Corner

What's your story?

By your name here

This issue of *Stepping Up* is giving Family Corner the day off so we could have some extra space for Jessica's bi-lingual piece. If you, or someone in your family, would like to contribute a story for this otherwise regular feature, please email your story of 500 words or less to editor@nwdsa.org. We love to hear more from our community, so don't be shy!

Buddy Walk News

10 Years and Going Strong

An Invitation from the Board of the NWDSA

As you can probably tell from the pages of this newsletter, we are excited about this year's Buddy Walk. Help us spread the enthusiasm and bring in some new faces to boogie down and celebrate our 10th anniversary. There will be two live bands – Bureau of Standards and Conjunto Alegre – new games for the kids, tasty munchies and more. The Rose City Rollers will mingle with the Jedi forces, and a Hula troupe will sway their hips with a team of local mascots.

The pledge forms have gone out in the mail, but if you would rather sign up online, head on over to buddywalk.kintera.org/nwdsa to register, build a team or make a donation. Even if you can't be at the walk, you can form a virtual team to raise money for all the important outreach and advocacy work of the NWDSA.

One of the best things about this year's Buddy Walk is the tremendous support we have received from volunteers. We have a fantastic committee of creative and committed individuals planning and organizing this year's walk. We could not have done it without this crew. If you see any of these individuals at the walk, thank them for their time and hard work, and ask them about just how much fun it is to work with us. We are always in need of more volunteers to help with events, outreach and general, day-to-day office work. Bring out your hidden talents and give us a call at 503-238-0522 to talk about how you can get involved.

The 2008 Buddy Walk will take place on Saturday, October 4th at the Rose Quarter. See the back of this newsletter for a parking pass, which is also available on our website, or avoid parking and take the MAX.

Celebration

Continued from page 1

The 1999 Buddy Walk was co-sponsored by the Willamette Valley Down Syndrome Association. With a chartered bus full of people and a fleet of minivans carrying food and supplies, 150 Portlanders headed down the freeway to Salem. The Salem walk was small, but it was our first taste of what a small group of parents could do if we set our minds to something.

With the 2000 Buddy Walk, we found our Portland home at the Rose Quarter Commons. The walk was organized by a handful parents sitting around a kitchen table volunteering their time and ideas. That first Portland walk drew about 350 participants, and set the stage for the years to come. Since then, the Portland Buddy Walk has grown to attract around 600 people. We have been joined by public officials from Portland Mayor Vera Katz to U.S. Senator Gordon Smith. Every year self-advocates and community advocates, parents and community members share their stories and help build the tradition that a small group of parents back in 1999 dreamed about.

Since those early days, the small group of committed parents has evolved into the NWDSA, and their dream of creating an important annual tradition has blossomed into the Buddy Walk as we know it today. The NWDSA would like to send a special thank you to Sunday Sheeley and the other parents involved in those first walks. Without your belief in an idea, and the work you put into seeing it through, we would not be coming together this year with a committee of more than 20 volunteers to celebrate our 10th anniversary Buddy Walk.

Sunday Sheeley at the 2002 Buddy Walk

Events

Portland Open Arms Playgroup: Join other parents and their children on the third 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 third Thursday from 5 – 7 PM, dinner will be provided. For more information see contact info for Portland Open Arms listed above.

Buddy Walk 2008: Invite your friends and neighbors and join us in celebrating the 10th anniversary of the Portland and SW Washington Buddy Walk on October 4th at 10 AM at the Rose Garden Arena. Check out alegremusic.com and bureauofstandardsbigband.com to get a preview of our entertainment for the day. If you plan on driving, bring the parking pass on the back of this newsletter. The Rose Quarter is also easily accessible by the MAX. If you would like to volunteer, please contact the NWDSA at 503-238-0522.

Hang out with Darth Vader at the Buddy Walk

Et Cetera

... All Born "In" photo gallery update: The gallery continues to make appearances around Oregon and Washington. The exhibit spent July at Portland City Hall, with a fabulous First Thursday event featuring live music by the Reggae Allstars. Thanks to Mayor-elect Sam Adams and his office for making this event possible. Special thanks to Pollyanne Birge for coordinating the evening. On August 18th, five banners made the trip to Spokane to meet with Congresswoman Cathy McMorris Rodgers at the genetic testing listening session.

... We want to send a huge thank you to Eleanor Bailey for her help planning and coordinating the Barnyard Summer Social at Old MacDonald's farm in Corbett on August 16th. Thanks also to all the volunteers who helped make the day go so smoothly. We had over 200 people in attendance, and the heat didn't stop anyone from having a great time. There were pony rides and hay rides, animals to talk to, good food and fun music down in the shade. Eleanor has been a wonderful addition to the office, and we hope she is able to continue working with us in some capacity as she moves forward in her life.

Chloe hangs on during a hay ride at the Barnyard social

... The Congressional Down Syndrome Caucus was formed by a bipartisan group of legislators in Washington, D.C. "The mission of the Congressional Down Syndrome Caucus is to educate members of Congress and their staff about Down syndrome. The Caucus will support legislative activities that would improve Down syndrome research, education and treatment and promote public policies that would enhance the quality of life for those with Down syndrome." For more information visit Rep. Cathy McMorris Rodgers' website at mcmorris.house.gov/0805DownSyndromeIndex.shtml. Call or e-mail your U.S. representative and ask if they have joined the Caucus. If they haven't, please encourage them to do so. You can find out who your representative is and their contact info at www.usa.gov/Contact/Elected.shtml.

Message

Continued from page 1

to discuss a variety of issues, including genetic testing. The Congresswoman expressed interest in learning more, and so the August listening session was arranged.

The meeting was a chance for Rep. McMorris Rodgers and her staff to hear directly from parents and professionals about genetic testing and its implications for our community. Cori Feist, a genetic counselor at OHSU, spoke about the history of genetic testing, the current use, and where testing may go in the future. Father Robert Spitzer, President of Gonzaga University in Spokane, discussed how ethical concerns around genetic testing might affect both public policy matters and decisions made by individual families. Two years ago the NWDSA commissioned a study from PSU graduate student Abi Coatney about the attitudes around prenatal diagnosis in the medical arena. Everyone who attended the listening session went home with a copy of this thought-provoking study.

As with all of the work of the NWDSA, the parents and self-advocates sat firmly "in the driver's seat" for this meeting. This value is at the core of all that the NWDSA does; we believe the most effective advocacy is achieved through partnerships between empowered parents and enlightened professionals working within a best practices framework.

In preparation for the meeting, we asked community members to share the story of their child's diagnosis. We presented each participant with a packet of these stories, so they could go home and read first-hand accounts from the true experts, the parents who have lived through the experiences we discussed. As usual, community advocate Eleanor Bailey stole the show with her Power Point presentation about living with Down syndrome.

Whether we are parents sharing our stories with friends or in the media, self-advocates promoting awareness at school or in the community, or a Congresswoman on the national stage, we are all in a position to work for positive change, and should not underestimate the power of our own stories. In the face of alarming statistics around pre-natal testing and abortion rates, it is important that each of us takes a minute to think about what we can do to promote Down syndrome awareness. Everyday advocacy is where change begins. If you are interested in joining with the NWDSA for this exciting and important work, please contact Angela Jarvis-Holland at 503-238-0522 or ajarvis-holland@nwdsa.org.

Cathy McMorris Rodgers and Angela Jarvis-Holland

NWDSA
northwest down syndrome association

Resourcefulness Center
6826 NE Glisan St.
Portland, OR 97213

Mailing Address
PO Box 9127
Portland, OR 97207

www.nwdsa.org

503-238-0522

For more contact info
please visit
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.

NWDSA
northwest down syndrome association
PO Box 9127
Portland, Oregon
97207

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 entire 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

BUDDY WALK™ PARKING PASS

Parking at the Rose Quarter is available for $2 with this pass. $10 without pass.

This pass is available to anyone attending the Buddy Walk on October 4, 2008

NWDSA
northwest down syndrome association

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

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The NWDSA would like to thank our new community partner, Printing Solutions, for donating part of the printing costs of this newsletter.

NWDSA Newsletter Committee
Editors: Abby Braithwaite,
Nancy Korf, Kim Jarvis
Production & Design: Jen Brandse