

TVDSA Newsletter

Newsletter Editor: Celena Auger

October 2014

In this Issue

The October newsletter is again packed full of useful information for all ages. This month there are two articles about reading supports that can be done at home to help success in school. For those families whose interest is a little older – an article discussing what real functional skills are may be of interest.

October is Down
Syndrome Awareness
Month. TVDSA always
celebrates it big with the
annual Buddy Walk. We
hope to see everyone in
downtown Boise October
11th. Enjoy pictures
throughout this newsletter
highlighting last year's
walk!

TVDSA is also celebrating October with daily posts on Facebook of local stories and pictures of those with the attribute of Down syndrome. Please send yours so your family member can be included!

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

2014 TVDSA Buddy Walk Saturday October 11th (Rain or Shine)

On-Site Registration available 8:30am-10:30am at Capital Park
Unfortunately, t-shirt size and color is not guaranteed after September 1st!
(\$25.00 Adults, \$15.00 for kids 12 & under)

Walk will start from Capitol Park at 11:00am, & walk to Julia Davis Park

Footivities at Julia Davis Park will continue through 2:00pm.



Entertainment/Activities:

- Raffle items include: Southwest Airline Tickets, a 7" tablet, Strider Bike, Restaurant gift cards, movie tickets, bowling, and more! 5 tickets for \$20.00
- Food Trucks (NEW) Several vendors with Buddy Walk Specials will offer food choices, bring cash with you (food is <u>not</u> included with registration).
- Performances: Mossi, a singer song-writer and voice of Brobee from the hit television show, Yo Gabba Gabba, Buster Bronco, and always a hit the All-Ability Dancers will be back again this year!
- **Bike Course:** Ride a Strider Bike through the **NEW** TVDSA Buddy Walk Bike Course (bike and helmets are provided)
- Games for the kids: kids can play 7 games for FREE throughout the park for prizes.
- Bounce Houses: 4 bounce houses for fun by all!
- Face Painting: Free face painting for anyone interested.
- Dancing: close out the walk with the annual stage dancing, open to everyone!

We hope to see you all there!

October – Down Syndrome Awareness Month

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

TVDSA <u>Calendar of Events</u>

October 7th:

TVDSA Board Meeting
7:00pm-9:00pm at A New
Leaf Contact: Kristie Yerger

October 11th:

TVDSA 12th Annual Buddy Walk 11:00am-2:00pm Capitol Bldg. to Julia Davis Park Contact: George Taylor

October 21st:

Best Buds at Linder Farms in Meridian from 5:00pm-6:30pm

Contact: Malu Mulholland







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Mended Little Hearts Comes to Boise

Mended Little Hearts is a sub-program of Mended Hearts, a national community based patient-to-patient service organization that gives the "gift of hope" to heart disease patients. Although, Mended Hearts has been around since 1951, the Mended Little Hearts program only started in 2004. The Mission of Mended Little Hearts is to empower families affected by congenital heart disease. Mended Little Hearts (MLH) provides a resource for families to share experiences and resources as members of a nationwide peer to peer support network.

Did you know that congenital heart defects are one of the three most common birth anomalies in the world affecting approximately 1 in every 110 babies each year? Congenital heart disease is a lifelong condition requiring special care. In 2009, hospital costs for children with congenital heart defects were estimated at \$1.5 billion.

MLH partners with hospitals to connect families in crisis with other parents who have survived the shock of learning their child has a heart defect. MLH helps others through peer to peer support meetings, educational programs, accredited hospital visiting programs, creating awareness about congenital heart defects and advocating on issues that impact the lives of those with congenital heart disease.

Julie DuBois is a Registered Nurse and the Pediatric Cardiovascular Services Coordinator for St. Luke's Children's Hospital. For years, they have tried to keep a small support group (Courageous Hearts of Idaho) for their heart children and their families going. But, with very few resources, it has been difficult. Recently, Jeff Middleton from Mended Hearts Boise, and Julie got together and a discussion of starting a Little Mended Hearts chapter in Idaho was met with a great deal of support and enthusiasm.

Julie is currently working on the Charter Process. One of the first steps of this process is identifying interested families who have children with congenital heart defects and adults with congenital heart defects. Little Mended Hearts requires 10 founding members; 7 of them must be families or caregivers of children with heart defects or adults who have congenital heart defects. These 10 founding members must sign a Charter Petition stating that they are willing to commit to forming and

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Reading and Down syndrome

Individuals with Down syndrome CAN become amazing readers! By teaching your child to read at a young age you will not only teach reading - you may even enhance speech! Not all children with Down syndrome will be able to commence reading at 6 months of age. However, it is important to understand that when you start 'early' you will not only benefit their reading skills, but also their speech and general communication skills. Whatever age your child begins to read, even if it is during their teen years, just know that it will allow a whole new world to open up to them!

Research involving reading and Down syndrome has shown (Buckley, SJ, Bird G. 1993) that approximately 70% of children with Down syndrome will end up with significant hearing difficulties at some point in their lives. As such, these children have stronger visual processing skills and better visual memory than auditory processing and memory skills. If a child cannot depend on hearing the correct phonetic sounds that correspond with phonemes, it is therefore much more difficult for them to process and remember that information for later recall and use. This is where the importance of introducing the whole word comes in.

By establishing a group of 'sight' words that are familiar with a child's world, such as names, foods, actions, colors, animals and belongings, you will begin to train their brain to understand that a word represents 'something'. Once that core group of single words is established, your child is guided into couplets, phrases and sentences. During this process, five dolch words are added into the group of words, ultimately allowing

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Teaching Real Life Functional Skills by Mary Schuh

Close your eyes for a moment and think about the most important skills you use to navigate through your day. What comes to mind? Is it the way you neatly make your bed? Cross the street? Provide the correct change when you purchase your morning coffee? Answer "yes" or "no" to basic questions asked of you? Or perhaps getting yourself dressed or using the microwave to heat up your lunch? I'm doubtful these are the skills that come to mind.

In the world of special education, we used to think that making a bed or change for a dollar, folding a napkin, and learning to prepare simple foods were important life skills that students with disabilities needed to learn. We also believed these skills were best taught in a segregated, functional, life-skills classroom and through community-based experiences separate from their peers without disabilities. Are these really the authentic life skills we want students to learn, practice, and realize in their lives?

A more generic and better understood view of functional life skills are those skills that assist us in managing and living a better quality of life. These are the skills that help us accomplish our dreams, live to our full potential, and exist as contributing members of our communities. There is no definitive list of functional life skills, and certain skills may be more or less relevant depending on life circumstances, culture, beliefs, age, geographic location, etc. A broader, more widely, accepted definition of important life skills are those skills that allow us to:

- Get along well with all kinds of people including individuals whose backgrounds and experiences are different from our own.
- Develop and maintain friendships and meaningful relationships.
- Work collaboratively with others.
- Identify, learn, and practice passions, interests, and talents to assist in making important life decisions such as career choices and motivating hobbies.
- Show up on time and be prepared for whatever is required.
- Communicate thoughts, ideas, opinions, and feelings in ways that are clearly understood.
- Read material that is stimulating and/or provides opportunities to learn.

If we can agree that the above list is more representative of "functional life skills" than making a bed or change for a dollar, where might be the best place for students to learn these skills? Thirty plus years of educational research informs us that by immersing students in the richness and diversity of an inclusive educational experience, students are more likely to learn important life skills such as communication, literacy, appropriate social behaviours, and following typical routines and schedules. An inclusive educational experience throughout one's academic career naturally provides adequate role models, age appropriate instruction, access to engaging information, high expectations, and the opportunity to learn about and get along with the diversity that makes up the human experience.

So where do students with disabilities learn skills like making a bed and change for a dollar? These skills can best be taught in the environments and typical routines in which they are most likely to be used. How many different ways can you think of to teach someone how to make a bed during typical routines (assuming educational teams believe this is a high priority for learning)? When we open our minds to creative possibilities for teaching and learning, and rely on routines that are typical for all students, the possibilities can be endless. For example, learning to make a bed is best taught in the morning after a person wakes, or during camp or an afterschool/weekend/summer job or volunteer opportunity at a hospital or nursing home. Making change for a dollar can happen in the school store, purchasing lunch or snacks in the cafeteria, or in a marketing class in high school.

Lifelong habits of learning and working are inherently promoted and developed through participation in typical educational experiences and traditional rites of passages. These experiences lead to connections, career and educational opportunities, increased social relationships, and a greater likelihood for entering adulthood as valued, contributing members of communities. Students with disabilities and their families must actively begin planning for the future well before the end of high school. For all students, setting goals and having positive dreams evolve out of a wide variety of school experiences including classes, extracurricular activities, internships, community service, relationships, and after school jobs. Inclusion and participation in school activities helps students better understand what they want for their future.

After 30 plus years of research, we are learning that not only are students with disabilities learning more and learning faster when they are educated in the general education classroom and typical routines with support; students without disabilities are also excelling in schools where All Means All.

Mary Schuh, Ph.D. has been with the Institute on Disability at the University of New Hampshire since its inception in 1987, working to coordinate family and consumer leadership development and educational systems change in support of inclusive schools and communities. She directs the National Center on Inclusive Education and is a member of the SWIFT (schoolwide integrated framework for transformation) Leadership team.

About The SWIFT Center Where All Means All: SWIFT (Schoolwide Integrated Framework for Transformation), a national K-8 Center, provides academic and behavioral support to promote the learning and academic achievement of ALL students in their neighborhood schools and general education classrooms, including students with disabilities and those with the most extensive needs. Get involved with SWIFT by signing up for the email list, connecting via the SWIFT Talk Community of Practice, liking SWIFT on Facebook, and following SWIFT on Twitter and Pinterest to learn how school communities across the country are benefitting from SWIFT Center resources.

Source: This article is reprinted with the permission of PEAK Parent Center and the author, Mary Schuh. Copyright 2014. All rights reserved. Permission to reproduce may be obtained from PEAK Parent Center at 800-284-0251 or www.peakparent.org.



Social Groups Page

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

D.A.D.S. will not have a separate gathering in October. We hope to see everyone at the Buddy Walk, October 11th at Capitol Park and Julia Davis Park in Boise.

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

MOM'S Night Out!

Moms will not have a separate gathering in October. We hope to see everyone at the Buddy Walk, October 11th at Capitol Park and Julia Davis Park in Boise.

Help Wanted: If you would like to help organize monthly outings, and fun activities for mothers of individuals with Down syndrome in the Treasure Valley, please contact Malu Mulholland. We are looking for a new Mom's Night Out! coordinator to take over.

For more information or questions, please contact: Malu Mulholland





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

Lil' Buddies will not have a separate playdate in October. We hope to see everyone at the Buddy Walk, October 11th at Capitol Park and Julia Davis Park in Boise.

<u>Help Wanted</u>: If you would like to help organize monthly outings and fun activities for infants-toddlers, ages birth-5

years with Down syndrome in the Treasure Valley, please contact <u>Malu Mulholland</u>. We are looking for a new Lil' Buddies coordinator to take over.

Need more information on **Lil'Buddies**? Please contact <u>Malu</u> <u>Mulholland</u>.

Best Buds Update:

Best Buds will be going to **Linder Farms** located at 7165 \$ Linder Road, in Meridian on Tuesday, **October 21st** from **5:00pm-6:30pm**. TVDSA will have a group area reserved. Children with Down syndrome get in FREE, parents are ½ price (\$2.00 for farm or \$5.00 for farm and corn maze)

Need more information on **Best Buds**? Please contact <u>Malu Mulholland</u>

Help Wanted: We are looking for a new Best Buds coordinator to take over. If you would like to help organize monthly outings, and fun activities for children in elementary school with Down syndrome, please contact Malu Mulholland





Cool Club Update:

Cool Club will not have a separate gathering in October. We hope to see everyone at the Buddy Walk, October 11th at Capitol Park and Julia Davis Park in Boise.

Need more information on **Cool Club?**Please contact: <u>Andrew Kopping</u> 208-350-9908

AIM Update:

AIM will not have a separate gathering in October. We hope to see everyone at the Buddy Walk, October 11th at Capitol Park and Julia Davis Park in Boise.

Need more information on **AIM**? Please contact <u>Lynda Wells</u>

See and Learn Language and Reading

See and Learn Language and Reading is an evidence-based teaching program designed to help children with Down syndrome learn to talk and to read. See and Learn Language and Reading teaches children to understand and use spoken language from first words to early grammar and simple sentences. It also introduces children to reading their first sight words, learning letter-sounds and using phonics for reading.

The design of See and Learn Language and Reading is informed by what is understood about how typically developing children learn to talk and read and what is known about the specific language learning difficulties of children with Down syndrome. Language development is usually delayed among children with Down syndrome relative to their general cognitive development. This may be due to a number of factors, including hearing loss, verbal short term memory and speech difficulties.

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Conferences, Workshops, Webinars & TVDSA Scholarship Information

IPUL FREE Webinar Series

October 28th

Times: 10:00am-11:00am

Topic: Bullying Prevention

This workshop is designed to introduce parents and professionals to a range of intervention strategies for the child who is the target of bullying. Things that can be used by the parent, child, family and school.

Register Here

Idaho Partnerships Conference on Human Services



October 30 & 31 at the Boise Riverside Hotel

Registration is Open!

Charmaine & Dylan Thaner will be presenting!

TVDSA Scholarships available!





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.



Reading (continued from Page 2)

the building of sentences. (These words consist of: is, are, and the.) Through a carefully structured presentation schedule, eReadingPro ensures that your child has seen every core word over 100 times before they see it within a sentence. The sentences are presented within fun and colorful books that you will create using the images provided.

After your child masters the core words individually, we encourage you to examine each word with them to see how the letters and sounds fit together to make up that word. This will assist your child in decoding unfamiliar words down the road and improve their phonemic awareness.

If you are interested in a solution where reading and Down syndrome are concerned, eReadingPro provides a systematic approach for parents to use not only at home with their children, but one that can be used at the school as well - ensuring continuity. We sincerely hope that you will enjoy using our system! Take a look at our program choice for reading and Down syndrome.

Featured Links: http://ereadingpro.com/reading-and-down-syndrome.htm

eReadingToGo! is our NEW iPhone/iPad app that allows your child to learn on the go, using an iPhone, iPod or iPad. Based on the system for teaching reading that has made eReadingPro such a success, this app follows the same basic concepts. Taking your child from single words, to couplets, phrases and sentences in a progressive, logical process, your child will be reading these sentences aloud in no time! Download it for FREE and try it out!

Little Mended Hearts (continued from Page 2)

supporting the potential Little Mended Hearts group. This Charter Petition will be submitted along with the completed Charter Application that Julie is working on. She has several families committed, but we want to let you know about this opportunity. Just signing the petition does not commit you to a leadership position or endless amounts of paperwork. In fact, we have several of the leadership roles filled. It will allow us to get the ball rolling, spread awareness and hopefully make a group available for families that feel that they are all alone in this.

TVDSA has been so welcoming. We have been invited to attend the Buddy Walk in October. We will have the petition at the walk, and be available for questions at Julia Davis Park. Please feel free to share this information with anyone that it could benefit.

To learn more about Little Mended Hearts visit: www.mendedlittlehearts.org. For more information on Mended Little Hearts Boise please contact Jeff Middleton at intouchwinthrop@hotmail.com or (208)830-2002 OR Julie DuBois at duboisi@slhs.org or (208)381-1978.



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



We're on the Web!

See us at:

www.idahodownsyndrome.org

www.iddiiodownsyndionie.org

Check us out on Facebook and Twitter!

See and Learn Reading (continued from page 4)

See and Learn Language and Reading presents language with visual supports (pictures and printed words) offering a tangible representation of words, word combinations and their relationship to real world objects and meaning, and building on the children's relative strengths in visual memory and visual processing.

See and Learn Language and Reading offers a step-by-step approach to promoting two key areas of language development:

- vocabulary development the number of words a child knows
- grammar development a child's ability to combine words into grammatical sentences

The program aims to build on and complement the language learning that occurs through a child's everyday interactions and play. It may also be suitable for other children with similar language delay and learning profiles.

See and Learn Language and Reading is suitable for supporting young children from around 12 months through to their early school years (around 6 or 7 years).

See and Learn Language and Reading program includes six steps:

- See and Learn First Word Pictures
- See and Learn More Word Pictures
- See and Learn Letters and Sounds
- See and Learn First Written Words
- See and Learn First Sentences
- See and Learn More Sentences

Source: http://www.seeandlearn.org/en-us/language-and-reading/



Where shopping & giving unite

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/communityrew ards searching by name or by Nonprofit (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.

GoodSearch and TVDSA

You search the internet all the time anyway, why not do it and earn money for TVDSA. Just go to: www.goodsearch.com 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.

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> Advisor: Lynda Wells

Community Outreach Chair: Erin Rosenkoetter

Secretary: Paul Auger

Vice President and Programs Chair: <u>Malu Mulholland</u>

Treasurer & Spanish Contact: <u>Lucy Olmos</u> Buddy Walk Chair: <u>George Taylor</u>

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