



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

TVDSA Newsletter

Newsletter Editor: [Celena Auger](#)

May 2012

In this Issue

The May issue is dedicated to *Early Elementary with Handwriting Helps and Talking with Your Child About Their Disability.*

The TVDSA Newsletter has a new look and format. Monthly newsletters will now be available online at www.idahodownsyndrome.org for viewing and sharing. Notifications will be sent out when the newsletter has been posted each month.

Did you miss the TVDSA End the R-word video? You can see it [here](#).

Meet Jake Preece

Jake is an almost-six-year-old fun and playful little boy. He loves to go to the park, dig in the dirt, ride his balance bike, sit by campfires, and play with his sisters. He started kindergarten this year and has learned to write his name, recognize some letters, and cut out different shapes on his own.

Jake's baby photo is on the cover of the TVDSA brochure; he's always attracted people's attention with his smile and social personality! Jake's latest thing is ropes: he loves to tie anything and everything up. He ties a rope to our tree out front, then ties it

to his tricycle and tries to pull the tree down! We couldn't imagine life without our Jake! He's inspired us to adopt a 4-year-old boy with Down syndrome from Russia. Jake says his name will be "Dude." We can't wait!



Handwriting Helps by: Carla Austin, Occupational Therapist

Handwriting is one of the major tasks facing the school age child. It is a realistic goal for most children with Down syndrome. This article explores some of the challenges faced by the young person with Down syndrome as they learn to write, the "compensations" frequently made by the individual as they spontaneously try to accomplish writing tasks, and the methods to address these difficulties. Low muscle tone throughout the arm and hand form a poor base for

beginning writing. A flattened palm and lack of stability on the little finger side of the hand decreases the ability to shape the hand and free up the thumb side of the hand to skillfully hold and direct a writing instrument. Handwriting does not require a great deal of strength but does require much control. The child with Down syndrome frequently compensates for this lack of control when beginning to write by grasping the pencil in a fist grip and directing

the pencil with movement of their whole arm. Frustration can rapidly interfere with completion of home and school work.

The following activities can help prepare the hand for beginning writing by building the arch in the palm and stability in the hand. These activities can also help the older child to have greater control and better endurance with writing tasks as well

Continued on page 3

May 8th:

TVDSA Annual Membership Meeting
7:00pm-9:00pm
A New Leaf, Meridian
Contact: [Erin Rosenkoetter](#)

May 9th:

IPUL Parent Support Group 6:00pm-8:00pm
Topic: Understanding ADHD, Boise
Contact: [Angela Lindig](#)

May 12th:

Lil' Buddies Playgroup
3:00pm-5:00pm at Davis' House in Boise
Contact: [Kristie Yerger](#)

May 12th:

Sibshop: 10:00am-1:00pm
Call: 433-8845 to register

May 15th:

TVDSA Board Meeting
7:00pm-9:00pm
At A New Leaf
Contact: [Paul Auger](#)

May 16th:

Best Buds: 5:30pm-7:30pm
Potluck and Get together at the Gallas' Game Room, Nampa, ID
Contact: [Kristie Yerger](#)

May 18th:

AIM & Cool Club
6:00pm – 9:30pm
Dinner and a Movie.
for more information, contact: [Freddie Gallas](#) or [Molly Benton](#)

May 19th:

D.A.D.S. Meeting from 6:00pm-8:00pm at Bounce! in Meridian.
Contact: [Gus Olmos](#)

June 15th:

Deadline for **TVDSA College Scholarships** for the 2012-13 Year
Contact: the [Scholarship Committee](#)

July 11th:

TVDSA Annual Picnic
Nampa, ID 6:30pm-8:30pm
Contact: [Lynda Wells](#)

July 19-22nd:

[NDSC Annual Convention](#)
Washington D.C.

Talking With Your Child About His or Her Disability

By: Adene Karhan, Special Education Resource Specialist

Understandably many parents have questions and concerns about when and how to talk with their child about his or her disability. What should you say? What if you can't answer their questions? Will talking about the disability make them upset?

While parents sometimes fear that talking with children about his or her disability will cause them to be upset, the reality is that when children don't have accurate information, they often construct explanations on their own, and these explanations can be filled with false beliefs and misconceptions. For example, the child who is struggling in school may have come to believe that he is "dumb." The child who has trouble controlling her impulsive behavior may feel that she is a "bad kid." Having more factual information about the disability allows the child to understand the struggles that he or she may face in the context of the disability, and often creates a sense of relief for the child. As children become more knowledgeable about their disability, they become more confident in their ability to overcome the challenges that they face. The following are a list of tips for talking with your child about his or her disability.

Adapt the information to the age of the child.

Young children think in very concrete terms, and information should be presented with short, simple facts. Allow them to ask questions. Don't be surprised if they change the topic quickly once their curiosity has been satisfied. They may randomly bring the topic back up again at a later date when another question pops into their head. By the age of 8-9, children are often interested in having more specific and elaborate explanations. Adolescents usually grapple with more abstract concerns, such as the impact that the disability is going to have on their life in the long-term. It may be helpful to allow the child time alone with a professional to ask questions that he or she may not want to voice in front of you. This is also a way to help the child learn how to become more proficient in self-advocacy.

Ask for the Child's Point of View

Start your conversation by asking for the child's perspective on the disability. The child may even initiate the conversation by talking about frustrations or problems that she is facing related to the disability. The child may be relieved to learn that the problems that he has been having in school are not his "fault." Work together to come up with a plan of action for addressing these struggles in the future.

Have More Than One Conversation About the Disability

After the initial conversation about the disability, children will often need time to process the information that has been given to them. They may not have a lot of questions early on, but as time passes and as they get older, they will have more questions. It is best to make the issue of the diagnosis an ongoing series of discussions rather than a single conversation.

Practice Telling Others About the Disability

Both parents and children will need to decide who they want to discuss the disability with and how much detail they want to share with others outside the family. Talk with your child about how much to share and how to respond to questions that others may ask about the disability. You may even want to role-play specific situations and help the child become more comfortable with dealing with

Handwriting Helps continued from Page 1

as increase general fine motor coordination for many manipulative tasks. Because these tasks require small objects, they should not be used with children who continue to mouth small objects.

1. Manipulate objects within the hand keeping the non-dominant hand in their lap. Using the dominant hand, place objects one at a time in their palm and encourage the child to move it into their fingers to place pennies in a bank, tiny pegs in a board, and beads onto a string held with the other hand.

2. Use small sugar tongs or children's chopsticks. The instrument should be held in an underhand rather than an overhand grip with the tool resting in the thumb web. Pick up cotton balls, marbles, or small beads and put them one by one into a container using tongs or eat a snack such as raisins using the tongs.

3. Practice pencil-walking down a pencil from the eraser end of the pencil held in the same underhand grip described above. The pencil should end up in the thumb web spacing resting in the C shape formed by a circled thumb and index finger. Pencil walking is a great turn taking activity for pencil games such as tic tac toe sharing one pencil

between each opponent using pencil walking with each turn.

4. Use a cupped palm to scoop beans or rice. Practice finger spelling words using sign language letters such as c, d, e, and o, encouraging cupping of the palm. Squeeze putty, clay or playdoh between the thumb and each finger. Practice thumb touching to the tip of each finger. Finger puppets or stickers can encourage young children to practice these movements.

5. Coloring within stencils, velvet coloring pictures and coloring books outlined with Wikki Stix build control especially if an adult help stabilizes the arm to encourage movement to be isolated in the wrist and hand. Scrapbook rub ons can help the older child practice the same movements in a more age appropriate way.

Give repeated practice and praise for a job well done!

The typical progression of learning to write starts with basic 3 lined paper with red base or bottom line, blue top line and dotted middle line. The typical child starts printing on large kindergarten 3 line paper progressing to making letters 1 inch in size by grade 2. Eventually the

child is able by grades 3 & 4 to use wide rule notebook paper for their writing assignments and will have cursive writing introduced and hopefully mastered to replace printing. Most schools use this progression in writing as part of their school curriculum and most of us remember learning by this method. The student with Down syndrome may find it difficult if not impossible to align their letters, words, or sentences on these smaller lines and often struggle with spacing of their letters.

Below is a partial list of available papers that address spacing and alignment difficulties frequently seen. Some of the products are costly, but a little can go a long way in helping a struggling student.

1. Alignment papers are available as Right Line Wide Rule Paper from the Pro Ed Company or as Raised Ruling Paper from the Mead Company. Each of these papers has a raised top and bottom line which can be felt as the pencil comes into contact with it. It helps the student control the pencil and align letters along the writing lines. A raised line paper can be made using Wikki Stix or a line of puffy craft paint along a writing line. Highlighters or light pencil shading can help provide color cuing of the different areas of the writing lines.

Teachers often use the dirt, grass, and sky analogy to help cue the child to the bottom, middle and top lines on 3 line paper. [The Handwriting Without Tears](#) program makes a paper that provides a 3 colored background of the different sections of the writing lines to assist in alignment.

2. Spacing papers may help the student or adult who has started to use notebook paper but does not leave appropriate space between words. Standard 4 to an inch graph paper provides assistance by placing 1 letter in each box and an empty box between words. The Mead Company produces a paper called RediSpace which provides spacing cues along the writing lines. For the beginner writer, most of us are familiar with the finger spacing method, but another technique is to color in the empty space between words on the model to be copied, allowing a student to better see the empty space.

Teachers and parents can partner together to select from customized papers and methods to assist students with varying levels of ability in having success putting pencil to paper.

"Down syndrome is NOT contagious, but my spirit is."

- Unknown



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

Social Groups Page

TVDSA Annual Membership Meeting:

Tuesday, May 8th

from 7:00pm-9:00pm

at A New Leaf

2456 N. Stokesberry, Meridian

Topic: In addition to going over the 2011 year, voting for 2012 Board Members and talking about the upcoming year's plans, our speakers will be Andrea & Brady Murray to share information on Reece's Rainbow.

We encourage everyone to attend this meeting as a lot of information will be shared.

For more information, contact:
[Erin Rosenkoetter](#)

TVDSA Annual Picnic:

Mark your calendars now:

Wed, July 11, 2012

at the Mager's Party Barn
4090 S. McDermott Rd, Nampa

More information in next
month's newsletter!

Lil' Buddies Update:

Lil' Buddies Playgroup:
Saturday, **May 12th** from
3:00pm-5:00pm at Davis'
house at 4257 N Vera
Street in Boise.

Happy Birthday to:
Quinn and Nicole

If your Lil' Buddy has a
May or June birthday
please email [Kristie](#) to

have your child
individually recognized
and added to the
Birthday list!

Need more information
on Lil' Buddies
Playgroup? Please
contact [Kristie Yerger](#).

D.A.D.S. Update:

The next D.A.D.S. Meeting will
be Sat, **May 19th** from 6:00pm-
8:00pm at Bounce! in Meridian.
Dads bring the kids (all of
them) so "Mom" can have the
night off! TVDSA will pay for
admission of Dad and children
with DS. Cost for additional kids
will be: under 2: Free, 3-12:
\$4.80, 13 & up=\$5.60

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

Best Buds (Elementary Group) Update:

May Outing:
Wednesday, **May 16th**
from 5:30pm-7:30pm

Potluck dinner and get
together at the Gallas'
Game Room, 11368
Greenhurst Ave in
Nampa.

Main dish and drinks will
be provided by TVDSA.
Please bring a side dish

or your favorite dessert to
share. Please RSVP to
[primary_ed@idahodown
syndrome.org](mailto:primary_ed@idahodown
syndrome.org) by the
14th.

There will be plenty of
time for fun – air hockey,
skee ball and other fun
games!

For directions, please call
Freddie Gallas: 453-4909.

Need more information
on Best Buds Social Group
or want to help organize?
Please contact: [Kristie
Yerger](#).

***"A community that
excludes even one
member is no
community at all."
– Dan Wilkins***

Cool Club (Jr./Sr. High) & Adults In Motion (AIM) Update:

May Gathering:
Saturday, **May 18th** from
6:00pm to
approximately 9:30pm

Activity: Dinner and a
Movie

We will meet at
McDonald's: 7222 W.
Overland Rd, in Boise, at
6:00pm for dinner. Then
we will go across the
street to the Overland
Park Cinema at 7051 W.
Overland Rd in Boise for
a movie. TVDSA will pay
for admission for each

person with DS.
Additional movie ticket
prices are \$3.00 for
adult, \$2.00 for students,
children and seniors.
Most of the PG movies
start between 7:00pm-
7:30pm depending on
the movie you choose.

For more information, or
to RSVP, please contact
[Molly Benton](#) or [Freddie
Gallas](#).



Announcing:

The TVDSA College Scholarship

Are you an Idaho resident,
TVDSA member, and self-
advocate with Down
syndrome, looking at
attending classes at a
college or university?
TVDSA now has a non-
financially based
scholarship for the 2012-13
school year. Applications
are due **June 15th**. To
request an application
please email the
[scholarship committee](#).

Conferences, Workshops, Webinars, Events & TVDSA Scholarship Info

Upcoming PEAK Webinars **FREE**

Grade to Grade
May 3, 2012 12:00-1:00pm
Key Ingredients for Effective IEPs:
May 8th from 5:30-8:30pm
Christy Blakely Webinar
May 15th from 12:00-1:00pm

Idaho Parents Unlimited (IPUL) Parent Support Group

May 8th
6:00pm-8:00pm
500 S. 8th Street, Boise
Topic: Understanding ADHD

For more information, contact [Jen](#)

Sibshops

Program designed for brothers and sisters, ages 7-14, of kids with special needs.

May 12th, June 9th
10:00am-1:00pm
Cost \$5.00 (Meal Provided)
Children's Home Society
704 N. 7th St. Boise
Call 433-8845 to Register

Down Syndrome at
[AutismOne](#)
May 24th, in Lombard, Illinois

Demystifying Medicaid

Presented by Alicia Ward from the Lily Pad. Sponsored by Elks Rehab. Learn how to apply for Medicaid/Katie Beckett, who qualifies and all about the Medicaid redesign
Thursday, **June 7th** 7:00-8:30pm at St. Luke's Meridian, lower level conference room
Free – but must register: 706-5549

[National Down Syndrome Congress Annual Convention](#)
July 19-22
Washington DC
Registration is Now Open!

TVDSA Scholarships

Are you considering attending an upcoming workshop or conference?

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.

Talking With Your Child continued from page 2

the curiosity of others. Some parents avoid the topic of their child's disability because they are afraid that they will say the wrong thing to the child. However, one of the most important things you can do as a parent is to help to "normalize" the disability and let the child know that home is a safe place to voice their concerns and frustrations. If you don't know how to answer a question that your child has, be honest with the child. For example, you could say, "That is a really good question. I don't have the answer for you right now, but I will call Dr. Smith in the morning and

schedule an appointment so that you can talk with him more about it." Teaching children how to articulate their concerns and questions and helping them to connect with others who can answer these questions is an irreplaceable self-advocacy skill that will benefit them at all future stages of development.

Source: A Quarterly Publication of the Parent Network of the Capital Region, NYC

Join the Celebration while Supporting TVDSA



Bubba Watson, a Boise favorite, won the Masters!

Back in 2003, Bubba was just getting his feet wet at the Albertson's Boise Open, and now he is on top. Don't miss your chance to see the future stars of the PGA Tour at the 23rd annual Albertson's Boise Open presented by Kraft, September 10-16, 2012 at Hillcrest Country Club. Thanks to Sara Lee TICKETS Fore CHARITY program, 100% of the ticket price will go directly to Treasure Valley Down Syndrome Association.

Order your tickets and support a worthy cause today, by visiting: www.albertsonsboiseopen.com

"If you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid."

- **Albert Einstein**



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PO Box 1404
Meridian, Idaho 83680

We're on the Web!

See us at:

www.idahodownsyndrome.org

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

Legislative Update by Deborah Waters

House Bill 609 unanimously passed in the Senate on March 20, 2012. This bill restored some of the cuts to Medicaid from last year. The bill includes the following three changes:

1. People with dual diagnoses will not have to choose between receiving skill training for their mental illness management (PSR) or

their developmental disability (developmental therapy).

2. The language in HB 260 that said that budgets for adults with developmental disabilities would be placed in tiers similar to what is being done with children's services redesign has been deleted.

3. Preventative and

restorative dental services for adults with disabilities on the DD and A&D waiver will be allowed.

House Bill 609 has a fiscal impact of \$1.5 million to the State General fund, and restores \$3.8 million in federal funds lost from last year's bill. Looks like we took a step in the right direction this year!

From the TVDSA Lending Library by Mary Anne Murphy

Kids with Down Syndrome

by Will Schermerhorn

Kids with Down Syndrome is the next in a series of DVD's that brings together parents and professionals from all around the world, to give an up-to-date and comprehensive guide from the years when kids learn to walk, to just before adolescence. Along with the joys of childhood come the everyday challenges of parenthood, such as toilet training and behavior

issues, and the demands of caring for a child with special needs, including IEP preparation and working with health care professionals. Parents whose children are preschoolers or elementary students will find this DVD pleasing to watch as well as informative. This DVD is available from the TVDSA library.

This DVD set is available from the TVDSA library. You 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.

Board of Directors:

President: [Paul Auger](#)
Treasurer & Advisor: [Lynda Wells](#)
Treasurer & Spanish Contact: [Lucy Olmos](#)
Buddy Walk Chair: [Melody Witte](#)
Librarian: [Mary Anne Murphy](#)
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Community Outreach: [Trish Vranish](#)
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Marketing: [Jason Woodward](#)

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