



TREASURE VALLEY  
DOWN SYNDROME ASSOCIATION

# TVDSA Newsletter

Newsletter Editor: [Celena Auger](#)

November 2014

## In this Issue

November begins the holiday season for us all. We hope you will bundle up and join us at the Boise Holiday Parade, November 22<sup>nd</sup>.

Mark your calendars now for the 2014 Christmas Parties for the individuals with Down syndrome in your lives. The AIM/Cool Club Christmas event will be December 5<sup>th</sup> and Snackin' with Santa will be December 6<sup>th</sup>.

On page 3, enjoy a follow up to the "Welcome to Holland" by Emily Perl Kingsley. "Welcome to Holland" gives a perspective of the journey a new parent of a child with special needs experiences. "Departing Holland" by Deborah Leigh Norman gives another parent's perspective of what happens after the initial arrival into Holland and what the future still holds.

Also included in this month's issue is a Buddy Walk recap, an introduction to Eli's Heart, and an article about talking about death to an individual with special needs.

Monthly and archived TVDSA newsletters are available on our website at: [www.idahodownsyndrome.org](http://www.idahodownsyndrome.org) for viewing and sharing.

## Christmas in the City



### Boise Holiday Parade 2014 : "Golden Christmas Memories"

TVDSA will be participating in our 2<sup>nd</sup> Boise Holiday Parade, on **Saturday, November 22<sup>nd</sup>**! The parade begins at 9:45 am. We will be **meeting at 8:45am**, exact location TBA. (It will be near the Boise Cascade Building at 11<sup>th</sup> and Bannock Street).

Come join the fun in supporting TVDSA, creating Down syndrome awareness in the Treasure Valley, and start the holiday season off with a memorable event.

Watch your email for all the details.  
Questions or ideas? Contact [Erin Rosenkoetter](#)



## Many Thanks to all who attended and participated in the 2014 TVDSA Buddy Walk.

The weather was perfect.

**Final attendance** was **1,466** plus all of our great volunteers.  
It was a little down from last year, but still a great showing.

### LOST & FOUND

We had a participant that lost her iPhone. We also have a few jackets that were recovered - one with a pair of reading glasses in the pocket. If you found a phone or are missing a jacket, please contact [buddywalk@idahodownsyndrome.org](mailto:buddywalk@idahodownsyndrome.org).

### UNCLAIMED WILL CALL

We had lots of Will Call bags unclaimed. If anyone wants to get their shirts contact [buddywalk@idahodownsyndrome.org](mailto:buddywalk@idahodownsyndrome.org).

### FEEDBACK

We need your thoughts. Please send all comments/feedback good or bad to [buddywalk@idahodownsyndrome.org](mailto:buddywalk@idahodownsyndrome.org).

TVDSA  
*Calendar of Events*

November 4<sup>th</sup>:

**TVDSA Board Meeting**  
7:00pm-9:00pm at A New  
Leaf Contact: [Kristie Yerger](#)

November 13<sup>th</sup>:

**AIM** at Fusions Glass Studio  
in Eagle at 5:00pm.  
Contact: [Lynda Wells](#)

November 18<sup>th</sup>:

**Best Buds** at Piggy Pigs  
Pottery in Meridian from  
5:00pm-6:30pm  
Contact: [Malu Mulholland](#)

November 20<sup>th</sup>:

**Moms Night Out!** at  
Firehouse Pizzeria in Kuna at  
7:30pm.  
Contact: [Malu Mulholland](#)

November 27<sup>th</sup>:

**Happy Thanksgiving**

December 5<sup>th</sup>:

**AIM & Cool Club Christmas  
Activity** Contact: [Lynda  
Wells](#)

December 6<sup>th</sup>:

**Snackin' with Santa** at  
Advanced Therapy Care  
from 12:00pm-2:00pm  
Contact: [Malu Mulholland](#)



*Happy Thanksgiving*

## How to Talk to your Child with Special Needs about Death by Jennifer Lovy

The first time I had a conversation with my son about death I mistakenly thought that his autism was going to shield him from the emotional burden of loss. I couldn't have been more wrong.

"Why do you look so nice?" asked Evan when I got home from a funeral. I told him where I was but did not expect him to understand because we had not experienced the death of a loved one nor did we have an occasion to talk about death with our children.

"Was it dark at the funeral?" asked my son, then five, who is obsessed with lights. I answered his question by telling him in great detail about the lighting at the funeral. By focusing my response on the lights I avoided the topic of death, thinking how fortunate he was to not have to experience the painful feelings of coping with such a profound loss.

His next question proved that I was the ignorant one. "Did you cry at the funeral?"

How did my son not only know what a funeral was but attach the appropriate emotion to the event? Two years later I still don't have a clue but I will never underestimate what my son knows or is capable of comprehending.

### Do I Keep my Child in the Dark?

Talking to any child about death is difficult. We want to shield them from the harsh and unpleasant realities of life and preserve their childhood ignorance and bliss for as long as possible. Sometimes we are lucky and other times we are forced to grieve together with our children.

This process can be especially difficult when you have a child with special needs. Often it's hard to know if they comprehend the situation or to what extent they understand. Furthermore, children with special needs may express their grief and feelings differently but their grief is not any less powerful.

### When, What & How to Tell

What we tell our children about death, as well as when we say it will depend on their age as well as our own beliefs and feelings and the specifics of the situation we find ourselves in. For example, the death of a close relative is different than the death of an acquaintance or even a tragedy on the news.

Each child understands and reacts differently but as parents we need to provide children with clear and truthful explanations. The following strategies should be kept in mind when talking about death with a special needs child:

#### 1. Prepare Your Child

Tell the child that a loved one is dying so it does not come as a shock. Of course death isn't always foreseeable. When the death of a loved one is unexpected and tragic, it is extremely difficult to explain something to our children that we don't even understand. In such a situation, children are intuitive and sense when something is going on so it is best to tell them the news as soon as possible.

#### 2. Use the word "Sad"

Begin your conversation with a statement such as "I'm afraid I have something very sad to tell you." This helps prepare the child somewhat for what you have to say to them.

#### 3. Choose your words carefully

Choose your words very carefully because children can be very concrete and literal in their thinking. Avoid referring to death as "going to sleep" or a "final rest." Such words may make them afraid to go to sleep out of fear they will not wake up. Similarly, saying

*Continued on Page 5*

## Departing Holland by Deborah Leigh Norman

When my second son was born two months early and later diagnosed with Down syndrome, somewhere in the flurry of reading I consumed, I came across the poem "Welcome to Holland" by Emily Perl Kingsley. Ms. Kingsley describes having a child with a disability like going on a trip to Italy but instead you land in Holland. In my state of confusion and numbness the words from Ms. Kingsley helped to give a framework to my feelings and much of my mind racing.

The hardest part for me was thinking about what this new member of our family would mean to my first son, then just three years old. I had a mix of fear and guilt for what my older son may have to deal with and for how his life would be negatively impacted. I knew that my husband and I would handle things; we were adults. But for my young son who had no choice in having a sibling enter his life, how would having a new brother and now a brother with a disability affect him?

Perhaps part of these feelings was the guilt that any parent may go through when they have a second child. The first child's life was going along just fine - did they really want or need a sibling? Most parents probably justify the new addition by thinking that even though the adjustment is hard at first, that the older child will be better off because the child will now have someone to share life with and, hopefully, have a lifelong friend even after the parents have died. However, when we found out our son has Down syndrome I wondered would he be able to share life with his big brother and be a friend and confidant? What did this mean for our family? I had a bright, curious, beautiful son - clearly in Italy, and now I had a son unexpectedly in Holland. How could I be two moms in two different countries, speaking two different languages?

I ventured into this new place and met some helpful moms and developmental therapists. I did not have answers to many questions but, like Holland, having a child with Down syndrome was turning out to be a welcoming and fine place. Holland is beautiful with remarkable architecture including the Canal district. This land of windmills evokes peace and serenity. Holland is one of the world's largest producers of flowers. Just the Keukenhof Gardens alone has seven million bulbs planted annually. The amazing museums such as the Anne Frank House are inspiring. Vincent Van Gogh lived in Amsterdam at one point in his life, and the Van Gogh Museum permanent collection has over 200 of his works.

I understood landing in Italy from my experience with my first son. Italy also has some incredible sites. Pompeii, the Pantheon, the Leaning Tower of Pisa, and the island of Sicily all offer history, scenery, and unique styles. No wonder Italy is one of the top five countries visited around the world with over 40 million visitors annually.

Somewhere along the way, however, I realized and, more importantly, I decided that I didn't have to stay in Holland or in Italy for that matter and I did not have to choose to blindly travel back and forth the 850 miles between the two countries. The rest of the world is pretty incredible too. I am one mother of two sons and we are connected. Like the Mississippi River a few miles from our house, we as a family flow through life together on all of its twists and turns sometimes quickly and sometimes meandering.

I have learned best from watching my two sons together. I see that my greatest worry - for my son having a brother with Down syndrome - has turned into the best gift in life and that his little brother has taught him things I never could. They share an amazing connection that continues to astonish me. I see the understanding, devotion and joy that they have most strongly for each other. They have showed me we speak the same language of love and that we will not be kept in separate places.

I have wondered why I feel differently than Ms. Kingsley and I believe it is because of her. Since she and many other parents worked for better opportunities for their child with a disability, there is more inclusion and acceptance. Her work and words had a positive influence on so many people.

Through time and travel, I am learning on this journey and I look forward with excitement and anticipation to where it leads instead of feeling like it is already defined by a diagnosis. In addition to Italy and Holland, I look forward to traveling to Shanghai, the Amazon rainforest, Paris, the Serengeti, and much more.

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For more information contact the author at:

[www.departingholland.com](http://www.departingholland.com)

@DebLeighNorman

[www.facebook.com/depart.daily](http://www.facebook.com/depart.daily)





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## Social Groups Page

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

D.A.D.S. will not be gathering in November.

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

### MOM'S Night Out!

Moms will be going to **Firehouse Pizzeria** located at 271 Avenue B, in Kuna on Thursday, **November 20<sup>th</sup> at 7:30pm**. Come join other mothers of individuals with Down syndrome for pizza and good conversation – you deserve a Night Out!

**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 be gathering in November.

**Help Wanted:** If you would like to help organize monthly outings and fun activities for infants-toddlers, ages birth-5 years with Down syndrome in the

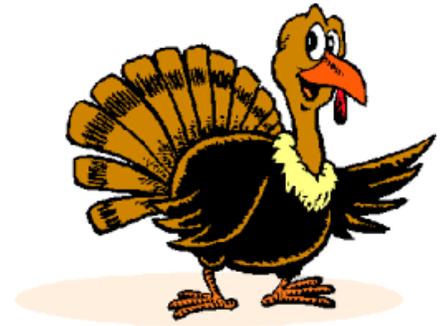
Treasure Valley, please contact [Malu Mulholland](#). We are looking for a new Lil' Buddies coordinator to take over.

Need more information on Lil'Buddies? Please contact [Malu Mulholland](#).

### Best Buds Update:

Best Buds will be going to **Piggy Pigs Pottery** located at 46 E. Fairview Ave., in Meridian on Tuesday, **November 18<sup>th</sup> from 5:00pm-6:30pm** to make Christmas gifts. TVDSA will cover the studio fee of individuals with Down syndrome. Pieces can be purchased from \$4.00 and up.

Need more information on Best Buds? Please contact [Jorliena Isaacson](#)



### Cool Club Update:

Cool Club will not be gathering in November.

Need more information on Cool Club? Please contact [Malu Mulholland](#).

**Help Wanted:** If you would like to help organize monthly outings, and fun activities for individuals with Down syndrome ages 12-17 in the Treasure Valley, please contact [Malu Mulholland](#). We are looking for a new Cool Club coordinator to take over.

### AIM Update:

AIM will be gathering at Fusions Glass Studio located at 135 N. 2<sup>nd</sup> Street in Eagle on Thursday, November 13<sup>th</sup> at 5:00pm. TVDSA will provide a sun catcher for each individual with Down syndrome. Please RSVP by November 12<sup>th</sup> with Lynda at 208-895-8944 (phone) or 208-590-1755 (text) so we know how many to expect. (If you don't RSVP, still come for the fun!)

Need more information on AIM? Please contact [Lynda Wells](#)

**NOTICE: There will be NO TVDSA Family Meeting in November**



## Conferences, Workshops, Webinars & TVDSA Scholarship Information

### IPUL FREE Webinar Series

**November 25th**

Times: 10:00am-11:00am

Topic: **Literacy is for All!**

New thinking about literacy for children with severe disabilities. Parents learn how to help their children with severe disabilities gain literacy skills.

[Register Here](#)

### 2015 Inclusion Works Conference

Engaging All Students in Inclusive Classrooms

**February 4-5<sup>th</sup>**  
San Marcos, Texas

[Registration Open Now](#)



Save the Date:

### PEAK Conference on Inclusive Education



**February 12-13<sup>th</sup>**  
Denver, Colorado

[Registration Opens Soon!](#)

### 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.

## Talking about Death (continued from page 2)

a loved one died because he or she was sick may make a child afraid that a cold, cough or other illness could be fatal. It's best to explain that only very bad illnesses can make a person die and sometimes the doctors cannot make that person better.

### 4. Celebrate Their Life

Following the death of a loved one, provide opportunities to remember and celebrate that person's life. It's important to allow a child the chance to talk about the person who has died but don't force your child to share thoughts and memories.

### 5. Participation

If rituals are important to the child, establish a ritual to help him cope with his loss. For example have or assist the child in writing a story about his loved one or putting together a memory box. For a non-verbal child or low functioning child, assist him in collecting pictures and other items that remind the child of the person who died. The child can then visit the project on a regular basis to honor the memory of the loved one.

Alternatively, you may want to find an activity that the person used to do with the child, such as playing a certain game, going to a particular place together or taking a walk together. Make sure to talk about the person who passed away to help with the healing process.

### 6. Take your child for a visit

Do not be afraid to bring their child to visit the person who is dying or attend the funeral. Both can be important in providing closure. However prepare the child for what he or she will see and how others may be reacting. If the child does not want to go, never force him or her. Instead, offer options like making a card, writing a note or bringing flowers to the grave.

### 7. Listen and be patient

Be patient with the child who may ask the same questions over and over again. Also make sure you are available to listen, talk or just spend time with the child as they grieve.

### 8. Books to read

Books such as the ones listed below are also excellent resources:

- *Creative Interventions for Bereaved Children* by Liana Lowenstein.
- *Why Did You Die?* By Erika Leeuwenburgh and Ellen Goldring
- *Get Rid of the Hurt* by Madeleine Brehm and Rachel Wenzlaff

Source: [Friendship Circle Blog](#), August 20<sup>th</sup>, 2013



TREASURE VALLEY  
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208-954-7448

We're on the Web!

See us at:

[www.idahodownsyndrome.org](http://www.idahodownsyndrome.org)

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

## Eli's Heart

I would like to introduce you to Eli's Heart, a 501 c3 organization that helps families with travel expenses associated with medical procedures. Our son Eli was born with Down Syndrome and has had several surgeries in his 2 years of life. We understand the future financial concerns for all families that have a child with Down syndrome, so we want to try to focus on supporting our community. For families that need to travel for surgeries, we provide plane tickets, hotel rooms, gas cards, meal cards, etc. Even though our website states our support is for heart surgeries, we are willing to support other procedures.

- Casey Craig, President, Eli's Heart

Website: [www.elisheart.org](http://www.elisheart.org)

Facebook: <https://www.facebook.com/pages/Eli's-Heart/487016554665419>

Email: [contact@elisheart.org](mailto:contact@elisheart.org)



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/communityrewards](http://www.fredmeyer.com/communityrewards) searching by name or by Non-profit (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.

## 2015 TVDSA calendars are now available for purchase

\$15.00 each

Please contact [Erin Rosenkoetter](#) or  
complete an [order form online](#) to order.



*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: [Kristie Yerger](#)

Advisor: [Lynda Wells](#)

Community Outreach Chair: [Erin Rosenkoetter](#)

Secretary: [Paul Auger](#)

Vice President and Programs Chair: [Malu Mulholland](#)

Treasurer & Spanish Contact: [Lucy Olmos](#)

Buddy Walk Chair: [George Taylor](#)

Self-Advocate: [Seth Paetel](#)

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

Mailing: PO Box 1404 Meridian, ID 83680; Check us out on [Facebook](#) and [Twitter](#)