

TVDSA Newsletter



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

Newsletter Editor: Celena Auger

January 2012



With the beginning of a new year, we decided a good topic for January was "Parents," new and old. Our role as Parents of a child with special needs is not a journey all would select. Nor is it a journey that is wished for before it begins. But it is a journey that when we are able to reflect, we generally appreciate the efforts, time and outcomes. We are able to celebrate every accomplishment with a smile, a tear, a hug or a big bang.

Here's wishing you the best for the New Year!
from: Treasure Valley Down Syndrome Association

Why Moms of Kids with Special-Needs, Rock!

- Because we never knew that "doing it all" would mean doing this much. But we do it all, and then some.
- Because we've discovered patience we never knew we had.
- Because we are willing to do something 10 times, 1,000 times if that's what it takes for our kids to learn something new.
- Because we have heard doctors tell us the worst, and we've refused to believe them.
- Because we have bad days and breakdowns and bawl fests, then we pick ourselves up and keep right on going.
- Because we manage to get ourselves together and out the door looking pretty damn good. Heck, we even make sweatpants look attractive.
- Because we are strong. Who knew we could be this strong.
- Because we aren't just moms, wives, cleaners, chauffeurs, cooks and women who work. We are also physical therapists, speech therapists, occupational therapists, teachers, nurses, researchers, coaches and cheerleaders.
- Because we give our kids endless love and still have so much love for our other kids, our husbands, and our family.

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* CPR Workshop!

* Two Choices

* Advocacy 101

Organizations Collaborate to Educate Medical Professionals

Affiliates nationwide are working with Lettercase to distribute complimentary copies of "Understanding a Down Syndrome Diagnosis" to obstetric medical providers at district American Congress of Obstetrics and Gynecology conferences across the country. The complimentary booklets are funded through a generous grant by the National Down Syndrome Society and the Kennedy Foundation.

- Because we understand our kids better than anyone else does - even if they can't talk or gesture or look us in the eye. We know. We just know.
- Because we never stop pushing, or hoping, for our kids.
- Because just when it seems like things are going OK, they're suddenly not, but we deal. We deal even when it seems like our heads or hearts might explode.
- Because when we look at our kids we just see great kids. Not kids with cerebral palsy/autism/Down syndrome or whatever label.

Adapted from the author's blog, lovethatmax.com

TVDSA CPR Workshop!

**Saturday, January 21st, 2012
at A New Leaf
2456 N. Stokesberry, Meridian
at 2:00pm**



75% of cardiac arrests happen at home.

A strong Chain of Survival can improve chances of survival and recovery for victims of heart attack, stroke and other emergencies.

CPR is one of the first of five links in the Chain of Survival. **Is your teen or adult with Down syndrome prepared to handle this type of emergency?** They should be.

This workshop is geared towards teens and adults with Down syndrome, but open to everyone. This is a hands on class with no written test, presented by the American Heart Association. Every participant who successfully completes the hands on exam will receive a CPR certification card.

Cost: \$5.00 for paid members and \$10.00 for non-paid members. (Membership applications will be available on site.)

We do need **RSVPs by January 13th, 2012** so the instructor will know how many mannequins to bring.

Please contact: [Kristie Yerger](mailto:kristie.yerger@tvdsa.org)

Watch an informative [presentation](#) on the ethics of prenatal testing which features Dr. Brian Skotko, Patricia Bauer and Mark Leach.

January TVDSA Meeting

January 10, 2012
7:00pm-9:00pm

at A New Leaf
2456 N. Stokesberry
Meridian, ID

**Topic: Sensory Processing
in Young Children**

The evening will cover Sensory Processing in young children; what it is, how it works and some practical ideas for parents to support sensory processing in everyday experiences with young children.

Presenter: Melissa Bandy, IdahoSTARS Statewide Project Director.

If you have future meeting topic suggestions, please send them to: [Kelly Zimmerman](mailto:kelly.zimmerman@tvdsa.org) or [Erin Rosenkoetter](mailto:erin.rosenkoetter@tvdsa.org)

Calendar of Events

January 10th:
TVDSA Membership Meeting
7:00pm-9:00pm
at A New Leaf in Meridian
Topic: Sensory Processing in Young Children.
Contact: [Kelly Zimmerman](mailto:kelly.zimmerman@tvdsa.org) or [Erin Rosenkoetter](mailto:erin.rosenkoetter@tvdsa.org)

January 14th:
Lil' Buddies Playgroup
3:00pm-5:00pm at Davis' house in Boise
Contact: [Kristie Yerger](mailto:kristie.yerger@tvdsa.org)

Two Choices

An Anonymous Email (worth sharing)

What would you do? You make the choice. Don't look for a punch line, there isn't one. The question is: Would you have made the same choice?

At a fundraising dinner for a school that serves children with learning disabilities, the father of one of the students delivered a speech that will never be forgotten by all who attended. After extolling the school and its dedicated staff, he offered a question: 'When not interfered with by outside influences, everything nature does, is done with perfection. Yet my son, Shay, cannot learn things as other children do. He cannot understand things as other children do. Where is the natural order of things in my son?' The audience was stilled by the query.

The father continued. 'I believe that when a child like Shay, who was mentally and physically disabled comes into the world, an opportunity to realize true human nature presents itself, and it comes in the way other people treat that child.'

Then he told the following story:

Shay and I had walked past a park where some boys Shay knew were playing baseball. Shay asked, 'Do you think they'll let me play?' I knew that most of the boys would not want someone like Shay on their team, but as a father I also understood that if my son were allowed to play, it would give him a much-needed sense of belonging and some confidence to be accepted by others in spite of his handicaps.

I approached one of the boys on the field and asked (not expecting much) if Shay could play. The boy looked around for guidance and said, "We're losing by six runs and the game is in the eighth inning. I guess he can be on our team and we'll try to put him in to bat in the ninth inning.'

Shay struggled over to the team's bench and, with a broad smile, put on a team shirt. I watched with a small tear in my eye and warmth in my heart. The boys saw my joy at my son being accepted.

In the bottom of the eighth inning, Shay's team scored a few runs but was still behind by three. In the top of the ninth inning, Shay put on a glove and played in the right field. Even though no hits came his way, he was obviously ecstatic just to be in the game and on the field, grinning from ear to ear as I waved to him from the stands. In the bottom of the ninth inning, Shay's team scored again. Now with two outs and the bases loaded, the potential winning run was on base and Shay was scheduled to be the next at bat.

At this juncture, do they let Shay bat and give away their chance to win the game?

Surprisingly, Shay was given the bat. Everyone knew that a hit was

January 14th:
AIM/Cool Club
4:00pm-6:00pm
2012 Planning Session
and Soup Supper
Contact: [Molly Benton](#)
or [Freddie Gallas](#)

January 17th:
TVDSA Board Meeting
7:00pm-9:00pm at
A New Leaf, Meridian
Contact: [Paul Auger](#)

January 19th:
Best Buds (Elementary)
Gathering at the
Idaho Aquarium
in Boise at 6:00pm
Contact: [Kristie Yerger](#)

January 21st:
TVDSA CPR Workshop
at 2:00pm at A New
Leaf in Meridian.
Tailored to teens and
adults with Down
syndrome. \$5.00 for
members, \$10.00
for non-members.
RSVP needed!
Contact: [Kristie Yerger](#)

January 23rd:
Lil' Buddies Playgroup
10:00am-12:00pm
at Westin's house in
Meridian
Contact: [Kristie Yerger](#)

January 24th:
D.A.D.S Gathering at
Fuddrucker's on Eagle
Road at Ustick.
6:30pm-8:00pm
Contact: [Jim Yerger](#)

February 9-11th, 2012:
PEAK Conference,
Denver, Colorado

Lil' Buddies

January Playgroups

Saturday, January 14th:
3:00pm-5:00pm at
Davis' house: 4257
N. Vera St. in Boise

Monday, January 23rd:
10:00am-12:00pm at
Westin's house: 7206 S.
Angel Way in Meridian

all but impossible because Shay didn't even know how to hold the bat properly, much less connect with the ball. However, as Shay stepped up to the plate, the pitcher, recognizing that the other team was putting winning aside for this moment in Shay's life, moved in a few steps to lob the ball in softly so Shay could at least make contact.

The first pitch came and Shay swung clumsily and missed. The pitcher again took a few steps forward to toss the ball softly towards Shay. As the pitch came in, Shay swung at the ball and hit a slow ground ball right back to the pitcher.

The game would now be over. The pitcher picked up the soft grounder and could have easily thrown the ball to the first baseman. Shay would have been out and that would have been the end of the game. Instead, the pitcher threw the ball right over the first baseman's head, out of reach of all team mates. Everyone from the stands and both teams started yelling, 'Shay, run to first! Run to first!' Never in his life had Shay ever run that far, but he made it to first base. He scampered down the baseline, wide-eyed and startled.

Everyone yelled, 'Run to second, run to second!' Catching his breath, Shay awkwardly ran towards second, gleaming and struggling to make it to the base. By the time Shay rounded towards second base, the right fielder had the ball. The smallest guy on their team who now had his first chance to be a hero for his team. He could have thrown the ball to the second-baseman for the tag, but he understood the pitcher's intentions so he, too, intentionally threw the ball high and far over the third-baseman's head. Shay ran towards third base deliriously as the runners ahead of him circled the bases towards home.

All were screaming, 'Shay, Shay, Shay, all the Way Shay!' Shay reached third base because the opposing shortstop ran to help him by turning him in the direction of third base, and shouted, 'Run to third! Shay run to third!'

As Shay rounded third, the boys from both teams, and the spectators, were on their feet screaming, 'Shay, run home! Run home!' Shay ran to home, stepped on the plate, and was cheered as the hero who hit the grand slam and won the game for his team.

'That day,' said the father softly with tears now rolling down his face, 'the boys from both teams helped bring a piece of true love and humanity into this world.' Shay didn't make it to another summer. He died that winter, having never forgotten being the hero and making me so happy and coming home and seeing his mother tearfully embrace her little hero of the day!

A footnote to this story: We all send thousands of jokes through the email without a second thought, but when it comes to sending messages about life choices, people hesitate. The crude, vulgar and often obscene pass freely through cyberspace, but public discussion about decency is too often suppressed in our schools and workplaces. If you would consider forwarding emails such as this one, you would probably sort out the people in your address book who aren't the 'appropriate' ones to receive this type of

Happy Birthday to
MacKenna & Mirabel

If your Lil' Buddy has a January or February birthday, please email [Kristie](#) to have your child individually recognized and added to our Birthday list!

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

Best Buds (Elementary Group)

January Gathering:
Thursday, January 19th
6:00pm
at the Idaho Aquarium
64 N. Cole Rd., Boise

TVDSA will pay admission for each child with Down syndrome and one parent.

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

Cool Club & AIM

The Christmas Party was a lot of fun. Thank you for all those that were able to come and celebrate.

Thank you to the Amazing Amigos and their performance of *Charlie Brown's Christmas*.

Our next gathering is

**Saturday, January 14th
from 4:00pm-6:00pm**
at
the Gallas' House
11368 Greenhurst Rd.
Nampa, ID

Topic: We will be discussing plans and suggestions for activities for 2012.

We will have a soup supper. Please bring your favorite Crockpot soup. We will provide rolls and dessert.

message.

The person who sent this email to me believes we all can make a difference. We all have thousands of opportunities every single day to help realize the 'natural order of things.' So many seemingly trivial interactions between two people present us with a choice: Do we pass along a little spark of love and humanity or do we pass up those opportunities and leave the world a little bit colder in the process? A wise man once said every society is judged by how it treats its least fortunate amongst them.

Advocacy 101 for Families

What is advocacy?

The word advocacy can mean different things to different people. Quite simply, advocacy means to actively support an idea or a cause.

Parents of children with disabilities often find themselves in the role of being an advocate for their child as well as the disability community as a whole as the two are intertwined. It is largely because of the work of parent advocates that children with disabilities were first allowed to attend public schools in 1975 when Public Law 94-142 was passed. This law was revised and called the Individuals with Disabilities Education Act (IDEA) in 1997, and re-authorized in 2004. For more information on IDEA, please visit the US Department of Education's website.

Why do I need to advocate for my child?

IDEA states that parents are equal members of both the Individualized Family Service Plan (IFSP) team and the Individual Education Plan (IEP) team. This is because parents know their child best and will always be a part of their child's life, unlike professionals who generally interact with a child for a year or two. IDEA recognizes that children are most successful when parents and professionals form partnerships to identify the strengths, needs, and developmental and educational goals for children with disabilities.

What are the characteristics of a successful parent/professional partnership?

- Open, honest, and effective 2-way communication
- Mutual respect for the role and expertise that parents and professionals bring to the IFSP process and meetings
- Both parents and professionals being knowledgeable of IDEA and the families' rights
- The ability to resolve disagreements in a quick and efficient manner
- Maintaining a child-centered focus

How do I effectively advocate for my child?

Advocating for your child can be an intimidating process. It takes practice. The most important thing to remember is that your contributions, ideas, and opinions matter! Your ability to effectively advocate for your child will impact his/her entire life. Here are some

There will also be game room activities for members and their siblings.

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

D.A.D.S. Group

Next Gathering:
Tuesday, January 24th
6:30pm-8:30pm

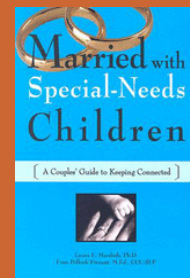
at the Fuddruckers
at Ustick and Eagle Road.

For more information
contact: [Jim Yerger](#)

From the TVDSA Lending Library

by Mary Anne Murphy

**Married with
Special-Needs
Children**
by **Laura E. Marshak
and Fran Pollock
Prezant**



Marriage is always a challenge, and the adventure of raising a child with all the usual needs plus special needs can add stress to a marriage. The authors draw upon their combined experience to present a supportive and practical guide for building a strong, cohesive marriage.

This book is available from the TVDSA library. You may reserve it by contacting the [Librarian](#). For a complete list of the books/DVDs available through TVDSA, check out our [Lending Library](#).

suggestions for effective advocacy strategies:

- Develop relationships. Get to know the members of your child's IFSP team.
- Practice good communication skills. Listen. When you are unsure about something, ask.
- Know and understand your emotions.
- Share with your child's team how you help your child at home.
- Learn good conflict resolution skills and understand the dispute resolution process as defined by IDEA.
- Understand your parental rights as defined by IDEA.
- Insist on natural environments for your child's services. Natural environments means, "providing services in the home and community settings in which children without disabilities participate."
- Inquire about assistive technology and how it might help your child. Assistive technology (AT) can be thought of as any item that supports a child's ability to participate actively in his or her home, childcare program, school, or other community settings. It is a broad term that includes items ranging from something as "low tech" as a foam wedge for positioning to something as "high tech" as a power wheelchair for independent mobility.
- Keep in mind a vision of your child's future and what you want for him/her. Share this with the IFSP team.
- Be specific about how you want the team to communicate with you- in person, over the phone, via email, etc. and how frequently.
- Don't be afraid to disagree. Use phrases such as, "I'm not sure I see that. Tell me when you see it happening," or "Tell me more about why you think my child needs this intervention," as ways to skillfully discuss the disagreement.
- Keep meetings and discussions child focused.
- Stay organized and keep records. Take notes at meetings and on phone calls and keep evaluation data and other IFSP documents.
- Be prepared. Come to meetings with an agenda of items you want to make sure are discussed.
- Put requests and questions in writing.
- Get support if you need it from a friend, family member, or professional advocate.

FAQ's:

Question: "Doesn't advocacy just lead to conflict?"

Answer: This is a common concern for people when they hear the word advocacy. Sometimes actively supporting your point of view will lead to conflict/disagreement, and sometimes it won't, depending on your individual situation and IFSP team. The thing to remember is that conflict and/or disagreement is not necessarily a negative thing. When done skillfully, everyone, especially your child, will benefit from all sides of an issue being discussed.

Question: "How do I raise a self-advocate? What can I do to help my child grow up to become an empowered self-advocate?"

Answer: As your child becomes older, you can teach him/her to be a self-advocate. The best way to do this is to first learn to be an effective advocate yourself. Your child will learn by watching you. When it feels right, start including your child in meetings and

Conferences, Workshops and Webinars

Pre-Registration now OPEN for the [PEAK 2012 Conference on Inclusive Education](#)

February 9-11, 2012
Denver, Colorado

2012 Elks Education Training Opportunities

(dates subject to change)

***Social Stories:** Monday,
February 13th, 2012

***Potty Training and Voiding Dysfunction:** Thursday,
April 5th, 2012

Trainings held at St. Luke's Meridian, Lower Level Conference rooms, 520 South Eagle Rd, Meridian from 6:30pm-8:30pm

For more information or to register, please call: 208-706-5549

TVDSA Scholarship Information

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.

For additional questions, please contact our [Scholarship Committee](#).

discussions about how he/she learns, what strategies support his/her learning, what his/her interests and strengths are, and what vision he/she holds for the future.

Question: "Where can I get more information on advocacy and effective advocacy strategies?"

Answer: The following organizations, publications, and resources can be helpful:

- Idaho Parent Unlimited
- *From Emotions to Advocacy- The Special Education Survival Guide*, by Pam and Pete Wright
- Wright's Law Website
- *Special Education, a Parent's Guide for Children's Success*, by Michael T. Bailey
- *The Everyday Guide to Special Education Law*, by Randy Chapman
- *The IEP Tool Kit*, developed by PEAK Parent Center, which includes a variety of advocacy resources including communication tip cards, a Power Point presentation, and other resource handouts.
- National Early Childhood Technical Assistance Center (NECTAC)

PEAK Parent Center www.peakparent.org - Summer 2011 SPEAKout Newsletter (Contact: email parentadvisor@peakparent.org or by phone 800.284.0251)



TREASURE VALLEY
DOWN SYNDROME
ASSOCIATION

Board of Directors

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About Treasure Valley Down Syndrome Association

For more information, articles, past newsletters and pictures, please visit our website at <http://idahodownsyndrome.org/>

Mailing: PO Box 1404 Meridian, Idaho 83680

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