

## **TVDSA Newsletter**

Newsletter Editor: Celena Auger

March 2013



There are a lot of BIG
TVDSA activities in March:
the Family Meeting on the
12th, World Down
Syndrome Day
Celebration on the 21st,
and the 3rd Annual Easter
Egg Hunt on the 30th. We
hope to see you at one or
all of the activities!

Included in this newsletter you will find the synopsis of a key note speaker at the DownsEd Conference as shared by attendee: Becky Preece.

This month, you will also meet Jennifer Rice, who recently took over the leadership of Lil' Buddies. Over the next several months we will be highlighting our social group volunteers that bring together our children of all ages. Get to know the leaders and why they do it

To partake in any social activity, you do not have to be a member or join the subgroup, just come and meet new people and have a good time!

Monthly and archived TVDSA newsletters are available on our website at: <a href="https://www.idahodownsyndrome.org">www.idahodownsyndrome.org</a> for viewing and sharina.



## Thursday, March 21, 2013 6:00pm - 8:00pm

#### **Location: the Clubhouse Event Center. in Boise**

7311 W. Potomac Dr. located near the Boise Towne Square Mall

Bring your entire family to enjoy a light dinner and dessert, entertainment, and dancing!!

See the following information for ways YOU and your LOVED ONE with Down syndrome can participate at this upcoming celebration.

- 1. **TVDSA got Talent** Calling all talented persons with Down syndrome! We want YOU to show off your talent at our celebration. Whether it is playing an instrument, singing the alphabet, dancing, showing a special painting, telling a story, or any other special talent you would like to share. Please contact <u>Erin Rosenkoetter</u> for more info.
- 2. <u>VIDEO CONTEST</u> put together a 2-3 minute video (slideshow, PowerPoint, etc.) that shows "How someone with Down syndrome has inspired me or changed my life." Anyone that has been influenced by a person with Down syndrome is welcome to submit a video (to include siblings, grandparents, parents, friends, teachers, etc.). Video submissions will be voted on the night of our celebration, and PRIZES will be awarded. Videos are due by March 15<sup>th</sup>.
- 3. <u>TVDSA T-SHIRT ART CONTEST</u> if you are a person with Down syndrome that loves to draw, this contest is for you! As part of a new fundraiser this year, TVDSA will be selling logo t-shirts. The winner of this art contest will have his/her art displayed on the shirt!!! All artwork must be turned in by March 15<sup>th</sup>.

For more information, or to offer your help, please contact: Erin Rosenkoetter

## 3<sup>rd</sup> Annual TVDSA All-Ability Easter Egg Hunt

## Saturday March 30th from 2:00pm-4:30pm At Guerber Park, in Eagle

2200 E. Hill Road

TVDSA invites all elementary and younger kids, and their families to join us.

There will be separate egg hunts for different age groups.

Plenty of eggs for everyone!

Back by popular demand, bunnies and chickens will be there.

The Eagle Fire Department will be there with a fire engine to explore too!

<u>Directions:</u> from State Street – head north on Hwy 55. Take first left hand turn on Hill Road, (heading West). The park is 0.2 miles up on the right hand side.

For more information or to help with this event, please contact: Kristie Yerger

#### Calendar of Events

#### March 7-8th:

Tools for Life: Secondary Transition and Assistive Technology Fair 2013: Everyone Can Work www.idahoat.org

#### March 12th:

#### **TVDSA Family Meeting**

7:00pm-9:00pm A New Leaf, Meridian Topic: Parent Panel Contact: <u>Erin Rosenkoetter</u>

#### March 16th:

AIM Pizza Party and Easter Egg filling from 3:00pm-5:00pm at Kristie Yerger's house in Eagle Contact: Freddie Gallas

#### March 19th:

**TVDSA Board Meeting** 7:00-9:30pm at A New Leaf Contact: <u>Paul Auger</u>

#### March 21st

#### World Down Syndrome Day

6:00pm-8:00pm at the Clubhouse Event Center in Boise

Contact: Erin Rosenkoetter

#### March 30th:

#### TVDSA 3<sup>rd</sup> Annual Easter Egg

**Hunt** 2:00pm-4:30pm at Guerber Park in Eagle Contact: <u>Kristie Yerger</u>

#### July 19-21st:

#### NDSC Conference

Denver Co
<a href="Registration">Registration</a> opens in March!

## TVDSA Family Meeting

March 12th

from 7:00pm-9:00pm at A New Leaf 2456 N. Stokesberry, Meridian

#### **Topic: Parent Panel**

Parents of children of all ages with Down syndrome, each that took different paths, will be available to answer questions on all topics – growth, education, puberty, independence, etc.

Come with your questions!

## High quality, evidence-based guidance and information for families: Shared by Becky Preece

DownsED Down Syndrome Education Conference, Newport Beach, CA November 7, 2009

"Downsed is a group that exists to advance the education and development of individuals with Down syndrome worldwide through research, information and support." Their goal is to share their research findings directly with us through publishing, website and training activities. Their website is found at <a href="https://www.downsed.org">www.downsed.org</a> (Londonbased) and <a href="https://www.downsedusa.org">www.downsedusa.org</a> (USA-based).

## <u>How Can We Best Help our Children to Achieve Their Potential?</u>

One of the first things the Professor Sue Buckley started with was to emphasize that children with DS are not globally delayed; that is, they are not delayed in all areas just because of their diagnosis. They are not like a car's engine, with all the parts there at birth and unchangeable. Rather, they are born with specific areas of difficulty/delay, and other areas of strength. Their areas of strength can be used to support their learning. Their brains grow and develop with input and activity.

Areas of difficulty include (this is recognizing that all of our kids are not the same, of course, in all areas, but some generalities can be made) learning from listening only, hearing and vision, verbal short-term memory (getting their ideas across in a conversation), and numbers.

Areas of strength include social understanding, empathy, and social skills (no big surprise here!) as well as self-help and daily living skills, visual short-term memory, visual learning, and reading. (All of the citations for research supporting this are included on the slides from the PowerPoint presentation).

Of course there is a wide range of individual differences in the severity of learning difficulties.

One of the most important things she emphasized was that our kids usually have a very early social understanding, and that it is very important to build upon this by expecting good behavior, and setting clear boundaries from infancy. They will use this understanding to be "difficult", and we should expect age-appropriate behaviors. She said that it could be considered the most important issue-like all other children-being able to behave in a

socially appropriate way (manage impulses and emotions) and to make friends and relate to others. Basically, having Down syndrome is NOT an excuse to behave badly. We shouldn't make excuses for our children; we should get help when we need it! Difficult behavior leads to stress for all the family.

It was also interesting to note that children with DS have similar levels of behavior problems as typically developing children of the same mental age (i.e. younger), but they have fewer difficult behaviors than others of the same chronological age with similar levels of learning difficulties (but not Down syndrome). They have more behavior difficulties than their same-age typically developing peers, mostly due to their speech and language delays. This is why inclusion is so important.

It shouldn't surprise us that their understanding greatly exceeds their ability to express what they understand. Our kids want to get their message across, but often find it difficult. Language is of utmost importance because "the speed with which you learn words is the speed with which you learn about the world." In other words, you can't think about or talk about something for which you don't have the words! Buckley displayed a very interesting graph that showed the relation between vocabulary and grammar. Basically it showed that more words=more grammar. Once kids know about 200 words is when they usually start to use grammar. For a typical child this comes between 18 months-3 years old. For kids with DS it is between 3-8 years old. There is a much bigger range for kids with DS.

As far as working memory goes, some very new research findings indicate that we need to compensate for their delay in this area by giving **short instructions and visual support**. There is also some evidence of effectiveness using games and computer programs. Their website has more information on this.

As far as **signing**, it does help to compensate for hearing loss; our kids are good at gesture; signing can reduce frustration as spoken words are delayed relative to comprehension; signs support good communication and language teaching, as well as comprehension of new

Continued on Page 3

## **High Quality Evidence** (Continued from Page 2)

words; they can aid intelligibility when speech is not clear; and children supported by signing may have larger vocabularies up to 4 years. However, the focus should always be on using signing as AUGMENTATIVE only-a bridge to speaking and by school age signs should only be used as necessary for individual children. Teaching talking is the priority in school.

Another interesting note was that research indicates that **teaching reading improves speech**, **language and working memory skills**. Printed words seem easier to remember than spoken words. One of the most remarkable slides was the one that compared inclusion to special schools in several different areas. Most remarkably, children who are mainstreamed into a regular classroom are able to improve their speech, language and literacy skills and bring them more in line with their other skills. The immersion in mainstream classrooms and the resulting immersion in **reading activities** may explain this gain-even for non-readers. **Speech and language is held back by hearing and auditory processing difficulties-print makes the language visual (one of their strengths!)**.

Inclusion is so important-teenagers fully included in mainstream classes had gains of more than 2 years in spoken language skills and 3 years in reading and writing. They also had gains in math, general knowledge and in social independence. They also tended to have better behavior. However, it is also important to note that both full inclusion as well as adapting the way we teach to the children's specific needs are key to the positive outcomes listed above. Behaviors were also better in mainstreamed classes. Only 10% of the children with DS had significant levels of behavior difficulties, compared to 30% who were in a special school.

## <u>Looking Forward: How do we support full inclusion and meaningful lives?</u>

"A family should be a circle, where everyone is as important as the other and no one person is on center stage the whole time." When Sue Buckley said this it really had a great impact on me. She really surprised me by talking mostly about balance. Our children have the right to an "ordinary life," she said. At first I thought, "Well, that doesn't sound great." But the more she talked about it, the more it made sense. Our children deserve to be like the rest of us: a playful, loving childhood, an angst-filled adolescence, and a meaningful adulthood that includes independent living, relationships, and jobs.

Our children go through life based on age just like everyone else-school at 5 years, puberty in early teens, out of school at 17-the milestones are the same. So we need to treat them according to their age, and have expectations accordingly. This will help them to fit in socially with the world around them and the people around them-the most important factor in a "good life".

As children, our kids with DS have the same needs as all children-the need to feel loved and valued-at home, at school, and in the community. One of the most important, if not the most important factor in how our children will grow and develop is based on the opportunities they have within our own families to learn and grow, to experience ordinary family life, social activities, etc. Ms. Buckley said, "If you have a choice to make between taking your child to therapy and taking your children to the park, for heaven's sake go to the park!! " What she means is that they will get all the therapy they need there, socially and physically, and also enjoy the interaction and belonging that those types of experiences engender. I don't know about you, but that really hit me so hard. There have been so many times I've had to take Jake to therapy and interrupt a great bonding activity to do it. Or other times when I've thought how fun it would be to take the kids swimming or to the park or activity center, but was too tired to follow through because of all the running around to different therapies we had done all day! It was very refreshing to have a professional, and highly educated woman and researcher, who knows all of the benefits of early intervention and therapies, etc. to say it's okay to not always be doing something "educational" therapeutic. Everything has a time and place and the importance is to try to maintain some sense of balance in our families, and not let our child with DS "take over" the family and its needs.

Another important topic she discussed was the importance of social competence. Friendships for our kids need active planning and support. Parents need to take initiative outside of school to see that their kids have opportunities to play with other kids. Full social inclusion needs planning in school. Drama, sports, leisure skills will help, and we should encourage a wide range of activities. Social skills and confidence are learned in social situations.



**Teacher Born with Down Syndrome Breaks Stereotype:** Click <u>here</u> to watch a short clip of a Columbia, South Carolina teacher and her story. Bryann Burgess is living proof that with motivation and a positive attitude there is nothing that can't be accomplished.

## Social Groups Page

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

D.A.D.S. will not be meeting at Fuddruckers this month due to Spring Break.

D.A.D.S. are asked to help use their muscles during setup and tear down of the event chairs and tables at the World Down Syndrome Celebration, March 21st from 6:00pm-8:00pm at the Clubhouse Event Center in Boise

For more information about **D.A.D.S**. please contact <u>Gus Olmos</u>

## **Moms' Night Out:**

There will be No Outing in March.

Please join TVDSA at the World Down Syndrome Celebration, March 21st from 6:00pm-8:00pm at the Clubhouse Event Center in Boise

For more information or to help organize, please contact <u>Kristie</u> Yerger

Are you interested in participating in one or more of the social groups? Unsure how to get started? You do NOT have to be a member of TVDSA or of the sub-group. Just come, meet new people, relax & have some fun!

## TVDSA Newsletter

## Page 4 of 6

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

March Gathering:

Lil' Buddies will not be hosting a playgroup in March. Instead, we hope you will attend the **World Down Syndrome Day Celebration**, Thursday, March 21<sup>st</sup> from 6:00pm-8:00pm at the Clubhouse Event Center in Boise.

In addition, please join us for the **3<sup>rd</sup> Annual Easter Egg Hunt**, Saturday, **March 30<sup>th</sup>** from 2:00-4:30pm at Guerber Park in Eagle. Need more information on **Lil'Buddies**? Please contact <u>Jennifer Rice</u>



## **Best Buds (Elementary) Update:**

March Gathering:

Best Buds will not be hosting an outing in March. Instead, we hope you will attend the **World Down Syndrome Day Celebration**, Thursday, **March 21**<sup>st</sup> from **6:00pm-8:00pm** at the Clubhouse Event Center in Boise.

In addition, please join us for the 3<sup>rd</sup> Annual **Easter Egg Hunt**, Saturday, **March 30**th from **2:00pm-4:30pm** at Guerber Park in Eagle.

Need more information on **Best Buds**? Please contact <u>Kristie Yerger.</u>

## Cool Club (Jr./Sr. High)

March Gathering: There will be no Cool Club Gathering this month.

Please join us at the TVDSA World Down Syndrome Celebration, March 21<sup>st</sup> from 6:00pm-8:00pm at the Clubhouse Event Center in Boise!

For more information about **Cool Club** please contact: <u>Melanie</u>
<u>Berlini</u>

## **Adults in Motion (AIM)**

March Gathering:

Adults in Motion will be having a **pizza party** while filling Easter Eggs for the TVDSA Easter Egg Hunt on March 16<sup>th</sup> from 3:00pm-5:00pm at Kristie's house: 478 E. Stonewater Ct. in Eagle (208-921-4300). Please RSVP for accurate pizza purchasing to Freddie: 409-718-0417. We will also be helping out at the TVDSA Easter Egg Hunt on March 30<sup>th</sup> from 2:00pm-4:30pm in Eagle.

For more information about **AIM** contact: <u>Freddie Gallas</u> or <u>Niculina (Nina) Bistriceanu</u>

# Boise Parks & Recreation's AdVenture Program Adaptive Recreation

Boise Parks & Recreation's Adaptive Recreation program provides a wide range of recreational, social and educational programs for youth and adults with disabilities. Individuals with disabilities can choose to participate with one of our adaptive recreation programs which are specifically designed for someone with a disability or utilize inclusion services in which accommodations may be provided so that an individual with a disability can fully participate in any of Boise Parks & Recreation's programs. Scholarships are available for youth and for adults with disabilities.

AdVenture offers classes, camps, outdoor trips, and recreation activities designed for people with a variety of disabilities including, but not limited to: orthopedic, spinal cord, neuromuscular, hearing and visual impairments as well as intellectual disabilities.

To learn more, please visit <a href="www.cityofboise.org/AdaptiveRecreation">www.cityofboise.org/AdaptiveRecreation</a>, call 208-608-7680 (TTY 1-800-377-3529), e-mail <a href="mailto:AdVentureProgram@cityofboise.org">AdVentureProgram@cityofboise.org</a> or like us on Facebook, <a href="www.facebook.com/bprAdVentureProgram">www.facebook.com/bprAdVentureProgram</a>.

## Conferences, Workshops, Webinars & TVDSA Scholarship Information

#### Trisomy 21 Conference

March 2, 2013

The Renaissance Hotel Houston, Texas

Tools for Life: Secondary Transition and Assistive Technology Fair 2013: Everyone Can Work

#### March 7-8th

at the Riverside Hotel in Boise Idaho Registration Now Open www.idahoat.org

#### It's My Business EXPO

#### March 7th 4:00pm-8:00pm

In the Aspen Room at the Riverside Hotel in Boise

Expo Admission is Free

Featuring the businesses, products, and services of people with disabilities.

#### Idaho Parents Unlimited Mid-Week Mini-Conference March 19-20<sup>th</sup>

Coeur d'Alene, Idaho

Free to Families! <a href="http://www.ipulidaho.org">http://www.ipulidaho.org</a>

## Northwest Conference on Families

Unlocking Doors: Effective Strategies for Engaging Families

#### April 11-13th

at the College of Idaho, Caldwell email



## Home Depot Workshop for Kids with Disabilities

## April 20th, June 15th, August 17th & October 19th

from 9:00am-12:00pm at the Meridian Home Depot: 1100 S. Progress Ave Meridian

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.

Come to one or come to all.

#### 2013 NDSC Conference: "Causecation" July 19-21st

Denver Colorado

Registration opens in March! convention.ndsccenter.org

#### Wrightslaw Conferences

Special Education Law and Advocacy

Various dates and locations across the U.S.

#### **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.

# Get to know our Social Group Leaders: Jennifer Rice parent coordinator for Lil' Buddies:

Hi everyone!

My name is Jennifer Rice and I'm the new organizer for the Lil' Buddies group. I'm originally from Hawaii, moved to Seattle for college (Go Huskies!), and we came to Boise two and a half years ago. My husband, Mark, and I have two kids, Caleb (5) and Charlotte (1). We joined TVDSA a little over a year ago after Charlotte was born and it has been a wonderful, supportive group. I'm excited to give a little something back now! I love to read, would do crafts all day if I could, tend to dance in the kitchen while cooking dinner, and am addicted to Pinterest.

Over the next few months we will highlight some of our different volunteers.



## **GoodSearch and TVDSA**

You search the internet all the time anyway, why not do it and earn money for TVDSA. Just go to: <a href="www.goodsearch.com">www.goodsearch.com</a> and select TVDSA as your favorite cause. Simply search Down syndrome, we can be found near the end of the list. Then every time you do an internet search a donation is made to TVDSA. Tell everyone you know about GoodSearch for TVDSA.

## **Idaho Gives Day, May 2nd, 2013**

TVDSA is lucky enough to be part of the 1<sup>st</sup> Annual Idaho Gives Day.
The date to save is May 2<sup>nd</sup> and it's online.

More details to come on this event in the coming weeks, watch your email.

For more information, contact Malu Mulholland





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

We're on the Web!

See us at:

www.idahodownsyndrome.org

Check us out on <u>Facebook</u> and <u>Twitter!</u>

# TVDSA 2013 Calendar Closeout Special



For \$15, the price of the Calendar, you get a Calendar <u>AND</u> a set of 11 unique TVDSA Note Cards!

(while supplies last)

You can order your calendars <u>online</u> or email <u>Kristie Yerger</u>

TVDSA needs your ideas. We are looking for your fun and interesting ideas for fundraising. Have a favorite place to go or eat - let us know.

All ideas are welcomed please email Malu at

<u>fundraising@idahodownsynrome.</u> <u>com</u>

## **Announcing the TVDSA Greeting and Note Cards!**

TVDSA has greeting & note cards available to purchase. The original calendar photo shoot pictures are now greeting & note cards!

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

To <u>view and order</u> the greeting/note cards visit our: website or contact: Kristie Yerger.

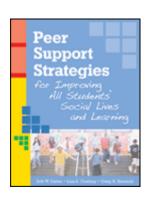


## From the TVDSA Lending Library:

# Peer Support Strategies by: Eric Carter, Lisa Cushing, and Craig Kennedy

These authors detail how peer support can help a student with disabilities to improve academic outcomes, social skills, and self-esteem. After convincing the reader of the importance of peer support, the authors explain how to implement peer support in the lives of students who need extra support.

Peer Support Strategies 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.

#### Board of Directors:

President: <u>Paul Auger</u> Advisor: <u>Lynda Wells</u>

Treasurer & Spanish Contact: <u>Lucy Olmos</u>
Community Outreach Chair: <u>Erin Rosenkoetter</u>
Fundraising & Membership: <u>Malu Mulholland</u>

Vice President and Programs Chair: Kristie Yerger

Secretary: Audrey Byrum

Buddy Walk Chair: Melody Witte
Buddy Walk Chair: George Taylor
Self Advocate: Seth Paetel

For more information, articles, past newsletters and more, please visit our website: <a href="http://idahodownsyndrome.org">http://idahodownsyndrome.org</a>
Mailing: PO Box 1404 Meridian, ID 83680; Check us out on Facebook and Twitter