



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

TVDSA Newsletter

Newsletter Editor: [Celena Auger](#)

November 2012

In this Issue

The November TVDSA newsletter is dedicated to medical prevention. Included, you will find the Health Care Guidelines for Individuals with Down syndrome for all age groups, Coping with a Complex Dual Diagnosis and helping to Build Your Child's Self Esteem.

The TVDSA Family Meeting and Social groups will be meeting again this month, with a new group starting up – for MOMS! See page 4 for more details!

TVDSA has a lot of Fundraising opportunities going on. If you haven't gotten your calendar yet, it isn't too late!

Thinking about attending a conference? There are a lot of great opportunities coming up, check out the lists on page 5!

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



The TVDSA Buddy Walk was a Success! Thank you!

Beautiful weather, Lots of people, Great entertainment!

Thank you to everyone that helped organize and everyone that came out to celebrate individuals with Down syndrome in our community!

The numbers are astounding and money is still coming in!
We had over 1,850 registered walkers!

Over \$35,000 was made for TVDSA to support next year's activities and events!

Thank you to our 2012 Platinum, Gold and Silver Sponsors:



Suggestions for Parents Coping with a Complex Dual Diagnosis by George T. Capone, M.D., Baltimore, MD

Dr. Capone is director of the Down Syndrome Clinic at Kennedy Krieger Institute and staff physician to the Neurobehavioral Disorders Unit. He also serves on the NDSC Board of Directors and co-chairs the Professional Advisory Council.

A complex dual diagnosis refers to someone with an intellectual disability and a neurobehavioral or psychiatric disorder. Most families find a dual diagnosis adds to the stress of family life. Some families are better able to adapt than others. Several different strategies appear to increase the chances for successful adjustment.

- Recognize and understand your child's differences. The first step in seeking help is recognizing when help is necessary to address the problem.
- When necessary, seek informed opinion and consultation.
- Be able to manage or tolerate uncertainty regarding diagnosis and management. Some conditions are both complex and unique to DS. There may not be a definitive diagnosis, but a working diagnosis may be enough upon which to develop a treatment plan.
- Be willing to embrace or tolerate the complexity of the "bio-psycho-social-medical model," which predicts that dual diagnosis is not easily explained simply by linking current symptoms to previous social circumstances, misfortunes, or stressful life events.

Continued on Pg 3

November 1st-2nd:

[Idaho Partnership Conference on Human Services](#)

Restore * Rebuild * Renew Strategies for Success
Riverside Hotel, Boise, ID

November 3rd:

Sprout Film Festival

2:00pm and 7:00pm
The Egyptian Movie Theater
Boise, ID
Contact: [Nicole Lang](#)

November 10th:

Lil' Buddie's Playgroup

3:00pm-5:00pm at Kaleidoscope
Contact: [Kristie Yergler](#)

November 13th:

TVDSA Family Meeting

7:00pm-9:00pm
At A New Leaf: 2456 N. Stokesberry
in Meridian
Contact: [Erin Rosenkoetter](#)

November 15th:

TVDSA Mom's Night Out

At 7:30pm at the Varsity Pub
Comedy Club in Meridian.
Cost \$4.00
Contact: [Kristie Yergler](#)

November 17th:

AIM & Cool Club -

3:00pm at Fusions Glass in Eagle
Activity: Creating Christmas
Ornaments **Please RSVP!**
Contact: [Freddie Gallas](#)

November 19th:

IPUL Parent Support Meeting

6:00pm-8:00pm
Topic: Preparing for a Healthy
Transition
Contact: jennifer@ipulidaho.org

November 20th:

TVDSA Board Meeting

7:00pm-9:00pm at a New Leaf in
Meridian
Contact: [Paul Auger](#)

November 26th:

Lil' Buddie's Playgroup

10:00am-12:00pm at Jabbers.
Contact: [Kristie Yergler](#)

November 27th:

D.A.D.S. Meeting

6:30pm-8:30pm at
Fuddrucker's in Meridian
Contact: [Gus Olmos](#)

Down Syndrome Health Care Guidelines

The following article is medical guidelines suggested for physicians in care of individuals with Down syndrome. TVDSA is providing these medical guidelines for informational purposes only. Please consult your Primary Care Physician for clarification and to determine if these guidelines are applicable to you or your family member.

Individuals with Down syndrome need the usual health care screening procedures recommended for the general population (including immunizations). Similarly, adults with DS should have health evaluations using the standard accepted practices. However, children with DS have an increased risk of having certain congenital abnormalities. Both children and adults may develop certain medical problems that occur in much higher frequency in individuals with DS. Below is a checklist of additional tests and evaluations recommended. They are based on our present level of knowledge and should be modified as new information becomes available.

Be certain to use the specific DS growth chart in addition to regular charts to record height and weight (for ages birth - 18). If the child is below the third percentile or falling off the expected percentiles, consider congenital heart disease, endocrine disorders (thyroid or pituitary) or nutritional factors. Because children with DS have a tendency to become overweight, always use the Weight v. Height plots on the growth charts for typically developing children; this will give a more realistic picture of appropriateness of a child's weight.

Neonatal (Birth-1 Month):

- Review parental concerns. Chromosomal karyotype; genetic counseling if necessary.
- If vomiting or absence of stools, check for gastrointestinal track blockage (duodenal web or Arteria, or Hirschsprung disease)
- Evaluation by a pediatric cardiologist including echocardiogram.
- Exam for plethora, thrombocytopenia
- Review feeding history to ensure adequate caloric intake
- Thyroid function test
- Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (at birth or 3 months)
- Pediatric ophthalmological evaluation (by 6 months) for screening purposes
- Discuss value of Early Intervention (infant stimulation)

Infant (1-12 months):

- Review parental concerns
- General neurological, neuromotor and musculoskeletal examination.
- TSH and T4 - thyroid function test (at 6 & 12 months)
- Evaluation by pediatric cardiologist including echocardiogram (if not done at birth).
- Well child care - immunizations
- Feeding consult, especially if constipated,

- consider Hirschsprung disease
- Auditory brainstem response (ABR) or otoacoustic emission (OAE) test to assess congenital sensorineural hearing (by 3 months if not done prior or if results were suspicious).
- Ear, nose, and throat exam (as needed), especially if suspicious of otitis media.
- Well-balanced, high fiber diet
- Ophthalmology (vision) exam (by 6 months and annually)
- Suggest looking into SSI, estate planning, and custody arrangements
- Verify continued family support

Childhood (1-12 years):

- TSH & T4 - Thyroid Function Test (annually)
- Echocardiogram by pediatric cardiologist if not done previously
- Behavioral Auditory Testing (every 6 months to age 3, then annually)
- Regular eye exams yearly if normal, or more frequent as indicated
- Lateral cervical spine x-rays to rule out atlanto-axial instability. Radiologist to measure atlanto-dens distance and neural canal width (at 3-5 years then as needed)
- General pediatric and neurological exam, to include signs of spinal cord compression: deep tendon reflexes, gait, Babinski sign
- Use Down syndrome growth charts and head circumference charts, as well as growth charts for typically developing children (plot height vs weight on latter)
- Screen for celiac disease IGA antiendomysium antibodies and total IgA (between ages 2 and 3)
- Questions about obstructive sleep apnea, ear, nose and throat exam (ENT) as needed
- Dental exam (2 years, follow up every 6 months after)
- Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) for cardiac problems (as indicated).
- Well child care: immunizations
- Evaluation by a speech and language pathologist to maximize language development and verbal communication.
- Monitor well-balanced, high fiber diet and regular exercise & recreational activities.
- Review parental concerns, current level of functioning, monitor behavioral problems.
- Continue speech therapy and physical therapy (as needed).

"What lies behind us and what lies before us are tiny matters compared to what lies within us."

-Ralph Waldo Emerson

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Suggestions for Parents Coping with Dual Diagnosis, (Continued from Page 1)

- Let go of "simplistic" developmental explanations which are sometimes used as a proxy in place of a truly informed understanding of complex issues. Complex problems rarely have simple answers – time, patience and perseverance may be required to understand what you're dealing with and to see benefit.
- Accept a reasonable level of risk (despite uncertainty) in order to achieve some benefit from a treatment plan.
- When parents work collaboratively with trusted professionals positive change will occur, especially when families are supported in their central role as primary caregivers. When parents and professionals do not work together, care can become fragmented and disorganized.
- Stay informed, communicate effectively and ask questions. When family members are knowledgeable about their child's condition and their skills and strengths are supported, they are able to participate or lead the care team effectively.
- Follow through with recommendations, medication monitoring and clinic follow-up.
- Be able to maintain other interests. It isn't healthy for anyone when a family's sole focus is on fixing one member's problems.
- Actively seek to simplify life, reduce stress and other commitments as required, without feeling guilty for doing so.
- Find appropriate support networks – even one or two – and respite. Families who know how and when to ask for support will have more stamina for the long haul.
- Just as a flight attendant reminds parents to secure their own oxygen mask first. . . seek mental health treatment for your own depression, anxiety, anger, sleeplessness, relationship challenges, and more. Parents who take care of their own needs are better able to take care of their child's.

Your Child's Mental Health: Building Self-Esteem in Children

Most parents have heard that "an ounce of prevention is worth a pound of cure" and it's especially true with self-esteem in children. All children need love and appreciation and thrive on positive attention. Yet, how often do parents forget to use words of encouragements such as, "that's right," "wonderful," or "good job"? No matter the age of children or adolescents good parent-child communication is essential for raising children with self esteem and confidence.

Self esteem is an indicator of good mental health. It is how we feel about ourselves. Poor self-esteem is nothing to be blamed or embarrassed about. Some self-doubt, particularly during adolescence, is normal, even healthy, but poor self esteem should not be ignored. In some instances, it can be a symptom of a mental health disorder or emotional disturbance.

Parents can play important roles in helping their children feel better about themselves and developing greater confidence. Doing this is important because children with good self esteem:

- Act independently
- Assume responsibility
- Take pride in their accomplishments
- Tolerate frustration
- Handle peer pressure appropriately
- Attempt new tasks and challenges
- Handle positive and negative emotions
- Offer assistance to others

Words and actions have great impact on the confidence of children, and children, including adolescents, remember the positive statements parents and caregivers say to them. Phrases such as "I like the way you . . ." or "You are improving at . . ." or "I appreciate the way you . . ." should be used on a daily basis. Parents also can smile, nod, wink, pat on the back, or hug a child to show attention and appreciation.

What else can parents do?

- **Be generous with praise.** Parents must develop the habit of looking for situations in which children are doing good jobs, displaying talents, or demonstrating positive character traits. Remember to praise children for jobs well done and for the effort.
- **Teach positive self-statements.** It is important for parents to redirect children's inaccurate or negative beliefs about themselves and teach them how to think in positive ways.
- **Avoid criticism that takes the form of ridicule or shame.** Blame and negative judgments are at the core of poor self esteem and can lead to emotional disorders.
- **Teach children about decision making and to recognize when they have made good decisions.** Let them "own" their problems. If they solve them they gain confidence in themselves. If you solve them, they'll remain dependent on you. Take the time to answer questions. Help children think of alternate options.
- **Show children that you can laugh at yourself.** Show them that life doesn't need to be serious all the time and some teasing is all in fun. Your sense of humor is important for their well-being.

Source: *Northshore Families Helping Families*, 2009

"Not everything that is faced can be changed, but nothing can be changed until it is faced."

- James Baldwin



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Social Groups Page

TVDSA Family Meeting:

Tuesday, November 13th
from 7:00pm-9:00pm
at A New Leaf
2456 N. Stokesberry, Meridian

Topic: Recap of the National Down Syndrome Congress Convention from local scholarship recipients: Brady & Andrea Murray. One area they will touch on is proper estate planning for special needs.

For more information, contact: [Erin Rosenkoetter](#)

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

When: Tuesday, November 27th from 6:30pm-8:30pm

Where: Fuddruckers on Eagle Rd. and Ustick in Meridian.

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

Moms' Night Out:

When: Thursday, November 15th from 7:30pm-9:00pm?

Where: At the Varsity Pub Comedy Club located at 1141 N. Eagle Rd. in Meridian.

Cost is \$4.00 per person
TVDSA will provide appetizers!

For more information or to help organize, please contact [Kristie Yerger](#)

Lil' Buddies Update:

November Play dates:

Lil' Buddies will play **Saturday, November 10th from 3:00pm-5:00pm** at Kaleidoscope, located at 7211 W. Franklin Rd in Boise. This is not a group therapy session. Kaleidoscope has graciously offered the use of their space.

Then, on **Monday, from 10:00am -12:00pm**

Lil' Buddies will play at Jabbers, located at 1210 N. Galleria Dr. in Nampa (in the Nampa Gateway Center).

TVDSA will pay admission for each child with Down syndrome that attends, parents are free. Don't forget

your socks! A [waiver](#) must be filled out prior to play.

Need more information on **Lil' Buddies Playgroup**? Interested in helping organize the monthly gatherings? Please contact [Kristie Yerger](#).

Best Buds (Elementary) Update:

Best Buds will not be meeting this month.

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



Adults in Motion (AIM) and Cool Club (Jr./Sr. High),

November Gathering: will be **Saturday, November 17th at 3:00pm**. We will be making Christmas ornaments at Fusions Glass, located at 347 S. Edgewood Lane (938-

1055). TVDSA will cover the cost of the ornament, but you **MUST** RSVP with [Freddie Gallas](#) (409-718-0417 or by email)

For more information about **AIM** contact: [Freddie Gallas](#).

For more information about **Cool Club** please contact: [Kristie Yerger](#)

The Sprout Film Festival

Presented by the [Arc of Idaho](#)

Entertaining and Memorable Films Related to Intellectual and Developmental Disabilities.

November 3rd at the **Egyptian Theater** in Boise
Show times: 2:00pm and 7:00pm

Ticket Prices: General Admission: \$10.00 + surcharge, Students, Seniors and People with Disabilities: \$8.00 + surcharge

Films included this year: [The Magic of J-Mac](#), [Determined to Dance](#), [Laser Beak Man](#), [Beautiful](#)

Treasure Valley Family Signing:

[Treasure Valley Family Signing](#) now offers family and professional classes/workshops through [Saint Alphonsus Family Center](#) in addition to their class offering at Idaho's indoor play place: [Just KidN Around](#).

Treasure Valley Family Signing offers classes with American Sign Language Vocabulary. Each class utilizes the catchy tunes, fun tools, and memorable characters from the PBS Show "Signing Time."

Conferences, Workshops, Webinars & TVDSA Scholarship Information

[Idaho Partnership Conference on Human Services](#)

Restore * Rebuild * Renew Strategies for Success

November 1-2nd
Riverside Hotel, Boise, ID

[Northeast Down Syndrome Education Conference](#)

Nov. 30th-Dec. 1st
Burlington, MA
DSE will be presenting!

[PEAK Parent Center Conference on Inclusive Education](#)

February 7-8, 2013
Denver, Colorado

[Wrightslaw Conferences](#)

Special Education Law and Advocacy

Various dates and locations across the U.S.

[r.i.s.e conference](#)

Respect, Inspire, Support and Educate 23rd Annual Parent Conference

January 18th & 19th, 2013
Portland, OR

[Down Syndrome Affiliates in Action Leadership Conference](#)

February 21-24th, 2013
Cincinnati, Ohio

Early Birds save \$100 if register before December 1st!

[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 everyone is eligible.

Please see our [Scholarship application](#) for the guidelines and how to apply today.

Idaho Parents Unlimited (IPUL) Parent Support Group

MONDAY, November 19th
6:00pm-8:00pm
500 S. 8th Street, Boise

Topic: Preparing for a Healthy Transition

FREE! Please RSVP.
For more information,
jennifer@ipulidaho.org

[Inclusion Works!](#)

February 7-9, 2013

The Renaissance Hotel
Austin, Texas
Registration closes January 27th!

[ID Miss Amazing Pageant](#)

February 8-9th, 2013
Boise, ID

[Trisomy 21 Conference](#)

March 2, 2013
The Renaissance Hotel
Houston, Texas

Health Care Guidelines (continued from page 2):

- Suggest enrollment in appropriate developmental or educational program; complete educational assessment yearly as part of IFSP (0-3 years) or IEP (4-end of schooling).

Adolescence (12-18 years):

- TSH & T4 – Thyroid Function (annually)
- Auditory Testing (annually)
- Cervical spine x-ray, as needed for contact sports and prior to anesthetic
- Monitor for obstructive airway disease and sleep apnea
- General physical and neurological examination (check for atlanto-axial dislocation)
- Eye examination (annually)
- Dental examinations (bi-annually)
- Monitor for obesity by plotting height for weight on the growth charts for typical children
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. Echocardiograms (ECHO) as indicated by clinical findings.
- Reinforce need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adolescents.
- Adolescent medicine consult for puberty/sexuality issues; health, abuse prevention and sexuality education
- Pelvic exam (if sexually active)
- Low calorie, high fiber diet; regular exercise program
- Smoking, drug and alcohol education
- Psychoeducational evaluations (every 2 years) as part of Individualized Education Plans (IEP).
- Begin function transition planning (age 16 years).
- Monitor independent functioning.
- Monitor for behavioral or emotional changes and/or mental health problems. Psychiatric Referral (as needed)
- Continued speech and language therapy (as indicated)
- Discuss plans for long term living arrangements within the community.
- Reinforce importance of good self-care skills (grooming, dressing and money handling skills)

Adulthood (Additional Tests Required in Adulthood):

- TSH and T4 – Thyroid Function Test (annually)
- Auditory testing (every 2 years)
- Ophthalmologic examination, looking especially for keratoconus and cataracts (every 2 years).

- Cardiac exam: listen for evidence of mitral valve prolapsed and aortic regurgitation: confirm suspicions with Echocardiogram as needed.
- Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adults with cardiac disease.
- Pap smear and pelvic exam (every 1-3 years after first intercourse). If not sexually active, single-finger bimanual examination with finger-directed cytology exam. If unable to perform, screen pelvic ultrasound (every 2-3 years). Breast exam (annually)
- Baseline Mammography at 40 years. Follow up every other year until 50 years old, then annually.
- Twice yearly dental visits
- Clinical evaluation for sleep apnea
- Low calorie, high fiber diet. Regular exercise. Monitor for obesity by plotting height for weight.
- Clinical evaluation of functional abilities (consider accelerated aging); monitor loss of independent skills.
- Neurological referral for early symptoms of dementia (decline in function memory loss, ataxia, seizures, and incontinence of urine and/or stool.) This may also represent spinal cord compression from atlanto-axial subluxation.

Above is based on the Health Care Guidelines for Individuals with Down Syndrome: 1999 Revision.

Sources for this article: Down Syndrome Research Foundation (reprinted with permission of DSRF, Burnaby, BC www.dsrf.org) and National Down Syndrome Congress www.ndsc.org. For direct links to their information and more in-depth description of the above recommended tests please refer to: [NDSC](#) and [DSRF](#). DSRF also has easy to use Record Charts for [Birth-12](#) and [13-Adulthood](#) as well as links for [Growth charts](#) and [Head Circumference charts](#).

While researching information for this article, we found some additional information that may be of interest: [The Personal Health Record](#) which can help individuals with DS take more control of their own health records, and [Promoting Health in People with Down Syndrome](#) from UK, which looks at each medical issue independently rather than by age.



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

PO Box 1404
Meridian, Idaho 83680

We're on the Web!

See us at:

www.idahodownsyndrome.org

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

Did you pre-order a TVDSA 2013 Calendar?



You may pick them up the November Family Meeting,
November 13th at 7:00pm.

Did you miss the pre-order?

No problem, you can still get them at
the November Family Meeting or order online at:

http://idahodownsyndrome.org/documents/Calendar_Preorder_Form.pdf

Shop With Scrip and Give Back To TVDSA

Purchase Gift Cards for holiday shopping, gifts for friends and family, dining, gas, entertainment, and more, & a percentage of all sales goes to TVDSA!

Visit www.shopwithscrip.com, set up a free account, link to TVDSA by using the enrollment code: BC8651D833664 and start shopping, all while donating money to TVDSA! Questions or problems contact [Malu Mulholland](#).

GoodSearch and TVDSA

You search the internet all the time anyway, why not do it and earn money for TVDSA. Just go to: www.goodsearch.com and select TVDSA as your favorite cause. Simply search Down syndrome, we can be found near the end of the list. Then every time you do an internet search a donation is made to TVDSA. Tell everyone you know about GoodSearch for TVDSA.

TVDSA & the Idaho Stampede

TVDSA will be teaming up with the Idaho Stampede for a fun night while raising money and spreading awareness. Mark your calendars now for **January 12, 2013**. Game starts at 7:00pm.

Tickets start at \$12 each. The ticket order form can be found on our [website](#).

Please order your tickets by Friday, January 4th, 2013.

Congratulations to Self-Advocate, Jeff Wilson!

Jeff Wilson was awarded the Mayor's Good Neighbor Award!

Great neighborhoods are the cornerstone of a livable city. The Mayor's Good Neighbor Award goes to individuals who have gone out of their way to help those around them, thus improving life in their neighborhoods. Jeff Wilson does just that every day.

Jeff lives in his own house with his dog Buddie, not far from his parents. He mows his next door neighbor's lawn, hand delivers Christmas cards, and always has a friendly "Hello Neighbor" for everyone. Jeff volunteers at the YMCA three mornings a week, takes a PE class at BSU and works in his Dad's office. Jeff is on the Boise Ghostbusters Basketball Team and attends the



Young Life Capernaum Club. His girlfriend, Christina, lives in Orlando, and he is a big fan of WWE (Worldwide Wrestling Entertainment).

TVDSA wanted to share how proud we are of Jeff Wilson and this recognition!

The mission of 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: [Paul Auger](#)

Advisor: [Lynda Wells](#)

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

Marketing: [Jason Woodward](#)

Fundraising & Membership: [Malu Mulholland](#)

Vice President and Programs Chair: [Kristie Yerger](#)

Secretary: [Audrey Byrum](#)

Buddy Walk Chair: [Melody Witte](#)

Buddy Walk Chair: [George Taylor](#)

Community Outreach Chair: [Erin Rosenkoetter](#)

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

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