

TVDSA **Newsletter**



Newsletter Editor: Celena Auger

November 2011

Double Issue in November?

This month, you will be receiving the Treasure Valley Down Syndrome Newsletter TWICE! They will both contain the same information, but available in two different languages. In recognition of many of our local, Hispanic families in the Treasure Valley that have children or other family members with Down syndrome, the November Issue is being dedicated to the Hispanic Community of the Treasure Valley. We hope that you will enjoy the information in this newsletter, whichever version you chose to read.

TVDSA will be updating our email distribution lists over the next several months. We look forward to specializing the ways we communicate with different interest groups within the TVDSA family.

Researchers Find Differences In Down Syndrome Rates Between Whites And Hispanics

From University of Cincinnati

Researchers at the University of Cincinnati have found significant differences in the prevalence of Down syndrome between Hispanic and non-Hispanic whites as well as distinct racial differences in the use of prenatal genetic testing to diagnose Down syndrome.

Their findings are published in the Jan. 15 issue of the American Journal of Epidemiology and are based on an analysis of data collected by the California Birth Defects Monitoring Program and the Genetic Disease Branch of the California Department of Health Services.

"There are very few databases in the country that attempt to collect 100 percent of the data on birth defects. California, which is the population I chose, actively ascertains that data," said UC doctoral student Jennifer Bishop, explaining why the analysis should provide a very accurate assessment of the true prevalence of Down syndrome in the population.

With the assistance of UC biology professor Carl Huether, UC mathematics professor James Deddens and California researchers

In This Issue

- * Differences in Down Syndrome Rates Between Whites and Hispanics
- * Working Together to Resolve Disagreements
- * Buddy Walk Thank You!
- * Advocacy Workshops

November TVDSA Meeting

**Tues, November 8th
7:00pm-9:00pm**

at A New Leaf
2456 N Stokesberry
Meridian ID
West of Eagle Rd between
Ustick and Fairview Ave

Claudine Torfs and Fred Lorey, Bishop analyzed data from 1989 through 1991. The data included both information on live births and prenatal diagnoses of Down syndrome. That's important, because many Down syndrome fetuses are spontaneously or electively aborted and would be missed by researchers looking only at live births.

"We really wanted to get as close a measurement as possible of the true prevalence in the population, because prenatal counselors often use these rates when they're trying to predict the outcome for older mothers," said Bishop.

Overall, Bishop found that the total prevalence of Down syndrome was slightly higher than figures previously reported in the literature. Apparently, that figure reflects the gradually increasing age of the American population.

The biggest surprise came when Bishop looked for differences among ethnic groups and races. "There seems to be a different type of pattern in Hispanic population," said Bishop. "The prevalence among younger mothers was higher in the Hispanic than in the other races and lower in the older maternal ages."

This does not mean that young Hispanic mothers have a greater risk than older Hispanic mothers. It simply means that when the researchers compared younger Hispanic mothers with younger white mothers, prevalence rates were higher for the Hispanic mothers.

Bishop looked at five-year age brackets, and for all age groups under 40, the risk of Down syndrome was significantly higher for Hispanics than for whites. For mothers over 40, the prevalence rates were significantly lower for Hispanics than for whites. However, the researchers still cannot explain why the difference occurred.

"What we found doesn't necessarily indicate a genetic difference," said Bishop. "It could be a socio-economic difference, a nutritional difference or an ascertainment difference. Did we really have all the cases?"

The other clear racial difference showed up when the researchers compared the prevalence of Down syndrome among live births and the adjusted prevalence of Down syndrome which included aborted fetuses. Whites showed a 46 percent decrease in Down syndrome births due to prenatal diagnosis compared with only a 10 percent reduction among Hispanics.

The researchers say the difference probably reflects several factors, including the availability of prenatal diagnostic services, the cost of those services, and differing personal beliefs on elective abortions.

Huether has found similar differences in previous studies comparing blacks and whites and mothers from different geographic regions.

*This article comes from Science Blog. Copyright © 2004
<http://www.scienceblog.com/community>*

Topic: Building A Strong Foundation for Literacy

Mary Anne Murphy will describe each step her family has taken to help their son learn to read and highlight the work of Down Syndrome Education International.

Down Syndrome Education International is a leading international charity dedicated to raising levels of educational achievement among children with Down syndrome. They have been at the forefront of developmental and educational research and evidence-based services improving outcomes for children with Down syndrome.

This presentation will be of particular interest to families with children age birth to five and to families of older children who have not learned to read.

There will be plenty of time after the presentation for small-group meetings and for browsing the library.

If you have meeting topic suggestions, please send them to: [Kelly Zimmerman](#) or [Erin Rosenkoetter](#)

November TVDSA Workshop

November 19th
2:00pm-4:00pm

at A New Leaf
2456 N Stokesberry
in Meridian

Sign Language Class
by Signing Time Academy
instructor, Krissy Fulton

The workshop is for parents only. Unfortunately, there will not be childcare available at this workshop.

Cost: FREE for TVDSA Members and \$5.00 for Non-TVDSA Members

Working Together to Resolve Disagreements: How Parents of Young Children Can Resolve Conflicts

Note: While parts of this article relate specifically to services for families whose children are ages birth to three years old, the overall strategies suggested relate to all families, no matter the age of their child.

When families with babies or very young children recognize that their child needs assistance or support, they are often thrust into a situation in which they have multiple service providers with whom they must interact. Since team meetings with all the individuals who are involved are often difficult to schedule, sometimes service providers and families aren't "on the same page," and differences of opinion and conflicts emerge. When situations like this occur, it's helpful for families to have strategies as they work to communicate with the professionals on their child's team to assure their child's needs are met. The tips below are intended to help families in these kinds of situations.



What Causes Conflict?

Conflict is a normal part of all relationships and occurs when there are differences in perspective. It is important to keep this in mind as you navigate services for your child and family. When conflict arises, it does not mean that one person is right and the other is wrong per say - it does mean that effective communication on both sides is necessary if there is going to be a resolution.

Conflict is usually caused by:

- *Different assumptions
- *Miscommunication
- *Blaming others for your emotions
- *Not communicating until you erupt (or the volcano syndrome)

Effective Communication Skills

Like any new skill, effective communication takes practice. Here are the key components of effective communication skills, taken from Marshall Rosenberg's book, Non-Violent Communication. For more information on non-violent communication, please visit The Center for Nonviolent Communication's website.

First, be a good listener. Don't plan your response while the other person is talking. Instead, focus your attention on trying to understand the other person's point of view, needs, wants, feelings, and ideas. Sometimes it can be helpful to paraphrase what you heard the other person say to make sure you understood. This helps eliminate incorrect assumptions. You could begin by saying, "I want to make sure I am understanding you correctly. I heard you say...." After you paraphrase what you heard, check your understanding with the other person, and give him/her the chance to say more.

Need more information on this or future TVDSA Workshops, please contact [Kristie Yerger](#)

Calendar of Events

November 8th:
TVDSA Meeting
7:00pm-9:00pm
Topic: Building a Strong Foundation for Literacy
Contact: [Erin Rosenkoetter](#) or [Kelly Zimmerman](#)

November 9th:
Elementary Social Group 5:30pm-7:30pm at Bounce! in Meridian
Contact: [Kristie Yerger](#)

November 9th:
IPUL Parent Support Group - Working for Change: The Power of a Personal Story
6:00pm-8:00pm Boise
Contact: [Angela Lindig](#)

November 12th:
Lil' Buddies Playgroup 3:00pm-5:00pm at Caleb's House in Eagle
Contact: [Kristie Yerger](#)

November 12th:
Cool Club & AIM Fusions at 3:00pm Making Christmas Ornaments!
Contact: [Molly Benton](#) and [Freddie Gallas](#)

November 12th:
Disability Advocacy Day Workshops
Idaho Falls

November 15th:
TVDSA Board Meeting 7:00pm-9:00pm at A New Leaf, Meridian
Contact: [Paul Auger](#)

November 19th:
TVDSA Workshop: Sign Language Class
2:00pm-4:00pm at A New Leaf, Meridian
Contact: [Kristie Yerger](#)

November 19th:
Disability Advocacy Day Workshops
Coeur d'Alene

"Did I understand you correctly? Is there anything else you'd like to add?" Let the person finish before you start responding to what he/she said. Try and put yourself in the other person's shoes. What might he/she be feeling/needing?

Second, make observations, not judgments. Observations are free from judgment, evaluation, or opinion. They are based on fact. For example, instead of saying, "The occupational therapist does not care about my son!" say, "The occupational therapist has not shown up for the past 2 appointments." Or, if talking directly to the person (which is always best) say, "I've noticed you haven't shown up for our last 2 appointments."

Third, express and take responsibility for your feelings. Sometimes, especially when strong emotions are involved (which can be often when you are dealing with the challenges of supporting a child with a disability) it can be difficult to express and take responsibility for your emotions. Avoid blaming others for how you feel. The simple way to do this is through the use of an "I-statement." For example, instead of saying, "You made me angry." say, "I feel angry." Don't get caught in the "volcano syndrome" style of communicating. This is when you don't express how you are feeling to avoid conflict. When you do this, emotions build up, and eventually, you explode. Conflict is most effectively resolved when it is dealt with immediately.

Fourth, connect your emotions to your needs. Usually, our emotions are telling us that our needs are not getting met in some way. When feeling strong emotions, take some time to figure out what it is you need, and add that to your "I-statement." For example: "I feel angry when I've cleared my schedule and you don't show up. I need to trust you to keep the schedule so my child can get the services he needs."

And finally, make a request. When making a request, you are asking to get your needs met. It is impossible to do this without knowing first what your needs are. When you make a request, you are not trying to control the other person or make a demand- instead you are honestly trying to acknowledge and communicate what you need from the other person to help resolve the conflict. "I would like to request that if you can't keep our appointment that you call me and give me as much advance notice as possible. I'd also like to make up the 2 missed OT sessions. Is that possible?"

Working Collaboratively to Resolve Problems

"The chances for resolving a conflict increase if the strengths of the relationship - the shared concerns and needs - are given more attention than the single point of separation." - Author Unknown

Throughout your child's life, you will work with many service providers, professionals, and teachers. Creating strong relationships with your child's support network is key to working together well and resolving conflict. When a strong relationship is in place, communication is easier, and less tense because trust has been established. For example, if you trust your child's Occupational Therapist (OT), and have a good relationship with her, when she doesn't show up, your first thought will not be that she doesn't care about your child.

November 22nd:
D.A.D.S. Meeting
6:30-8:30pm
at Fuddruckers on Eagle
Rd. Contact: [Jim Yergler](#)

November 28th:
Lil' Buddies Playgroup
10:00am-12:00pm
at Just Kidn' Around in
Meridian
Contact: [Kristie Yergler](#)

December 3rd:
Disability Advocacy
Day Workshops
Twin Falls

December 10th:
Disability Advocacy
Day Workshops - Boise

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

Lil' Buddies

November Playgroup Dates:

Saturday, November
12th:
3:00pm-5:00pm at
Caleb's House: 478 E.
Stonewater Ct. in Eagle

Monday, November 28th:
10:00am-11:30am at
Just Kidn' Around,
2374 E Cinema Drive in
Meridian, ID
Entrance fee for Lil'
Buddies will be paid by
TVDSA. Parents are free
with child. Don't forget
your socks!

Happy Birthday to: Colin!

If your Lil' Buddy has a
November or December
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](#)

Tips for Building Collaborative Relationships

- Point out the positive/good things you see your child's service providers doing. Everyone likes to feel appreciated.
- Avoid miscommunication by practicing the communication skills above.
- If you are not satisfied with something, speak up immediately. Don't let things build up.
- Ask for agreements in writing to avoid misunderstandings.
- Ask providers if there is anything you can do to support them as they do their job (i.e. provide more information about your child, offer water or snacks, etc.)
- Honor your commitments, just as you would expect your service providers to honor theirs.
- Listen to the opinions of others and express your own. Recognize disagreement and conflict as a natural part of any relationship.

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TVDSA Spotlight:

Meet Mikaela Olmos

True love, that's what our daughter Mikaela has taught us. She's taught us that true love is unconditional. It means that you love your children not for their abilities and talents or for their accomplishments, but for whom God made them to be. When we learned of Mikaela's diagnosis, just minutes after her birth, we were fearful of what was to come but we trusted in God's plan. We knew He would equip us with the knowledge, patience, humility, understanding to raise our beautiful daughter with confidence, and an immense amount of LOVE! She has taught everyone in our family, that we should always be positive and hopeful in all circumstances. Mikaela has empowered us to be faithful in our role as parents and always seek to provide support and motivation to each one of our children. This desire to help her has also motivated us to help other families who may not have a sense of hope or positive outlook about their child's diagnosis.



We have been fortunate enough to be surrounded with a very supportive community of family, friends, and professionals. However, we've also come to realize that not all families who have a child with special needs are this lucky. Because of this, we have chosen to be active in our community and be a part of the effort to raise awareness about Down syndrome and be a bridge for Spanish speaking families to seek out the resources their child needs. We

Elementary

Elementary Social Group

Wed, November 9th
5:30pm-7:30pm

at Bounce!

490 E. Schiller Lane,
Suite 100, in Meridian
Conveniently located
near the Meridian Exit off I-
84

Entrance for child with Down syndrome will be paid by TVDSA. Parents are free with child. Dinner will be served.

Need more information on the Elementary Social Group or want to help organize? Please contact [Kristie Yerger](mailto:Kristie.Yerger@peakparent.org)

Cool Club & AIM

The Cool Club and the Adults in Motion (AIM) will both meet on:

Saturday, November 12th
at 3:00pm
at
Fusions
347 S. Hedgewood Lane
In Eagle

Activity: We will be making glass ornaments for Christmas.

As TVDSA will be paying for the activity, we do need a head count of those participating. Please RSVP to [Molly Benton](mailto:Molly.Benton@peakparent.org) or [Freddie Gallas](mailto:Freddie.Gallas@peakparent.org)

D.A.D.S. Group

The D.A.D.S. next gathering will be

Tuesday, November 22nd
6:30-8:30pm

At the Fuddruckers
on Eagle Road

For more information contact: [Jim Yerger](mailto:Jim.Yerger@peakparent.org)

know that with each milestone Mikaela reaches, we will be reaching milestones as well. With each new sign or new word she learns, we learn something new too. We know that God has a bigger plan for Mikaela and for our family. We are simply taking the small baby steps forward everyday to fulfill the role we have been given. With faith and hope we know that we will help Mikaela live life to the fullest and she will continue to teach us and everyone she meets how to TRULY LOVE!

- Submitted by Lucy and Gus Olmos

Additional Links to Articles available in both English and Spanish

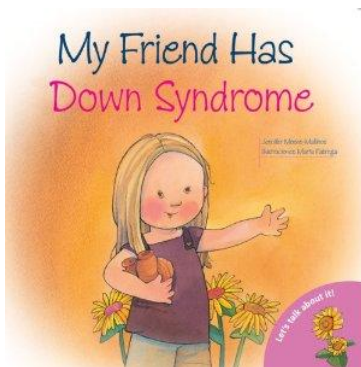
With this being the first TVDSA Newsletter that is truly extended to all of our readers, it was difficult to select which articles to have included in the printed text of this newsletter.

Here are additional topics and links to other articles (available in both languages) that were not selected, only because of the length of articles, not for their content:

- * [Down Syndrome Fact Sheet](#) from the National Dissemination Center for Children with Disabilities
This article gives tips for the parent and the teacher
pdf files: [English version](#) / [Spanish version](#)
- * [Intellectual Disability](#) from the National Dissemination Center for Children with Disabilities
pdf files: [English version](#) / [Spanish version](#)

From the TVDSA Lending Library
by Mary Anne Murphy

My Friend Has Down Syndrome by Jennifer Moore-Mallinos



This sensitively written book is a story about two children who meet at summer camp and the warm friendship that develops between them despite the fact that one of them has Down syndrome. Both girls learn that everybody is good at something, and that by helping each other overcome their fears and difficulties, they can accomplish a great deal. *My Friend Has Down Syndrome* inspires and encourages children to overcome

Winter Special Olympics Team

Despite the heat, it's time to start thinking about the Special Olympics Winter Games

High Valley is now recruiting for alpine skiers and snowboarders.

For more information please contact [Deborah Havens](#)

Animated Cartoon Features Down syndrome

Punky - the first ever animated cartoon featuring a lead character with Down syndrome - is going global with Target Entertainment. Target has pledged to donate half of global sales commissions to support Down Syndrome Education International's work to improve education for young people with Down syndrome.

To read more, or watch a short 30 second introduction of Punky, go to the [dse blog](#).

Idaho Parents Unlimited

IPUL Parent Support Group

November 9th
6:00pm-8:00pm
500 S. 8th St. Boise

**Topic: Working for
Change: The Power of a
Personal Story**

In preparation for Disability Advocacy Day and Medicaid Matters, come learn how to write your personal story to help change policies and procedures you are passionate about.

For more information or to register for this workshop, please contact [Angelo Lindig](#)

barriers that can exist between kids with Down syndrome and their playmates.

This book is available in both Spanish and English editions 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](#).

Thank You Sara!



Treasure Valley Down Syndrome Association wants to express our appreciation to Sara Mitton Cox for the dedicated service she has rendered in serving on our board for the past five years. Sara joined our board in 2006, after hearing about the Buddy Walk. Sara knew firsthand the blessing that individuals with Down syndrome can bring to their families and friends, as Sara's older brother Justin has Down syndrome. She wanted to share the message that people with Down syndrome should be respected and included just like everyone else. Sara's enthusiasm and experience from working in non-profit marketing for five years was

just the jump start that our group needed to see a larger vision of what TVDSA could become. Sara served as Secretary, Vice President, and helped co-chair the Buddy Walk for several years. Sara served as President of TVDSA for two years from May of 2009 until May of this year. Sara has the unique ability to bring together people with great ideas and skills and motivate them to work together to accomplish amazing things! Sara served as co-chair of our Buddy Walk 2011. She sacrificed many hours of her own personal time to ensure that the Buddy Walk would be a success! Sara wrote the script and was the force behind the PSA that was broadcast on several TV stations in the weeks before our Buddy Walk. In the past five years Sara has touched the lives of all who have had the pleasure of working with her. While Sara will no longer be serving on our board, she will continue her legacy of advocacy for individuals with Down syndrome. Sara will now have more time to dedicate to her husband Tim and two step-sons. Thank you Sara for all that you have helped TVDSA to accomplish in the past five years! You have left your signature on our hearts!

Conferences, Workshops and Webinars

PEAK Webinars:
[Lunchtime IEP Training Series](#) - FREE
from 12:00pm-1:00pm
each day:
Listen to one or all!

* Tues, Oct 25th
Preparing for the IEP

* Tues, Nov 15th
Content of the IEP

* Tues, Nov 29th
**Implementation and
Follow Up of the IEP**

Pre-Recorded PEAK
Webinars, available at
your convenience, at no
charge:

[El IEP: Un Instrumento para
Realizar las Posibilidades](#)

[Creating Circles of
Support](#)

[Communication that
Really Works](#)

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

Thank you for participating in this year's Buddy Walk!

We could not have asked for a nicer day, October 8th in downtown Boise. Still a little wet in spots, but the sun was shining down on everyone at Julia Davis Park!

This year we had OVER 1,400 Registered Walkers, **our largest walk yet!** To match, it was also **the Largest Earning Buddy Walk for TVDSA**, earning more than \$30,000!



It could not have happened without YOU and Your Support!

We would also like to Thank our Corporate Sponsors this year, once again:

C.K. Quade Law, PLLC.
Scentsy, Inc.
Primary Health Medical Group
Idaho Inflatables
Speech Tree
Wirestone
Alaskan Airlines
Idaho Gastroenterology Associates
Southwest Airlines

Becoming a Love & Logic Parent

This course provides simple and practical techniques for parents with kids of all ages to raise responsible kids, have more fun in their role, and easily and immediately change their children's behavior(s). This is the approach of choice among leading educators, parents and the professional world.

Where: Parent Education Center South
446 Lake Lowell Ave
Nampa, ID 83686

When: 6:00-8:00pm

Two sessions available:

* **Monday nights:**
Nov 7, 17, 21, 28, Dec 5 & 12th

* **Wednesday nights:**
Jan 25, Feb 1, 8, 15, 22 & 29th

Cost: \$15.00 for parent handbook

Child care is available but you must reserve a spot before the class begins.

Questions / to enroll, contact: Peggie Tietzort
468-4600 x 1063

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.



FREE WORKSHOPS- Nov/Dec 2011:

Advocacy Workshops Offered
Saturdays, 9:00am-3:30pm

November 12th -Idaho Falls - E. Id. Tech College: 1600 S. 25th E
Bldg #6, Health care Room #6163 & 6164

November 19th -Coeur d'Alene - Harding Center: 411 N. 15th St.

December 3rd - Twin Falls - T.F. Reformed Church: 1631 N
Grandview Dr. N.

December 10th - Boise - State Capitol: 700 W. Jefferson

Each Day, the following workshops are available:

Medicaid 101: Learn how Medicaid works, who is eligible, and who gets which services. Learn about the changes to Medicaid services

that occurred during the 2011 legislature.

Your Voice, Your Story: Talking to Your Legislator: you don't have to be a policy expert to talk effectively with your legislator. Instead there is power in telling your own story. This session will give you a basic outline for telling your story and then you will have the chance to practice with others so you can get comfortable speaking up about the things you care about.

The Movement Continues . . . Rebuild, Restore, Renew: Medicaid is an important part of the fabric of supports that helps people with disabilities to live in the community. This session focuses on what we must do to rebuild a quality community system of support, restore vital services that have been eliminated by recent budget cuts and renew our commitment to advocating for choice and independence for all Idahoans.

Legislative Process: If you would like to know how the legislative process works and how you can keep up with what is happening, this workshop is for you. Learn about how laws are made, the role of leadership and committees, the importance of rules, and how budgets are set. Do you know who represents you in the legislature? This session will show you how to find out.

Medicaid Matters In My Life: Self advocates, parents, providers and community leaders united last year to send a clear message to legislators that "Medicaid Matters." This session tells the story of a campaign that made a difference in protecting vital community services for Idahoans with disabilities. Local advocates, parents and providers will share their stories.

Limited Space - Register Now:
[Medicaid Matters In Idaho](#)

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



TREASURE VALLEY
DOWN SYNDROME
ASSOCIATION

Board of Directors

President:	Paul Auger	VP & Programs Chair:	Kristie Yerger
Treasurer & Advisor:	Lynda Wells	Secretary:	Audrey Byrum
Marketing Chair:	Angela Bowman	Transitioning Treasurer:	Lucy Olmos
Buddy Walk Chair:	Melody Witte	Board Member:	Wayne Blakeman
Community Outreach:	Trish Vranish		
Librarian:	Mary Anne Murphy		

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!](#)
