

# TVDSA Newsletter

Treasure Valley Down  
Syndrome Association

February 2011

Newsletter Editor: Celena Auger

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TREASURE VALLEY  
DOWN SYNDROME ASSOCIATION

## The February newsletter focus is "Elementary"

The elementary years are difficult for all. Incoming Kindergarten parents begin the process of IEP meetings, learn about accommodations versus modifications and start a long journey of involvement in the school system. They also learn about advocacy and the law, for the next 12+ years. Parents with 5th and 6th graders are beginning to prepare for transition from elementary to middle school as well as prepare for adolescence and puberty. These years are very important for all kids to grow, experience, and become individuals.

It is the goal of this newsletter to provide information to all age groups and extended family members. We hope to give you the support and information necessary to improve awareness and acceptance of all individuals with Down syndrome in both academic and social environments.

Please make sure to check out the upcoming events and activities throughout the newsletter and in the calendar of events.

*A Slightly Humorous Take on the IEP Process:*

## IEPs According to Dr. Seuss Author Unknown

Do you like these IEPs?  
I do not like these IEPs  
I do not like them, Jeeze Louise  
We test, we check  
we plan, we meet  
but nothing ever seems complete.  
Would you, could you  
like the form?  
I do not like the form I see.  
Not page 1, not 2, not 3.  
Another change,  
a brand new box. I think we all  
Have lost our rocks.  
Could you all meet here or there?  
We could not all meet here or there.  
We cannot all fit anywhere.  
Not in a room  
Not in a hall  
There seems to be no space at all.  
Would you, could you meet again?  
I cannot meet again next week  
No lunch, no prep  
Please hear me speak.  
No, not at dusk and not at dawn  
At 4 p.m. I should be gone.  
Could you hear while all speak out?  
Would you write the words they spout?  
I could not hear, I would not write  
This does not need to be a fight.  
Sign here, date there,  
Mark this, check that.  
Beware the student's ad-vo-cat(e).  
You do not like them  
so you say  
Try it again! Try it again!



## Did you miss the January TVDSA Meeting?

Here is a synopsis of the meeting:

Speaker: Dr. Jason Ellison, MD  
with Idaho Pediatric  
Gastroenterology

Dr. Ellison spoke about gastrointestinal issues in Down syndrome. Issues discussed were: constipation, gastroesophageal reflux (acid reflux), thyroid disease, diabetes, and celiac disease. Because autoimmune conditions are more prevalent in someone who has Down syndrome, yearly screening is essential.

Dr. Ellison recommended that, along with yearly complete blood count (CBC), children with Down syndrome be screened for thyroid disease, diabetes and Celiac disease (tTG).

Thank you to Kelly Zimmerman for setting up this wonderful speaker.

Do you have a suggestion for a topic or speaker for a TVDSA meeting? Please contact either [Kelly Zimmerman](#), [Karleen Lemon](#) or [Erin Rosenkoetter](#).

and then you may.  
If you let me be,  
I'll try again  
and you will see.  
Say!

I almost like these IEPs  
I think I'll write 6003.  
And I will practice day and night  
Until they say  
"You've got it right".



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## When "They" Say. . . By Kathy Everett, Alpharetta, GA

I.E.P. Those three little letters instill fear in the hearts of many parents who have a child with a disability. Others have no clue what they mean.

In the past 22 years, I have attended hundreds of IEP (Individual Education Program) meetings. Some were for my own daughter, Jennifer. Sometimes, I provided a hand to hold or a friendly face in the crowd for other parents who needed it. The process of creating an IEP can be long and confrontational, short and cooperative - or anything in between. The key is for parents to know what to say when "they" say (fill in the blank).

In my journey, I have learned many things that I share with other parents to help them on their journey. When a school member says something you disagree with for your child, your response is key. Here are some of the most common comments said at IEP meetings and what you can say to counter them.

**We've never done that before.** Well, let's see how we can figure out how to do it.

**She will get more attention in a small group setting.** The average self-contained class has eight students all with significant special needs, while the general education classroom has an average of 20 students, but statistically only one will have significant special needs.

**Your child requires more attention than I can give in my class. I have 20 other students that need my attention.** I understand and it sounds like you do not have enough support in the class to help with all your students. Then maybe a paraprofessional is necessary. OR. . . All

## Calendar of Events

### February 3rd:

Elks' Rehab Free Workshop:  
Making Sense of  
Communication Symbols  
7pm-8:30pm  
(Details below)

### February 3rd:

Building Babies Better  
Workshop 6:30pm-8:30pm  
(Details below)

### February 5th:

Idaho Stampede Basketball  
game featuring Idaho Cheer  
Adaptive Cheerleading  
Squad half-time  
performance at 7pm

### February 10-12th:

[Peak Conference](#) on  
Inclusion: Expand Your  
Toolbox and Construct New  
Possibilities. Denver, CO

### February 11th:

Cool Club  
5:30pm-9:30pm?  
Dinner and a Movie  
in Nampa.  
Contact: [Molly Benton](#)

### February 12th:

Lil' Buddies Playgroup  
3pm-5pm at Moses'  
house in Boise.  
Contact [Kristie Yerger](#)

### February 12th:

Adults in Motion  
1pm Valentine Crafts and  
Community Service Project  
Contact: [Freddie Gallas](#)

### February 15th:

TVDSA Board Meeting  
7pm-9pm at A New Leaf  
Open to all

### February 23-26th:

[Inclusion Works 2011](#)  
Austin, TX  
Registration due February  
11th

### February 26th:

TVDSA Mini-Workshop  
9:00am-12:00pm  
Legal Planning for Life  
After 18!  
Contact: [Paul Auger](#)

### February 28th:

Lil' Buddies Playgroup  
10am-12pm at Mikaela's  
house in Boise.  
Contact [Kristie Yerger](#)

students need to be challenged and you should not feel like you are the only one who can teach my child. I am sure there are several other children who would love to help out my child. We all know that helping someone else learn reinforces what is being taught. Peer tutoring is a wonderful opportunity for everyone in the class to learn.

**He needs to be with other kids that are like him. He will feel always left out and unable to really compete with his peers.** My child needs to be around age-appropriate peers in real life situations to learn how to get along with others in the real world. Research shows that all children benefit from inclusive classrooms.

**It isn't fair to have a child in the class who is learning, have to teach someone else. It isn't their responsibility.** We all know that kids learn from kids. Kids build competence by teaching someone else because it reinforces the skills they are learning themselves.

**She really needs adaptive PE (or art or music).** I understand my child has limitations; but she will benefit from access to the general curriculum, just like all of the other students do. And, in a class like PE (or art or music) just learning to follow directions or changing clothes is a skill my daughter needs for life.

**They need to be in adaptive PE so they don't get hurt.** Don't you have any other children that ever get hurt? My child needs to learn how to play in social environments. What can I do to help you have the supports so that he can safely participate? Let's work together to plan what supports will help him participate safely.

**She is so far below grade level, she cannot even. . .** I understand my child can't . . . That is why we have differentiated instruction. The curriculum needs to be modified so that she can continue to progress and learn.

**He is not at the level of the other children.** I know he isn't at the level of the other children. That is why he has an IEP. I don't expect him to be at the same level as his peers, but I do expect us to use a modified curriculum where we can identify the supports that are necessary and helpful for him to learn.

**We are concerned about her life and/or job skills. That is why he needs to be in this class.** I really appreciate your concern. There are many things I can replicate at home and I can teach my child. But I cannot recreate a high/middle/elementary school environment. My child needs to experience that just like any other child. I will teach my child life skills. I can take my child to the grocery store. I need her to learn how to be around other people.

In communication, one of the most important things to remember is to keep the conversation focused on your child and his needs. It's what he needs, not what you want for him. It sounds simple, but the key is semantics. Always think about how you phrase a question or statement to encourage the response you want. I never ask if something can be done. I ask how it is going to happen. It is important to be knowledgeable and realistic about what your child can and cannot do. Know the law - but use it sparingly. Honestly, you and the educators want the same thing: for your child to learn in

March 2nd:

Spread the Word to End the Word

March 21st:

World Down Syndrome Day

April 29-30th:

[r.i.s.e. Conference](#) (Respect, Inspire, Support & Educate)  
Spirit Mountain Casino  
Grand Ronde, OR

August 5-7th:

Annual [NDSC Conference](#)  
San Antonio, TX

**Spread the Word to  
End the Word  
National Campaign**



What are you doing?

Need some ideas? Check out the official [website](#), watch this [video](#), only your imagination is the limit!

### **Help NEEDED:**

The Lil'Buddies and Elementary groups will be joining forces for an **Easter Egg Hunt** in April. (More details to come).



We need: Volunteers and plastic eggs to help make this event a success.

Please contact [Kristi Yerger](#) or [Celena Auger](#) if you are interested in helping.

a healthy, caring environment. Sometimes, we just have differing philosophies of how to accomplish that. Good luck and remember an IEP is not carved in stone. It can be changed.

*Kathy Everett is a certified teacher in both general education and special education who directs her own consulting business, Kathy Everett Consulting, to assist parents in navigating school systems. She also has a daughter with Down syndrome.*

## **A MOTHER'S WISH LIST FOR A TEACHER**

*Written by: Diane O'Rourke-Bankus © 2003*

1. Please don't assume that you know what it is like to parent my child. The only person who can possibly relate to my hopes and my dreams, my burdens and my fears, and the difficulties I face, is GOD!

2. Please respect me for knowing my child better than anyone else. Please accept the ideas I share as tools to help improve a situation for my child, not words of criticism towards you.

3. My child does not speak well. We aren't able to enjoy the reciprocal conversation about her day at school that you are able to enjoy with your own children. Please communicate with me and allow me to communicate with you, so that I may know about her day. I would like to be able to help her with her difficulties and praise her for her efforts.

4. Please don't tell me I can't FIX my child. I was complimented by God that he selected me for this journey - parenting a special needs child. God grants me the serenity to accept the things I cannot change...the most difficult of all being that my child has special needs. I can't FIX that and make it go away and I don't need to be reminded of that fact. But God also grants me the serenity to change the things I can. My child is full of motivation, a love for learning, a willingness to improve herself, and pride in her accomplishments. Please respect me for encouraging her to be all that she can be. Please respect her for her very hard work and accomplishments. No, I can't FIX her disability. But I can provide her with all that she needs to make it easier to live with. And by the way, God grants me the wisdom to know the difference.

5. Allow me to believe in miracles. After all, I do live with one. Don't slam the doors on my hopes and my dreams.

6. Please respect me for the time, the effort, and the challenge of educating myself in the different areas of the special needs of my child. I have a need to learn all that I can about my child and how she sees the world. I am willing to share this information with you, hoping it will make your job a bit easier. My knowledge also enables me to help others, which gives me great joy!

7. Please know that I am tired. There are days when I need some positive reinforcement or a kind word. Because I understand that NEED, I try to provide the same to you and all who are involved in helping my daughter be

## Meet Gabrielle Hannah and her mother, Stephanie



Some have told me, that the day I had Gabrielle was the most traumatic in my life. It wasn't. The only thing traumatic about that day was the process of giving birth to her... there were so many complications... They used all their resources to get her delivered. When NICU took her away and worked on her. The doctor came back and told us they thought she might have Down syndrome. All that mattered to me was she was alive and had ten fingers and toes. I loved her the moment I saw her. It was one of the best days of my life.

Yes it was a shock that she had Down syndrome. Out of all the thoughts that went through my head the thing that made me cry was the worry I had how others would treat her. I know Mike and I and her family would love her no matter what. However, I haven't had to worry about that too much! Everywhere we go I hear people say "HI GABBIE!" and they come up to give her a hug. Even adults that work with her say hi and say how awesome she is. They tell me how polite and what a great girl she is and what a great job we're doing with her.

Gabrielle was a very healthy baby. She had no health issues besides a tiny hole in her heart that healed up on its own. We always said she just crossed the line with her big toe. She was a very happy and loving baby. Gabby was an adventurous toddler who loved to play with her babies and swim and climb on everything. She's always had an amazing giggle that warms your heart and makes you smile no matter what kind of day you

all that she can be. When my "gas tank" is empty, it needs to be refilled!

8. Please know that I respect and appreciate all that you do. I know that your job is almost as demanding as mine. When God selected me for this journey, he sent angels along to help me. YOU ARE ONE OF THEM! Thank You!

*This article was originally published in the Autism/Asperser's Digest Magazine in 2003. Diane O'Rourke-Bankus is a national advocate for children with special needs. She is also an educational advocate (special education and the law) helping parents. She is also the mother of a now, nineteen year old diagnosed with PDD-NOS.*

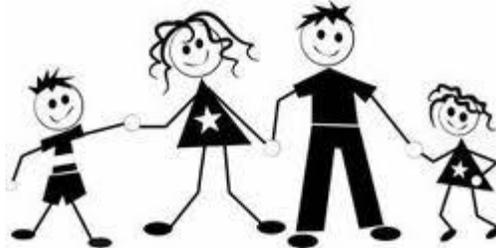
## TVDSA February Mini-Workshop

**Saturday, February 26, 2011**

9:00am - 12:00pm

**Topic:** Legal Planning for Life After 18!

**Speaker:** Charlene K. Quade, Attorney,  
C K Quade Law, PLLC



*This presentation is appropriate for families of children and adults of all ages with disabilities. The child is never too young to start planning for their future.*

Location: TBA

Cost: \$5.00 per person - WHAT A DEAL!!!!

Who should attend? Parents, professionals, and service providers. Open to everyone. Share the information with those you know, or bring a friend.

**CEU's** and Certificates of Attendance for those needing education or training for licensure is available.

Pre-registration is encouraged but not required.

For more information or to pre-register, please contact: [Paul Auger](#), TVDSA Programs Chair

have.

Gabrielle is now a very wonderful 9 year old. She loves to play outside and loves to hike, fish and camp. She plays baseball and rides her bike. You'll never catch her without a book to read or to draw in. Gabby loves to paint on canvas and ceramics. She adores Woody from toy story and Tinker Bell. She's doing really well in school and really enjoys her friends and little sister Emily.

Submitted by Stephanie Barton

### Adults In Motion Reminder & Updates

The next Adults In Motion (AIM) meeting will be **February 12th** at 1pm at the home of Freddie Gallas, in Nampa.

**Activity:** Meet, have refreshments and decorate valentine cards. As a community service project, some of the cards and small gifts will be assembled for the children in the oncology ward at St. Luke's in Boise.

Those members able to meet at St. Luke's on February 14th about 3:00pm will deliver the cards and gifts.

AIM is open to new members and welcomes everyone!

For further information or to **RSVP** contact [Freddie Gallas](#), 409.718.0417

## Beyond "Two-Dimensional" Thinking

### Revolutionary Common Sense by Kathie Snow

#### Disability is Natural, E-Newsletter, Oct 13, 2010

It goes by many names - - EITHER/OR, BLACK/WHITE, YES/NO, ALL/NOTHING - - but whatever it's called, two-dimensional thinking can be a recipe for conflict, stress, diminished opportunities and other less than desirable outcomes. Some of us engage in two-dimensional thinking only occasionally, during specific circumstances; while for others, it's routine - day in and day out, regardless of the issue.

Children typically operate from a YES/NO frame of reference. This may simply be a consequence of their youthful inexperience, or it could be the result of the world they inhabit; being under the power of adults- parents, teachers, and others - where YES or NO are the only options. Teenagers (and adults, too) often embrace the ALL or NOTHING thought process. A teen, for example, may say "All the other kids are doing it!" While in adults, being inflexible or rushing to a judgment without exploring all the options are often manifestations of BLACK/WHITE thinking.

Perhaps it's not surprising that two-dimensional thinking is so prevalent - we're surround by the "opposite pairs." In our homes and offices, lights, TVs, ovens, car engines, and other things are either ON or OFF. A person is either employed or unemployed. We think in terms of fat/skinny, tall/short, wet/dry, open/close, up/down and more. And most of us have heard the familiar adage, "There are two sides to every story." Respecting this bit of wisdom may have been helpful to us in the past. However, this also represents two-dimensional thinking, for there are probably *many* sides to every story.

But we can change this. We can learn to examine the "gray areas" between the BLACK and WHITE. We can choose to respond, "Maybe. . ." or "Let's think about it, " and then consider the "how, when, what and why." Because no one, regardless of age, needs to be limited to only two options in decision-making. And when it comes to disability issues, getting beyond two-dimensional thinking can increase opportunities for success and inclusion, and we'll look at those in more detail.

A child or adult who has been diagnosed with a developmental disability may later be the recipient of a "behavioral" diagnosis as well. For example, when the only way one has to communicate is through behavior, others may label these actions as "behavioral problems." In other cases, a "behavioral label" may be the result of what the person has learned at the hands of parents, educators and others. For example, if Eric's parents or teachers don't think he's capable of "higher level thinking" (or if the adults out of habit, routinely practice two-dimensional thinking) *all Eric will learn is YES/NO thinking*. Thus, when he is older, Eric will not have learned to distinguish, to question or negotiate, or to employ critical thinking methods when making decisions for himself. He'll be stuck with

## Cool Club Dinner and A Movie

Our next gathering  
for Cool Club will be  
**Friday, Feb. 11th at 5:30pm**

**Activity:** We will meet at Wendy's (intersection of Caldwell Blvd. and Midland Rd. in Nampa) for dinner at 5:30pm. After dinner, we will then head to the Nampa Reel Theater to watch a 7pm movie. Everyone is encouraged to choose the movie of their choice and we will watch the show(s) together in groups.

**Cost:** Dinner is on your own and the cost of the movie is \$2.00 per person.

Questions or to RSVP  
contact [Molly Benton](#)

## Enjoy Basketball or need an excuse for a night out?

Wings Adaptive Cheerleading Squad will be performing at halftime during the Stampede basketball game **February 5th at 7:00pm.**

Cost is \$10 with \$4 going to the cheer booster club.

[Idaho Cheer](#) is the only All-Star cheer program in the state of Idaho which has a squad for individuals with special needs. They not only compete and perform in Idaho, but throughout the west!

For tickets, please contact [Jinny](#) at the Idaho Stampede office: 388-4667. You must mention you are with Idaho Cheer to get the discounted \$10.00 tickets. You can pick up the tickets at will call that evening.

simplistic BLACK/WHITE thinking. This will limit Eric's opportunity for success, and it may also cause others to perceive Eric as incompetent.

Sadly, and too frequently, children and adults with disabilities have been judged incompetent to make even the simplest decisions about their own lives. But have we ever considered that we may *have never allowed them to experience the naturally-occurring opportunities to think for themselves, and to learn how to make thoughtful decisions?* We can and should rectify this oversight, and it's never too late to do so!

To read the rest of this article, click [here](#).

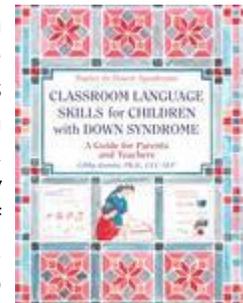
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## From the TVDSA Library

With Mary Anne Murphy

### Classroom Language Skills for Children with Down Syndrome by Libby Kumin

Renowned therapist Dr. Libby Kumin is an expert in the speech and language challenges of people with Down syndrome. In this book she addresses specifically the communication needs of children during the school day. As a reader might expect, she reviews evaluation procedures that identify language challenges and the various models of services that could be provided. But, in addition, she provides plenty of information and ideas so that your child's team can develop creative solutions to a wide variety of language needs, thus leading him or her to communication success in the classroom. One especially wonderful chapter is called "The Language of The Hidden Curriculum." This chapter details the array of possibilities in the unspoken expectations that may occur in any classroom. Typically developing children may quickly come to understand the "hidden curriculum" and adapt to ways in which a new teacher's expectations differ from those of the last one, but a child with Down syndrome may not catch on as well or may be more easily confused. This chapter helps adults to teach a child how to succeed with classroom rules and expectations, whether they are clearly communicated or not.



## February IPUL Events

Wednesday, February 9th  
6:00 pm - 8:00 pm  
IPUL Monthly Support Group

### Topic: Open Forum

Parents are welcome to come and network with others, and find out about the resources IPUL has to offer, including workshops which can be requested at any time.

**New Location!** 500 South 8th Street, Boise

For additional information or to register, contact: [Angela Lindig](#)

## Idaho Special Olympic Winter Events

February 5 - [Area 3/4 Winter Games](#) at Bogus Basin and [Area 1/2 Winter Games](#) in Kellogg, ID and Silver Mountain Resort

February 18th - [Blizzard Bash](#) - Sportsman Warehouse - Meridian ID

February 19th - [Penguin Plunge](#) Sportsman Warehouse - Meridian ID

March 2nd - [Spread the Word to End the Word](#) National Campaign

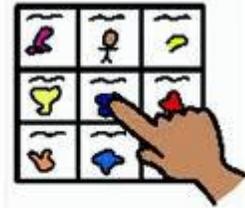
March 11th-13th - [State Winter Games](#) in McCall/ Cascade ID (159 ways to participate!)

## Elks Rehab FREE Workshop:

### **Making Sense of Communication Symbols: How to pick them, how to use them, and how to have fun doing it!**

Presenter: Anne M. Kuhlmeier, M.A., CCC, ATP

Description: Your child has communication problems and isn't speaking. Your speech therapist and/or teacher have started using pictures at school and asked you to use them at home. You are concerned that by adding pictures, you will inhibit your child's ability to speak. You are willing to try pictures, but you don't know what pictures you need, or how to use them. Or, maybe your child brought a communication book home, but you don't know where to start and no one has shown you how to use it. The pictures keep getting lost because your child's favorite activity is pulling them out and throwing them around. Come to this presentation for some answers on why and how to use pictures, how to select the right pictures and how to make using them fun.



When: Thursday, February 3rd 7:00pm-8:30pm

Where: St. Luke's Meridian, lower level conference rooms

Cost: **FREE!**

Please call 706-5549 to sign up



### **Workshop: Developmental Environments**

When: February 3, 2011 from 6:30pm-8:30pm

Where: St. Alphonsus' Regional Medical Center, McCleary Auditorium, 1055 N. Curtis Road in Boise

## TVDSA Board of Directors

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**Description:** This seminar will present the foundational sensory motor skills that develop during prenatal and neonatal time periods. Five key principles will be discussed for building a solid sensory motor foundation. This information can be used to design environments and provide activities to enhance children's development. Considerations in building these environments include lighting, sound, play surfaces, and appropriate toys. While the focus will be on infants in the first year of life, the principles are applicable to toddlers and preschoolers.

**Presenter:** Roxanne Small, P.T. is a registered physical therapist with over 30 years of experience in pediatrics. She is the author of *Building Babies Better*.

**Cost:** \$10.00 (Scholarships available)

For more information visit her [website](#) or email [Roxanne Small](#)

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### Announcing a new addition to the TVDSA Board:

We would like to thank and welcome **Angela Bowman** to the TVDSA Board. Watch for more information on her addition to the group in the March newsletter.

**Are you interested in serving on the TVDSA Board?** There is still one seat available at this time. In addition, at our annual Membership Meeting in May, there may be additional seats opening up. Please contact [Sara Cox](#) or [Joyce Page](#) with any questions, inquiries or nominations.

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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/>

**Treasure Valley Down Syndrome Association**

**Mailing:**  
PO Box 1404  
Meridian, Idaho 83680

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



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