

# **TVDSA Newsletter**

Newsletter Editor: Celena Auger

February 2016

#### In this Issue

February is the month of "love." We love our children, our spouse, but don't forget to take time for yourself, to love you!

This month's newsletter is FULL of events, activities, and opportunities. TVDSA is hosting "The Art of Advocacy in Education and Legal Planning for Life After 18" on February 20<sup>th</sup>. TVDSA is also a sponsor of the Resource Expo at the Family Caregiver Conference held at BSU on the 20<sup>th</sup>. Many of our social groups have activities planned, and World Down Syndrome Day is right around the corner. Mark your calendars today!

You will also find information about some of the events TVDSA has planned for 2016: iCan Bike Camp in June, Vacation Package – "Disneyland for Four" Raffle, a Golf Tournament, and the TVDSA Calendar is making a comeback! Consider helping with one or more of these, and help 2016 be a year to remember!

Also included this month is an article of tips on Self-Determination and how to help raise our children to be self-determined when they are older.

Don't forget to check out the numerous conferences and workshops on Page 5. It seems to be the season! There is something for everyone.

Monthly and archived TVDSA newsletters are available on our website at;<u>www.idahodownsyndro</u> <u>me.org</u> for viewing and sharing.

### Parents of children/youth/adults with any type of disability:

Get peace of mind from knowing what to do for your child, when it needs to be done, and how to do it.

# Sign Up For This Workshop Today! The Art of Advocacy in Education and Legal Planning For Life After 18

Join attorney Char Quade and advocate Charmaine Thaner Saturday, Feb. 20th 8:30 - 3:00 (lunch provided) St. Luke's Hospital in Meridian, Idaho

Members of Treasure Valley Down Syndrome Association\$15.00Non-members of TVDSA\$25.00

Register by emailing conference@idahodownsyndrome.org

Sponsored by the Treasure Valley Down Syndrome Association

Click here for the full page version with additional information about this opportunity.



### Save the date! Monday, March 21 is World Down Syndrome Day! Come celebrate with TVDSA!

Details will be provided in the March newsletter.

<u>Want to help this year's celebration be grand?</u> Please contact Erin Rosenkoetter at <u>community@idahodownsyndrome.org</u>

### TVDSA <u>Calendar of Events</u>

#### February 2<sup>nd</sup>:

**TVDSA Board Meeting** 7:00pm at A New Leaf. Contact: <u>Kristie Yerger</u>

#### February 6<sup>th</sup>:

Lil' Buddies 1:00pm at Zoo Boise for "Wild at Heart" event. Contact: <u>Elisha Jimenez</u>

#### February 13th:

**Best Buds Valentine's Date** at 1:00pm at Boise Aquarium Contact: Danielle Williams

#### February 20th:

The Art of Advocacy in Education and Legal Planning for Life After 18 8:30am-3:00pm at St. Luke's Meridian. Lunch included. Register today! Contact: <u>Reme Echevarria</u>

#### February 27th:

**Cool Club** at 2:00pm at Ceramica Contact: <u>Brenda Taylor</u>

#### March 21st:

#### World Down Syndrome Day Celebration Contact: Erin Rosenkoetter

June 6<sup>th</sup>-10<sup>th</sup>:

Treasure Valley iCan Bike Camp. Registration opens March 1<sup>st</sup>.

Contact: Paul & Celena Auger

### 5<sup>th</sup> Annual Disability Awareness Day

#### February 23<sup>rd</sup> 9:00am-3:00pm Idaho Capital Building 4<sup>th</sup> Floor

Join people with disabilities, families, providers and friends to create a strong Idaho disability awareness community.

- Collect information about the ABLE Act
- Learn about the new rules provided by Home and Community Based Services (HCBS)

Sponsored by: Consortium for Idahoans with Disabilities <u>www.idahocid.com</u>

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# **Self-Determination**

Self-determination is about youth with disabilities taking control of their lives. Strategies to assist your son or daughter in developing self-determination skills can be found here:

#### Tips to encourage self-determined behavior

- ✓ Encourage youth to make choices about everyday activities
- ✓ Encourage youth to set priorities
- ✓ Help youth identify strengths, interests, and preferences
- Talk to youth about the process of setting goals, including barriers they may encounter
- ✓ Educate yourself and youth about rights

#### How should I talk to youth about their disability?

- ✓ Focus on the youth not the disability; talk about the many unique gifts the youth brings to the class
- ✓ Having strong expectations of youth will influence their achievements
- Provide honest and specific feedback to youth; praise efforts and help them accept criticism when it is warranted
- ✓ Use person-first language and terms youth can understand
- Know that by having frank discussion with youth, you are modeling important selfdetermination skills

#### Tips for Raising a Self-Determined Child

- Never give up on your youth
- Teach them that they are equal to anyone else, even though they have a disability
- ✓ Meet the obstacles together as a family
- ✓ Let them know they have a disabilities and what that means for them
- ✓ Know the rights of a person with a disability and let others know too
- ✓ Push them to be the best they can be
- Allow some opportunities without parents for youth to experience their own strengths
- ✓ Support them to get out among other people to learn. Allow them to meet other people with disabilities, hear their stories and what they have overcome.
- ✓ Let them know they have a role. Give them opportunity to do it themselves. Give them responsibilities from a young age.
- $\checkmark$  Listen to preferences and honor them.
- ✓ Let other people tell them things they might not listen to coming from their own parents.
- $\checkmark$  Enable them to know their strengths, interests, and who they are.
- ✓ Accommodate to the disability in the family, and realize that meeting each other's needs goes both ways: family to youth; youth to family.
- ✓ Be involved. Talk to all teachers, and help your youth move forward in their lives. Support their decisions and work gradually to turn over the reins.
- ✓ Communicate love freely
- ✓ Have faith; time is a factor. Self-determination doesn't happen overnight.
- ✓ There is joy in the journey. Disability is only a part of it.

Source: Virginia Department of Education's I'm Determined Project www.imdetermined.org/parents

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### **Treasure Valley iCan Bike Camp 2016**

June 6<sup>th</sup>-10<sup>th</sup>, the <u>iCan Shine bike program</u> will be back in Idaho at the Homecourt YMCA in Meridian to teach individuals with disabilities <u>ages 8 & older</u> how to ride a conventional bike and become a lifelong independent rider.

<u>Rider Registration opens March 1st</u> Registration will be open through May 15th, on a first come first serve basis. Only a limited number of slots are available.

Cost for the week long camp, t-shirt and safety helmet is:

Non-TVDSA members: \$199.00

**Returning riders:** \$25.00 discount\*

TVDSA Members: \$149.00

\*To qualify, rider they must have attended the Treasure Valley iCan Bike Camp in 2014 or 2015 & payment received by May 1<sup>st</sup>, 2016.

Multiple Family Member Registration: \$25.00 discount per rider in the same immediate family and household.

iCan Bike uses a fleet of adapted bicycles, a specialized instructional program, and a trained staff to teach individuals with disabilities how to ride a bike. Riders attend the same 75-minute session each day for five consecutive days (M–F) whereby they are physically assisted and encouraged by two volunteer "spotters."

Over the course of the 5-day camp the adapted bike is adjusted to gradually introduce more instability in an effort to challenge riders at their own individual pace. Success in learning to ride a bicycle is a major accomplishment. Learning to ride builds confidence and an improved self-image. Over the past two years, over 80% of the participants became independent riders of a traditional 2-wheeled bike at the Treasure Valley iCan Bike Camp. We hope to have the same results this year!

For more information, please email Paul & Celena Auger at tvicanbike@idahodownsyndrome.org.

### **Special Needs Legislative Update** by Virginia Beringer

#### NATIONAL UPDATES:

As stated last month, **Every Student Succeeds Act** (ESSA) was made into law December 10th. An important piece of this law is the **Universal Design for Learning** (UDL). UDL is a set of principles for curriculum development that give all individuals equal opportunities to learn. Although Idaho has not established state specific guidelines, advocates are encouraged to spread the principles throughout the state and more specifically to the school districts. See more <u>by clicking here</u>.

As many may know, the **ABLE (Achieving a Better Life Experience) Act** was passed December 19, 2014 (PL 113-295). This federal law allows tax-free savings accounts for individuals with disabilities without eligibility penalties for government assistance and services. You can learn more about ABLE <u>by clicking here</u>. The ABLE Act in Idaho will be also discussed at the TVDSA mini-conference on February 20<sup>th</sup>.

#### **IDAHO UPDATES**

On January 7, 2016, Governor Otter presented the **Primary Care Access Program** (PCAP) as an alternative to federal Medicaid expansion. For more information on this Program, <u>click here</u>. Close the Gap Idaho, a coalition of 120 organizations, argue the PCAP will not be a suitable alternative to Medicaid expansion. Close the Gap Idaho website: <u>http://closethegapidaho.org</u> and their <u>press release</u>.

THE BOTTOM LINE: PCAP would be limited to "basic preventative, physical and mental care. Services also include basic lab, x-ray, pharmacy and limited office based behavioral health services, depending on availability at a given clinic. Hospital stays, emergency department use, or specialty care are NOT included".

Additional Governor-supported efforts: proposed funding for a behavioral health center in southern Idaho to address Idahoans who are mentally ill and high risk for expensive interventions; additional \$270,600 in general funds for the vocational rehabilitation program to capture an additional \$1 million in federal funds, and additional \$340,000 in general funds for reducing the wait list in the Extended Employment Services (EES) program.

Source: Weekly updates on Idaho Legislation sessions from Community Partnerships of Idaho, Inc., (CPI) by Bibiana Nertney

You can contact your legislators in a variety of ways: Telephone call, personal visit, a letter or even e-mail. <u>http://legislature.idaho.gov/howtocontactlegislators.htm</u>

If there is an area of legislature you would like more information on please email <u>Virginia Beringer</u> with your interest/request.



# **Social Groups** Page

## **Mom's Night Out!**

#### No Mom's Night Out! in February.

Valentine's Challenge: Go on a date with your spouse/significant other.

For more information about Mom's Night Out! contact Reme Echevarria by email or by phone (call/text) at 208-866-4095





"Little League is for Everyone!"

Open to ALL, ages 5 and up, with any kind of special needs. Everyone welcome. Teams are set up by age and ability.

TVDSA is proud to sponsor two teams this year.

Season runs from Mid-April through June. Registration fee: \$35.00 Registration Deadline: March 15th

Click here for more information, or contact: Tammy Cluff: idchallenger@aol.com or 208.362.3072

# Lil' Buddies

Lil' Buddies is going to the "Wild at Heart" event at Zoo Boise, Saturday, February 6th at 1:00pm. We will have valentines to pass out to the kids, plus they can participate in the Zoo Boise event. It is free for everyone. We will meet at the front entrance at 1:00pm.

"Wild at Heart at Zoo Boise is a family friendly Valentine's themed event full of fun things to do. There

will be face painting, photo-ops, and special Valentine themed enrichments for all the Zoo Boise animal residents. Plus, you'll be able to make a Valentine's Day card for your favorite animal! Admission is free."

Need more information about Lil' Buddies? Please contact: Elisha Jimenez at 208-871-4780



**Best Buds** 

The Best Buds Valentine's Date will be Saturday, February 13th at 1:00pm at the Boise Aquarium located at 64 N Cole Rd, in Boise.

TVDSA will provide lunch and pay for admission for those with Down syndrome and their siblinas. Parents and other adults will need to pay their \$8.00 admission.

### **Cool Club**

In February, Cool Club will be meeting at Ceramica for some creativity and fun! Please join us on Saturday, February 27th at 2:00pm at Ceramica, located at 1002 S. Vista Ave. in Boise in the Vista Village Shopping Center. TVDSA will pay for a pottery piece and the studio fee for each teenager with Down syndrome.

We will be having lunch inside at the picnic tables and then explore the aquarium afterwards. Please RSVP by February 10<sup>th</sup> for lunch preparation, and let Danielle know if there are any dietary restrictions.

For more information on Best Buds contact Danielle Williams at 208-794-8995.

Additional pieces can be purchased by the parent. Snacks will also be provided. Please RSVP by February 12th.

For more information about Cool Club or to RSVP contact Brenda Taylor at 208-724-5226.

### Free Home Depot Workshop for Kids with **Special Needs!**

When: Saturday, February 20th from 9:00am - 12:00pm



Who: Open to ALL Ages!

Where: Meridian Home Depot at 1100 S. Progress Ave, Meridian, ID

This free workshop provides a fun, quiet, low stress, warm, and welcoming environment for kids with special needs of all ages and abilities. Various materials and kits will be provided for the enjoyment of all!



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## **Conferences, Workshops, Webinars & TVDSA Scholarship Information**

#### 5<sup>th</sup> Annual Family Caregiver Conference Moving Conversation to Action

#### Saturday, February 20<sup>th</sup> 8:00am-4:00pm

Friends in Action, BSU and IPUL have come together to make this a conference you don't want to miss! <u>Click here</u> for more information.

Registration is \$30 per person and includes the Conference, Resource Expo, Lunch and Parking.

Registration is now open!



#### Opportunities for Parents IPUL – On a Roll Tour

No matter where you are in Idaho, IPUL is here to help, support, and answer your questions! Please visit their <u>website</u> <u>calendar</u> for further information on opportunities in your area.

 

 February 3rd:
 Boise – Understanding Idaho's Services for Children

 February 4th:
 Bonners Ferry – Success with the IEP and Tools for your Tool Box, TBI

 February 5th:
 Kellogg – Bullying Prevention, Success with the IEP, & TBI

 February 5th:
 Salmon – Tools for Toolbox and TBI Awareness and Support

 February 6th:
 Lewiston – Success with the IEP and TBI Awareness and Support

 February 6th:
 Idaho Falls – Success with IEP, TBI and One-on-one IEP Reviews

 February 16th:
 McCall – Working for

Change and TBI Awareness and Support

#### Idaho Miss Amazing Pageant April 8-9<sup>th</sup> Nampa Civic Center

Miss Amazing offers exciting opportunities for girls and women 5 and older to explore their potential and enhance their strengths.

For four years the Idaho Miss Amazing Pageant has been celebrating the multifaceted identities, valuable abilities and strengths of girls and women with disabilities. Idaho Miss Amazing is so much more than a pageant. It is a platform for girls and women with disabilities to share their abilities and ambitions. It is an experience that inspires all people to empower themselves and each other.

To become involved either as a participant, volunteer or sponsor – please visit www.idmissamazing.com

#### IPUL Workshop Wednesday, February 10<sup>th</sup> from 6:00pm-9:00pm 4619 Emerald Suite E, Boise

**Topic: Planning for a Healthy Transition:** This training prepares youth for transitioning to adulthood with a goal of independent healthcare management.

Please RSVP at 208-342-5884, but RSVP not required.

Can't make it in person?

Attend the webinar on **Tuesday, February 23**<sup>rd</sup> . Same topic – two times to choose from: <u>11:00am-12:00pm</u> or <u>9:00pm-10:00pm</u> Click time to register.

To contact IPUL: 208-342-5884 or parents@ipulidaho.org

#### 2016 PEAK Conference on Inclusive Education

Denver, CO February 25-26<sup>th</sup>, 2016 http://conference.peakparent.org

Inclusive education is a process of school reform that creates equality in education and increases achievement for ALL students, including students with disabilities. PEAK Parent Center's annual Conference on Inclusive Education holds the tools you need to reinvent schools to be places where all students can achieve success!

**Registration is Now Open!** 

#### 2016 Tools for Life: Secondary Transition and Assistive Technology Fair March 1-2<sup>nd</sup> Riverside Hotel Boise, ID

Tools for Life is for transitioning youth with disabilities and all who support them. Attendees include educators, special educators, therapists, counselors, service providers, job developers, other rehabilitation specialists, and especially high school students with disabilities and their families.

The theme of the 2016 Tools for Life Fair is **Making** Assistive Technology Work For You! Throughout the two-day event, there will be keynote speakers and presentations around employment, assistive technology, postsecondary education, and self-advocacy/selfdirection.

For more information, <u>click here</u>.

#### 11<sup>th</sup> Annual All Born (In) Cross-Disability Best Practices Inclusive Education Conference

Portland, OR Saturday, April 23<sup>rd</sup>, 2016 http://allbornin.org/abi-conference/crossdisability-inclusion-conference/

This is an exciting day for parents, caregivers, and professionals working to end segregation in neighborhood schools and the community. Come celebrate and learn how we can use Universal Design for Learning and Best Practices to reach and teach every child. Share, learn and make connections so that we can all go forth to open the eyes of the wider community to the fact that our children are all born "in".

Pre-Registration is Now Open!

#### The application for the O'Neill Tabani Enrichment Fund is now available!

The mission of the O'Neill Tabani Enrichment Fund is to offer financial assistance to young adults with Down syndrome – 18 and older – who are continuing to enrich their lives by taking classes or enrolling in postsecondary educational programs. Read more and download the application, <u>click here.</u>

For any questions or concerns regarding the O'Neill Tabani Enrichment Fund, please either send an email to <u>otef@ndss.org</u> or call 1-800-221-4602



We're on the Web! See us at: www.idahodownsyndrome.org

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

### Welcome New TVDSA Board Member!

TVDSA is excited to announce, for the first time, in a very long time our board of directors is full! We welcome and thank all of the individuals that are donating their time to support individuals with Down syndrome in the Treasure Valley.

TVDSA is excited to introduce the latest board member.

#### <u>Dylan Thaner – Self-Advocate Chair:</u>

Dylan has a talent for creating his dreams! He was the first student with Down syndrome who attended the University of Colorado, Colorado Springs. One of his passions is being on stage, as a public speaker or as a burlesque dancer. Dylan is happy to be asked to serve on the TVDSA Board. He likes to share his ideas, work with others, and make sure people with Down syndrome know they are good enough.



### <u>Call for Volunteers – please help!</u>

TVDSA is planning a full year of activities and events in 2016. The following committees are in need of some help to make them a success. Please consider helping in an area of interest.

#### Vacation Package – "Disneyland: Family of Four" Raffle Sales:

This year TVDSA will be raffling off a Disneyland Vacation! It will include 3 day hopper for 4, airfare, and hotel! Ticket sales will start in March. We need help selling tickets! If interested, contact Kris Goodwin & Reme Echevarria at fundraising@idahodownsydrome.org.

#### Calendar Committee:

The TVDSA Calendar is making a come-back for 2017! If you are interested in helping create this one-of-a-kind calendar please contact Erin Rosenkoetter at community@idahodownsyndrome.org

#### Technology Committee:

Calling All Techies - TVDSA needs volunteers to participate in a Technology Subcommittee. If you are a professional technology expert or just a self-made techie we can use your input. Our first task will be discussions and recommendations for updates to the TVDSA website. If you are interested please contact George Taylor at webmaster@idahodownsyndrome.org.

#### Golf Tournament Committee:

Calling All Golfers (and non-golfers) - TVDSA will be hosting a 2016 Golf Tournament and needs volunteers for a planning committee. Whether you play golf or not, your help would be appreciated. Prior golf tournament planning experience is a bonus! This committee will be planning the event, getting sponsors, and getting participants for the event. If you are interested please contact George Taylor at golf@idahodownsyndrome.org.

The mission of the 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>Kristie Yerger</u> Vice President: <u>George Taylor</u> Advisor: <u>Lynda Wells</u> Co-Fundraising: <u>Kristine Goodwin</u> Co-Fundraising: <u>Reme Echevarria</u> Legislative Chair: <u>Virginia Beringer</u> Treasurer & Spanish Contact: <u>Lucy Olmos</u> Secretary & Membership: <u>Paul Auger</u> Marketing & Buddy Walk Chair: <u>Jason Robles</u> Community Outreach Chair: <u>Erin Rosenkoetter</u> Programs Chair: <u>Andrew Kopping</u> Self-Advocate Chair: <u>Dylan Thaner</u>

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