



TREASURE VALLEY  
DOWN SYNDROME ASSOCIATION

# TVDSA Newsletter

Newsletter Editor: [Celena Auger](#)

May 2014

## In this Issue

We kick off the May newsletter with Acts of Kindness. Today, May 1<sup>st</sup>, is the 2<sup>nd</sup> Annual Idaho Gives Campaign. TVDSA hopes you will consider selecting TVDSA as one of your nonprofit causes.

Please take a moment and watch the news report from North Carolina, for a n act of kindness in a heart-warming story.

You can also find articles about Fostering Independence, 15 Reasons for Inclusive Classrooms, and interesting information on the link between Down syndrome and arthritis.

Do you have some extra time you want to donate to TVDSA? On page 5 you can find three opportunities to help TVDSA.

Don't have the "time" but still want to "help" – check out page 6 for some easy ways to benefit TVDSA while living your normal busy lives.

As usual we have another busy month of activities. Check out the Social Page for age group, parent and family meetings. Hope to see you at one or more of the activities.

Monthly and archived TVDSA newsletters are available on our website at: [www.idahodownsyndrome.org](http://www.idahodownsyndrome.org) for viewing and sharing.



## Idaho Gives Day 2014

Idaho Gives is a special day for philanthropy across Idaho. May 1<sup>st</sup> is a day for Idahoans to come together with one voice of support for our nonprofits, big and small. A day for you to find your passion, donate to your favorite causes and share in the excitement!

Join us at <http://idahogives.razoo.com/story/Tvdsa> **TODAY May 1, 2014** to make a contribution to the nonprofit you support. Last year Idaho raised \$578,735 from 6,192 individuals who gave to 541 nonprofit causes.

**TVDSA hopes you will select TVDSA as your nonprofit cause this year.**

## Act of Kindness

A North Carolina family was dining out when their 8-year-old son, who has special needs, began getting loud and hitting the table. A waitress then surprised the family. "I'll try to do this without crying," the waitress told the family. "But another customer has paid for your bill tonight and wanted me to give you this note."

[Read more](#)



## TVDSA

Calendar of EventsMay 1<sup>st</sup>:**Idaho Gives Day**[www.idahogives.org](http://www.idahogives.org)May 10<sup>th</sup>:**Lil' Buddies** from 10:00am-

12:00pm at Charlotte's

House in Boise. Contact:

[Jennifer Rice](#)May 13<sup>th</sup>:**TVDSA Family Meeting**

7:00pm-9:00pm at

A New Leaf in Meridian

Contact: [Erin Rosenkoetter](#)May 17<sup>th</sup>:**AIM** from 11:00am-1:00pm

TVDSA Olympic Spring

Games at Peppermint

Park. Contact: [Lynda Wells](#)May 20<sup>th</sup>:**Cool Club** from 6:00pm-

8:00pm at Jump Time in

Meridian. Contact:

[Andrew Kopping](#)May 21<sup>st</sup>:**Moms Night Out!** at

5:30pm at Les Boise Park in

Boise. Contact: [Carrie](#)[Ormsby](#)May 28<sup>th</sup>:**Best Buds** 4:00pm-5:30pm

at Settler's Park in Meridian.

Contact: [Malu Mulholland](#)May 24<sup>th</sup>:**Lil' Buddies** from 9:30am-

11:30am at Jabbers in

Nampa. Contact:

[Jennifer Rice](#)June 18<sup>th</sup>:**TVDSA Family Picnic** 6:00-8:30p **NEW LOCATION:** KlienerPark Contact: [Lynda Wells](#)**Fostering Independence in Children**

Every parent and caregiver wants their children to lead a happy life. When we dream about the future, parents have hopes that their children will be part of a community, have friends, live independently, and enjoy health and well-being. We already know that the skills and behaviors children develop early in life lay a strong foundation for their adolescence and adulthood. For this reason, we need to think about how we can begin early to promote lifelong independence for our children.

Consider for a moment what the following three images have in common:

- An infant smiles widely at her reflection as she looks into a mirror which is placed on the floor in front of her.
- A toddler reaches for and grabs the toy he wanted off the shelf.
- A preschooler uses her walker to get to the other side of the playground where her friends are playing.

All of these images show a child interacting with the world by making simple choices. Another way to think about this is that these children have some sense of control over their environment. You may hear professionals use the term self-determination to describe this important concept. Self-determination is about being able to express choices, identify preferences and have a sense of independence or autonomy about our own lives.

**What Should We Know About Self-Determination in the Early Years?**

Basically, self-determination is about making choices and decisions that affect one's own life. It's about a child knowing who she is, what she wants, and how to go about getting it. Some examples of self-determination in early childhood are choosing who to play with, where to create a block tower, or getting napkins from the drawer to help set the table for dinner.

Many people think of self-determination as a basic civil right that all human beings deserve. Many also believe that having opportunities for self-determination improves a person's quality of life. For children with disabilities, acquiring skills related to self-determination is especially important. This is because their freedom to move around, express themselves clearly or interact with others may look different than what other children typically do. Some adults may mistakenly provide more support for a young child with disabilities than the child might actually need. We know that sometimes when a child is consistently overprotected or prevented from taking even small risks, he may learn to feel helpless or dependent, rather than self-reliant.

Click to [read more](#) on [How Parents can Promote Self-Determination](#) or a personal story about [one young woman's journey to independence](#) (25 year old Betsy who has Down syndrome).

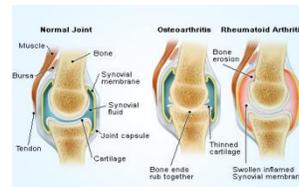
Source: PBS Parents

**Fifteen Reasons to be in the Regular Classroom**

1. All students can make friendships.
2. All students can have access to the curriculum.
3. All students can be true members of a group.
4. Everyone can benefit from models of age appropriate language and communication.
5. Everyone can benefit from models of age appropriate behavior.
6. Research shows that life outcomes of students in inclusive classrooms are better.
7. Better advocacy skills, sense of agency for all.
8. Everyone can do better academically.
9. Everyone can do better socially.
10. It is socially just and right.
11. Everyone gets more access to certified content area specialists.
12. Everyone can get more access to specialists.
13. It teaches everyone about the beautiful range of humanity.
14. We decided long ago that separate but equal is inherently unequal.
15. It is the law!



Source: the Facebook page called "[Inspire Inclusion](#)"



## Arthritis and Down's Syndrome: there's a link

**It is thought that arthritis is six times more common in children with Down's Syndrome than in healthy children. Despite this, the time it takes for them to be diagnosed is considerably longer. Arthritis Research UK is now funding research to try and improve the situation, Jane Tadman reports.**

Youngsters born with the genetic disorder, Downs syndrome, face many problems from the very beginning. As well as learning difficulties, they also have a higher chance of developing other conditions such as congenital heart disease, sight and hearing problems, and Alzheimer's.

There's another condition that should be added to that list. As many as two per cent of all Down's youngsters have an inflammatory form of arthritis similar to juvenile idiopathic arthritis (JIA), called Down's arthropathy (many doctors, in fact, think it is JIA, just occurring much more often in these children). This may be six times more common than arthritis in healthy children.

In fact, according to pilot research carried out by Maureen Todd, a clinical research nurse in pediatric rheumatology at the Royal Hospital for Sick Children at Yorkhill's department of child health in Glasgow, that figure could be even higher.

"Our pilot study showed that health professionals often fail to diagnose arthritis in children with Down's Syndrome," explains Maureen. "On average it took two years from the onset of symptoms to diagnosis, in stark contrast to the four months it took for diagnosis of juvenile idiopathic arthritis in otherwise healthy children.

"This highlights a need for improved education of joint assessments in these children. The routine health checks these children already receive are an ideal opportunity to target education and to make sure that arthritis is picked up at an early stage."

Arthritis Research UK has now awarded Maureen a Barbara Ansell fellowship in pediatric rheumatology to take her work further. (The Barbara Ansell fellowship was set up using an endowment from the late, legendary pediatric rheumatologist Dr Barbara Ansell, who devoted her life to improving the lives of children with arthritis.)

So why are there such difficulties in picking up arthritis in Down's youngsters? Most are already in the healthcare system because of their complex physical needs. Maureen has a couple of theories.

"Arthritis doesn't seem to be considered very early on in Downs syndrome children because they are prone to other chronic musculoskeletal conditions such as joint hypermobility, low muscle tone, dysplasia of the hips, and instability of the neck joints," she says.

Another reason is that children with Down's don't appear to express pain in the same way that other children do. And because they fail to mention it, even though their joints may be visibly affected, it seems to be overlooked by the medical profession.

The reasons why Down's children are more prone to arthritis are complex. "There is more autoimmune disease in these youngsters, and they're more prone to leukemia," explains Maureen. The type of arthritis they get is very similar to psoriatic arthritis in its development, which she plans to investigate further as part of her fellowship.

After identifying Down's children in Glasgow via community pediatricians, she is seeing affected youngsters with a whole spectrum of disability aged between two and 16, in clinics at Yorkhill. The aim is to find out more about what types of arthritis develop, how severe it is and how many joints it affects, as well as the prevalence of other musculoskeletal disorders.

Maureen is examining their joints, and, with podiatrist Gordon Watt, examines their feet, performs weight, height and arm span and other tests, and looks at their muscle tone. Their parents fill in questionnaires about their background and family history.

The youngsters are then offered a referral to see pediatric rheumatologist, and former Arthritis Research UK senior lecturer, Dr Janet Gardner Medwin, who is supervising Maureen's fellowship.

Maureen is planning to hold focus groups involving children and their parents, and also to target school nurses who regularly see Down's Syndrome children to raise their awareness of the links between the condition and arthritis. And, importantly, she will look at the barriers that health professionals face in identifying joint problems in routine care. She will then develop a targeted educational package aimed at all health professionals that deal with Down's, and also families, so that children can be diagnosed – and treated – earlier. There are also plans for a larger UK-wide project, helping to identify cases of arthritis in children with Down's, leading to future clinical trials.

- See more at: [Arthritis Today](#)



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## Social Groups Page

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

D.A.D.S. will not be meeting  
in May.

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

### MOM'S Night Out!

May 21<sup>st</sup> at 5:30pm

It's Ladies Night at Les Bois Park.  
Come for an evening out at the  
horse races and you could win  
a gift card from TVDSA!

**NO Gambling is required!**

In addition, TVDSA will buy snacks for  
those that attend.

For more information or questions,  
please contact: [Carrie Ormsby](#).

### TVDSA Annual Meeting

May 13<sup>th</sup> from 7:00pm-9:00pm

at A New Leaf

2456 N. Stokesberry Ln, Meridian

**Topic:** 2013-14 TVDSA recap, board  
ballots due, plus learn about the  
recent Wrightslaw Conference.  
Three attendees will share important  
information they learned: the law, IEP  
etiquette, and measuring progress  
using the bell curve.

For more information contact  
[Erin Rosenkoetter](#)

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

May Playdates:

Lil' Buddies will be meeting on Saturday  
**May 10<sup>th</sup>** from 10:00am-12:00pm at  
**Charlotte's house** located at 12067  
Goldenrod Ave. in Boise.



We will also gather on Saturday, **May 24<sup>th</sup>** from 9:30am-11:00am at **Jabbers** located at 1210 N. Galleria Drive in Nampa. TVDSA will pay for individuals with DS. Don't forget your socks!

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

### Best Buds (6-11 years of age) Update:

**Best Buds** will be FISHING! on **Wednesday, May 28<sup>th</sup>** from 4:00pm-5:30pm at **Settlers Park** in Meridian. The Idaho Fish and Game's "Take Me Fishing" trailer will be on sight to help. Fishing equipment can be checked out for free during this time. If you have your own equipment, please bring it. Idaho children 13 years and under can fish without a license.

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



### Cool Club (12-17 years of age) Update:

**Cool Club** will be going to **Jump Time** on May 20<sup>th</sup> from 6:00pm-8:00pm. Jump Time is located at 1375 E. Fairview Ave. in Meridian. TVDSA will pay for entry fees for those with Down syndrome, along with some drinks and snacks. Everyone will have to sign a [liability form](#).

Please show up a little before 6:00pm, to get everyone checked in. Don't forget your socks!

Need more information on **Cool Club?** Please contact: [Andrew Kopping](#) 208-350-9908

### Adults in Motion Update:

**Saturday May 17<sup>th</sup>** from 11:00am-1:00pm **AIM** will be hosting the first ever TVDSA **Olympic Spring Games at Peppermint Park**, located at 2030 S. Sumpter Way in Boise (near Pepper Ridge Elementary in Pepper Hills Subdivision at Overland and Cloverdale). There will be games, races,

some metals, a torch run, and a LOT of outdoor fun by all! We will serve a light lunch (sandwich, chips and cookie). If you have special dietary needs please let us know!

Need more information on **AIM?**  
Please contact [Lynda Wells](#)

### Ruby's Rainbow Scholarships

Ruby's Rainbow is a non-profit dedicated to the higher educational needs of adults with Down syndrome, granting scholarships nationwide for post-secondary education, vocational or enrichment classes. We have funds available for the fall semester of 2014 with the deadline for applications being July 6<sup>th</sup>. The application is ready and up on our website [www.rubysrainbow.org](http://www.rubysrainbow.org). If you have any questions you can also email Liz Plachta, president and co-founder or call at 512-879-7801

## Conferences, Workshops, Webinars & TVDSA Scholarship Information

### 4<sup>th</sup> Annual Sprout Film Festival

Three Entertaining and Memorable Films related to Intellectual and Developmental Disabilities

**May 1<sup>st</sup>:** 7:00pm  
at The Flicks, Boise

**May 2<sup>nd</sup>:** 10:00am & 7:00pm  
at The Egyptian Theatre,  
Boise

Tickets: \$10 General, \$8  
Students, Seniors and those  
with disabilities.  
Information: 208-422-1759

Illinois Includes  
May 7-8, 2014  
Rosemont, IL

[Registration now open!](#)

### FREE: IPUL Webinar Series

**May 27<sup>th</sup>**

Pick from: 10:00am, 1:00pm  
or 6:00pm for 1 hour each.  
**Topic: Secondary Transition**  
prepare for transitioning from  
high school to post-  
secondary education or  
employment, includes: IEP  
transition planning.

### 2014 NDSC Annual Convention

July 11-13<sup>th</sup>, 2014  
Indianapolis, IN

**"Setting the Pace"**

Early bird registration closes:  
**May 30<sup>th</sup>**

Convention Registration  
closes: June 25<sup>th</sup>



### 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 all TVDSA members are eligible.

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

## Treasure Valley iCan Bike Camp 2014

June 9<sup>th</sup>-13<sup>th</sup> at the Homecourt YMCA

The [iCan Shine bike program](#) will be in Meridian, Idaho this summer to teach individuals with disabilities ages 8 & older how to ride a conventional bike and become a lifelong independent rider! **Rider registration has been extended to May 15<sup>th</sup>.**

**We need volunteer spotters!** If you are interested in supporting someone in learning this valuable mode of independent transportation please fill out the volunteer packet on the [website](#) **before May 15<sup>th</sup>!**

For more information visit:

<http://icanshine.org/boise-id/>

or contact Paul Auger at

[tvicanbike@idahodownsyndrome.org](mailto:tvicanbike@idahodownsyndrome.org).



## WANTED: New Board Members

TVDSA is seeking to fill multiple vacancies on the Board of Directors. Interested parties must be able to commit to attending monthly meetings as Board members will be asked to offer feedback and input with regards to current and or future projects. No compensation or fees will be paid to board members.

Interested parties should send a letter of interest along with past and current experience relevant to working with special needs populations, as well as any Boards in which you have been a previous member. Please note, previous experience and/or loved one with Down syndrome is NOT required. Please email this information to Kristie Yerger at: [president@idahodownsyndrome.org](mailto:president@idahodownsyndrome.org).

## The 2014 TVDSA Buddy Walk

The 12th annual TVDSA Buddy Walk will be held Saturday, **October 11<sup>th</sup>**. This is not only an event to raise awareness about Down syndrome, but is also a main fundraising event for TVDSA. The funds raised from this event allows TVDSA to continue to provide other free services throughout the year. As in previous years we are sure that fun will be had by all. Look for more information on this in the coming months. If you are interested in volunteering to help the day of the Buddy Walk please email Malu Mulholland at: [vicepresident@idahodownsyndrome.org](mailto:vicepresident@idahodownsyndrome.org)

### **Buddy Walk Planning Committee Volunteers:**

2014 Buddy Walk Planning Committee Volunteers **are needed now**. The planning for the 2014 TVDSA Buddy Walk is underway and we need committed volunteers that can consistently participate in meetings twice a month to plan and organize this great event. The only required skill is the willingness to help but all other skills are welcome. We have several committees that need leaders and participating members. This event can only be a success with your help. To volunteer or for more information please email George Taylor at [buddywalk@idahodownsyndrome.org](mailto:buddywalk@idahodownsyndrome.org).



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](http://www.idahodownsyndrome.org)

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



**You can help TVDSA earn donations  
just by shopping with your Fred  
Meyer Rewards Card!**

Here is how the program works:

- Sign up for the Community Rewards program by linking your Fred Meyer Rewards card to TVDSA at [www.fredmeyer.com/communityrewards](http://www.fredmeyer.com/communityrewards) searching by name or by Non-profit (NPO) number **93128**.
- Every time you shop and use your Rewards Card you are helping TVDSA earn a donation!
- You still earn your Rewards Points, Fuel Points and Rebates just as you do today.

## October - Awareness Month Preparation

In October we will be sharing 31 days of pictures on our Facebook page, and would love to highlight your loved one with Down syndrome.

Please send a picture and short paragraph to celebrate DS Awareness Month to Malu Mulholland at [vicepresident@idahodownsyndrome.org](mailto:vicepresident@idahodownsyndrome.org)



100% of your ticket purchase goes directly to the charity of your choice through the Hillshire Brands TICKETS for CHARITY™ program!

Don't miss any of the exciting golf action at the Albertsons Boise Open presented by Kraft at Hillcrest Country Club - [buy your tickets today!](#) Not only will you get a chance to see the Future Stars of the PGA TOUR, but you will also be contributing to your favorite local charity!

## Shop with AmazonSmile and support TVDSA:

AmazonSmile is a simple and automatic way for you to support TVDSA every time you shop, at no cost to you. When you shop at [smile.amazon.com](http://smile.amazon.com), you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com with the added bonus that Amazon will donate a portion of the purchase price to TVDSA.

Visit [smile.amazon.com](http://smile.amazon.com) and select Treasure Valley Down Syndrome Support Group as your favorite charity "BEFORE" you start shopping and TVDSA will receive 0.5% of the purchase price from your eligible AmazonSmile purchases.

*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.*

### Board of Directors:

President: [Kristie Yerger](#)  
Advisor: [Lynda Wells](#)  
Community Outreach Chair: [Erin Rosenkoetter](#)  
Secretary: [Paul Auger](#)

Vice President and Programs Chair: [Malu Mulholland](#)  
Treasurer & Spanish Contact: [Lucy Olmos](#)  
Buddy Walk Chair: [George Taylor](#)  
Self Advocate: [Seth Paetel](#)

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](#)