



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

TVDSA Newsletter

Newsletter Editor: [Celena Auger](#)

October 2013

In this Issue

October is National Down Syndrome Month.

This month's newsletter has a goal of "inspiration." Included is an article of change for individuals with Down syndrome compared to a decade ago, and information about the new National Down Syndrome Registry.

We encourage you to take 4 minutes to [watch the video](#) of animated, articulate, Megan Bomgaars in her message of "[Don't Limit Me!](#)" Be warned - you may need a tissue nearby.

Monthly and archived TVDSA newsletters are available on our website at: www.idahodownsyndrome.org for viewing and sharing.

Have you **Marked Your Calendar?** The TVDSA 11th Annual Buddy Walk is **October 12th**



The TVDSA Buddy Walk will be held Saturday, October 12th at 11:00am. All ages and abilities welcome!

On-site Registration and Will Call will be open from 9:00am-10:30am at Capitol Park.

The walk will start promptly at 11:00am at the corner of Bannock and Capitol Blvd. We will walk down Capitol Blvd to Julia Davis Park to enjoy live entertainment, bounce houses, games for the kids, lunch and a raffle.

Raffle Preview: This year's items include: **Southwest Airline tickets, Disneyland tickets, BSU Football tickets** for game against New Mexico, **Sun Valley Ski Passes** for the family, salon treatments and numerous restaurants. **Raffle tickets will be \$5.00 each or 5 for \$20.00.** Tickets will be available at both parks.

It's NOT TOO LATE to register for the 2013 Buddy Walk!
[Online registration was extended to October 6th.](#)

On-site Registration open October 12th 9:00am-10:30am:

* Adult registration (13 & up): \$25.00 Child registration (12 & under): \$15.00

Your registration fee includes a t-shirt (only online registration will guarantee t-shirt availability), and a food ticket.



Thank you to the following 2013 Buddy Walk Sponsors!

Media Sponsor:
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Platinum Level:
Boise Inc./Boise Cascade Co.
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Gold Level:
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CK Quade, Law PLLC
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Southwest Airlines
Speech Tree
YMCA

Silver Level:
Denton County Animal ER, TX
Disney Resorts
Kaleidoscope
IdaCorp
Railco, LLC

Bronze Level:
Community Partnership of ID
Elevated Dance Project
Micron



October 1st:

TVDSA Board Meeting
7:00-9:30pm at A New Leaf
Contact: [Kristie Yerger](#)

October 12th:

TVDSA Buddy Walk
11:00am-2:00pm
Capitol Park to Julia Davis
Park in Boise
Contact: [George Taylor](#)

October 15th:

Best Buds: 5:30pm-7:30pm
Linder Farms in Meridian
Contact: [Malu Mulholland](#)

October 17th-18th:

**Community Partnership
Conference**, "Seeing
Beyond", Boise

October 19th:

**Home Depot Workshop
For Kids with Disabilities**
9:00am-12:00pm at the
Meridian Home Depot

October 19th:

AIM Halloween Party from
6:00pm-9:00pm at the
Mager's Party Barn in
Nampa
Contact: [Freddie Gallas](#)

October 22nd:

Cool Club: 6:00pm-8:00pm
JumpTime in Meridian
Contact: [Andrew Kopping](#)

October 26th:

Lil' Buddies: 11:00am
At ASL Expressions in Boise
Contact: [Jennifer Rice](#)



"Don't Limit Me"

By Megan Bomgaars

Please watch the four minute [video](#) of the aspiring public speaker and young woman with Down syndrome sharing her message.

The lives of the 250,000 Americans with Down syndrome today are radically different than a generation ago.

Tim Norton was devastated when his daughter was diagnosed with Down syndrome shortly after her birth in 2006.

He envisioned her growing up tragically disabled. The years ahead seemed filled with darkness.

A chance encounter on a ski slope, just a few months after his daughter was born, changed Norton's outlook on Down syndrome and the prospects for his daughter's happiness.

While skiing near his home in Massachusetts, a gifted teenage skier with Down syndrome, Melissa Joy Reilly, glided past him at the crest of a hill. Norton had noticed Reilly earlier in the day but said nothing. "Melissa stopped in front of me and said, 'Hello, how are you?' " says Norton, of Westford, Mass. "I said, 'Great. What a great night to be skiing.' "

And, just like that, Norton's life was changed. "Without her even knowing it, without her even trying — it was quite remarkable — I got just the positive lift that I needed," says Norton, whose daughter, Margaret, is now 7. "She opened my eyes to what the possibilities could be for my daughter," says Norton, a ski instructor. "It was like, 'Wow, this isn't a big black hole. This is a girl who can walk and talk and ski.' "

STORY: [With Down syndrome diagnoses, comes a wrenching choice](#)

Like Norton, many people are surprised to learn of the dramatic improvements in health and quality of life for children and adults with Down syndrome. Advocates for people with Down syndrome feel a new urgency to spread the word about these advances, as more women undergo prenatal tests for Down syndrome and other genetic conditions. The lives of the 250,000 Americans with Down syndrome today are radically different than a generation ago, says Brian Skotko, co-director of the Down syndrome program at Massachusetts General Hospital. People with Down syndrome now live to an average of 60 years, according to the national society. Just a generation ago, they lived to an average of only 25. Many graduate high school. Some take college classes. Some get married. About one in five has a job, says pediatrician Kathryn Ostermaier, medical director of the Texas Children's Hospital Down Syndrome Clinic.

On May 5, 2013 36-year-old named Karen Gaffney received an honorary doctorate from Oregon's University of Portland. University officials believe she may be the first person with Down syndrome to receive such a degree.

And the best may be yet to come, Skotko says. Thanks to early intervention, better therapies and educational opportunities, the generation of children with Down syndrome today may be the most accomplished ever, he says.

In March, a 15-year-old Oregon boy became one of the first people with Down syndrome to climb to a base camp on Mount Everest — a height of 17,600 feet.

Research by Skotko and others finds that life with Down syndrome is far happier — for parents, siblings and children themselves — than most imagine. One of Skotko's studies showed that among more than 2,000 parents on the mailing lists of Down syndrome organizations, only 4% of parents regretted having a child with the condition. Nearly 99% of people with Down syndrome say they're happy with their lives, and 96% say they like how they look, Skotko's survey found. Among siblings, 88%

The lives of the 250,000 Americans with Down syndrome today (continued from Page 2)

say their brother or sister with Down syndrome has made them a better person. There's a chance that these surveys paint an overly sunny picture, Skotko says, because people who belong to Down syndrome groups may be better off than those who lack this connection.

Advances in Down syndrome "need to be a part of prenatal counseling," says Ostermaier, an assistant professor at Baylor College of Medicine. "As physicians, we're supposed to give people accurate information so they can make informed decisions." Children with Down syndrome do face additional health challenges. They have a greater risk of respiratory problems, certain rare leukemias and are more likely to need surgery to correct bowel and colon problems. About half of babies with Down syndrome are born with congenital heart defects. In the past, many died at birth. Today, surgeons can repair heart defects.

Children with Down syndrome today also can benefit from a variety of early interventions, she says. These include: physical therapy; occupational therapy; speech and language therapy; and feeding and swallowing therapy, to assist with problems caused by low muscle tone. Because babies with Down syndrome tend to be "visual learners," they can learn to communicate with sign language months or years before they master speech, Ostermaier says. Boston-area mom Melissa Coe is already teaching her daughter, 14-month-old Lily, to sign words such as "father."

Specialized preschools also can help kids with Down syndrome make the transition to a regular kindergarten class, Ostermaier says. New therapies may one day help alleviate some of the symptoms of Down syndrome, such as intellectual impairment, Ostermaier says. Preliminary clinical trials are now being done with drugs designed to improve memory and learning.

Reilly, now 26, illustrates what people with Down syndrome can accomplish when allowed to reach their full potential, Skotko says. She remains an avid skier. In February, Reilly won a silver medal in the slalom competition at the Special Olympics World Winter Games in South Korea. She often accompanies Skotko as he teaches doctors and medical students about Down syndrome.

Skotko says even doctors often know relatively little about Down syndrome. Surveys show that medical students and residents get little training on the condition. It's important, Skotko says, for people with Down syndrome to tell their own stories. Skotko, whose sister has Down syndrome, credits her with teaching him lessons about patience, kindness and perseverance. While



Melissa Reilly poses with the silver medal that she won after finishing in second place at the 2013 Special Olympics in February in Pyeongchang, South Korea. (Photo: David Reilly)

learning to ride a bicycle was easy for him, Skotko says it took his sister three summers. "She is a life coach for all of us in the family," Skotko says. "She has taught us so many life lessons about how to be patient when the world wants the answer now, how to keep on going when others may quit."

Reilly, who lives with her parents, is more active than most Americans: swimming, bicycling, even kayaking in Alaska. She works as a teacher's aide once a month. And she works for a state senator two days a week, taking the train into Boston by herself. She handles mailings, makes deliveries and answers phones. "I love everything" about her job, Reilly says. "I have a lot of friends at work. They all think of me as part of the office ..." "People with Down syndrome and other developmental disabilities are very can-do people," Reilly says. "They are very able."

Norton, who has gotten to know Reilly and her family well, says she continues to inspire him: "I hope my daughter grows up to be just like her."

Source: USA TODAY, Liz Szabo May 9, 2013



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

Social Groups Page

Dads Appreciating Down Syndrome (D.A.D.S.) Meeting:

D.A.D.S. will not be meeting.
We will see you at the Buddy Walk!

For more information about **D.A.D.S.**
please contact [Gus Olmos](#)

Moms Night Out

Date: TBD

Bunco at Carry Ormsby's house
located at 2418 W. Astonete Dr.
in Meridian.

Come, kick back and relax ,and have
a few laughs. Everyone is asked to
please bring a snack to share.

Admission: please bring a prize no
more than \$2.00 (instead of cash)
wrapped.

TVDSA will provide the Grand Prize.

Please RSVP to [Malu](#) so we can
have enough tables ready!

For more information contact: [Malu
Mulholland](#). If you have suggestions
for outings please share!



Lil' Buddies (age birth-5 years) Update:

October Gathering:

Join us at **ASL Expressions**, a sign language
learning center for their free ASL story time,
Saturday, October 26th at 11:00am. ASL
Expressions is located at 1843 N. Wildwood
in Boise, off Fairview between Cloverdale
and Five Mile.



Need more information on **Lil'Buddies?**
Please contact [Jennifer Rice](#)

Best Buds (Elementary) Update:

October Gathering:



Best Buds will be going to [Linder Farms](#)
**Tuesday, October 15th from 5:30pm-
7:30pm.** Admission for individuals with
Down syndrome will be covered. Cost:

\$5.00 for adults. Admission includes
the corn maze and farm. We hope to
see you there!

Need more information on **Best Buds?**
Please contact [Malu Mulholland](#)

Cool Club (Jr./Sr. High)

October Gathering:

Cool Club will be going to **JumpTime**
located at 1375 E. Fairview Ave in
Meridian on **Tuesday, October 22nd** from
6:00pm-8:00pm. An [online waiver](#) and

registration form is needed for
each participant. Cost for
individuals with Down syndrome
will be covered by TVDSA

Please RSVP to: [Andrew Kopping](#)
(208) 350-9908 if you plan to
attend.

Adults in Motion (AIM)

October Gathering:

AIM will be having a **Halloween Party**
with the Amazing Amigos group at the
Mager's party barn (4900 S. McDermott
Rd. in Nampa) on **Saturday, October 19th**
from 6:00pm-9:00pm. Please bring a
finger food snack and wear a costume.

There will be funny photo
opportunities for all.

For more information about **AIM**
contact: [Freddie Gallas](#) or [Niculina
\(Nina\) Bistriceanu](#)



PLEASE: Update your Profile with TVDSA.

Please follow the "[update subscription preferences](#)" link at the very bottom
of any email notification from the Treasure Valley Down Syndrome
Association. This will allow you to make sure you get information about the
social groups and events appropriate to you and your family member as
he/she continues to grow. We know interests change, this will limit the
information you receive from TVDSA to areas that you are interested in. We
hope you will not "*unsubscribe*," but "[update subscription preferences](#)" so
we are able to serve you appropriately.

Sincerely,
TVDSA Board of Directors



Conferences, Workshops, Webinars & TVDSA Scholarship Information

Community Partnerships of Idaho Conference "Seeing Beyond"

A conference providing training for those who serve and support individuals with disabilities and mental illness.

October 17th & 18th
Boise ID

[Registration](#) is OPEN!

This conference qualifies for the TVDSA Scholarship, if interested!

Home Depot Workshop for Kids with Disabilities

October 19th
from 9:00am-12:00pm
at the Meridian Home Depot: 1100 S. Progress Ave
Meridian, ID

Free workshop is geared to provide a fun, quiet, low stress, warm and welcoming environment for kids with special needs of all ages and abilities. Various methods will be provided.

Idaho Parents Unlimited: Is Your Child a Target of Bullying?

Oct 22nd 6:00-8:00pm
Advocates for Inclusion:
958 W. Corporate Ln, Nampa
Register: Kathie@ipul.org
Come learn a range of intervention strategies!

Inclusive Higher Education: Moving from Good Ideas to Great Outcomes

November 16th & 17th
Washington, DC
[Information](#) and Registration

[Wrightslaw Conferences](#)

Special Education Law and Advocacy
Various dates and locations across the U.S. including April 3, 2014 in Boise, ID.

TVDSA Scholarships

Did you know that TVDSA supports members in gathering information at local and national conferences and/or workshops?

The TVDSA Scholarship program is NOT income based, so everyone is eligible.

Please see our [Scholarship application](#) for the guidelines and how to apply today.

LIVE Webinar series sponsored by the Center on Disabilities and Human Development in collaboration with the Idaho State Department of Education

- **Transition to Work for Youth with Significant Disabilities** – Oct. 14th, 24th, 31st: 4:00-6:00pm
- **The Common Core State Standards with moderate/severe Disabilities** – Dec. 9th: 4:00-6:00pm
- **Comprehensive Planning for Students with Autism** – Feb. 13th: 4:00-6:00pm
- **Universal Design for Learning: Curriculum for ALL Learners** – April 9th, 16th, 23rd 4:00-6:00pm
<http://www.idahotc.com/forcredit.aspx>

TVDSA is giving away a bike!

A lightly used Mobo Triton Pro three wheel bike has been donated **for a lucky Cool Club or AIM member with Down syndrome** at the Annual Christmas Party in December. The bike is designed for riders 4' to 6'3" and up to 250lbs. It is chainless (no gears), very easy to use and great for a leisure ride.

In order to be eligible to win, interested individuals/families must be a current and paid 2013-14 TVDSA member. Not sure if you are a current member? Please contact [Lucy Olmos](#), TVDSA Treasurer.

The drawing will be made at the TVDSA AIM/Cool Club Christmas party, and the winner must be present to win.

If you have any questions, please contact: [Paul Auger](#), TVDSA Marketing Director.



NIH Launches first National Down Syndrome Registry

The National Institutes of Health (NIH) has launched [DS-Connect](#), a Web-based health registry that will serve as a national health resource for people with Down syndrome and their families, researchers, and health care providers.

Participation in the registry is free and voluntary. Individuals with Down syndrome, or family members, on their behalf, may sign up to create personalized profiles with information about their health histories, including symptoms, diagnoses, and medical visits. The website has been designed to ensure that all information remains confidential. The site will separate users' names from their health information, so that individuals may compare their health information with that of all other participants in an anonymous manner.

DS-Connect is for people of all ages, not just children. Right now, there is little data on older individuals with Down syndrome, and that's been a problem. People with Down syndrome are living longer, and researchers and physicians will require information about the health issues and needs of these individuals to make recommendations about their health care.

The [Down Syndrome Consortium](#), a public-private group established in 2011 to foster the exchange of information on Down syndrome research, will be a critical player in helping to disseminate information about the registry to the Down syndrome community. The consortium includes individuals with Down syndrome and their family members, representatives from professional societies and advocacy groups, and NIH scientists.



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

PO Box 1404
Meridian, Idaho 83680
208-954-7448

We're on the Web!

See us at:

www.idahodownsyndrome.org

Check us out on
[Facebook](#) and [Twitter](#)!

2014 TVDSA Calendar Pre-Orders

Order your 2014 TVDSA Calendars today and pick them up at the Buddy Walk on October 12th!

Calendars are only \$15.00 and feature many individuals with Down syndrome from the Treasure Valley.

Click on: [Online Order Form](#) to place your pre-order today!

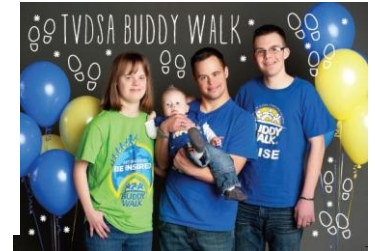


TVDSA Greeting and Note Cards!

TVDSA has greeting & note cards available to purchase.

You can purchase a set of 11, with one of each of the prints, or a set of 10, of a single print. **Cost: \$7.00** per set.

To [view and order](#) the greeting/note cards visit our: [website](#) or contact: [Kristie Yerger](#).

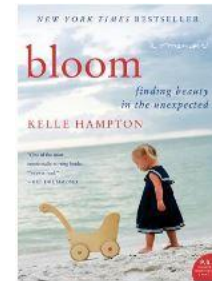


From the TVDSA Lending Library:

Bloom: Finding Beauty in the Unexpected – A Memoir
by: Kelle Hampton

From the outside looking in, Kelle Hampton had the perfect life: a beautiful two-year-old daughter, a loving husband, and a thriving photography career. When she learned she was pregnant with their second child, they were ecstatic. But when their new daughter was placed in her arms in the delivery room, Kelle knew instantly that something was wrong. Nella looked different than her sister, Lainey, had at birth. As her friends and family celebrated, a terrified Kelle was certain that Nella had Down syndrome—a fear her pediatrician soon confirmed. Yet gradually Kelle embraced the realization that she had been chosen to experience an extraordinary and special gift.

With lyrical prose and gorgeous photography, *Bloom* takes readers on a wondrous journey through Nella's first year of life—a gripping, hilarious, and intensely poignant trip of transformation in which a mother learns that perfection comes in all different shapes



Bloom is available in the TVDSA library. Members may reserve it by contacting the librarian at library@idahodownsyndrome.org.

For a complete list of the books/DVDs available through TVDSA, please check out our [Lending Library](#).

The mission of Treasure Valley Down Syndrome Association is to enhance the quality of life for persons with Down syndrome by promoting inclusive environments, providing accurate information to parents, families, and the community, and by advocating respect, dignity, and appropriate supports for people with Down syndrome.

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For more information, articles, past newsletters and more, please visit our website: <http://idahodownsyndrome.org>
Mailing: PO Box 1404 Meridian, ID 83680; Check us out on [Facebook](#) and [Twitter](#)