

TVDSA Newsletter



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

Newsletter Editor: Celena Auger

February 2012

Medical Concerns for Individuals with Down Syndrome

Since we had a positive feedback from the May 2011 TVDSA Newsletter covering general medical concerns individuals with Down syndrome may experience, we decided it was time to highlight a couple more. In this month's newsletter, you will find an article related to Alzheimer's and the relation to the 21st chromosome, thus increasing the incidence in adults with Down syndrome. We have also included an article on the Atlanto-Axial Instability issue, what it is and what to look for. Many families will encounter the Atlanto-axial instability issue one way or another, as your child with Down syndrome grows and gets involved with various sports or activities.

It is not the intent of TVDSA to give medical advice, only to supply the information that may be relevant to your loved one. If you have any questions or concerns regarding the health care of your loved one with Down syndrome, please consult with your primary care physician.



Make sure to check out the updated lists of conferences, workshops, and webinars (some are FREE) in the side bar of this month's newsletter! Don't forget about the TVDSA Scholarship program if you are a paid member! It is not just for the big NDSC Conference, it could be used for any of these listed, and much more!

Disability Advocacy Day at the State Capitol

Friday, February 3rd, 2012
8:00am-3:00pm

Public Hearing on the State Budget:

8:00am-10:30am Garden Level Auditorium

Advocacy Groups Information Booths:

All day beginning at 8:00am - 4th Floor Rotunda

1 on 1 Meetings with Legislators: All day



For more information, click [here](#).

In This Issue

- * Alzheimer's and Down Syndrome
- * World DS Day Activities in the Treasure Valley
- * Atlanto-Axial Instability Among People with Down Syndrome

Alzheimer's and Down Syndrome

Alzheimer's Disease, a degenerative neurological disorder characterized by progressive memory loss, personality changes and loss of functional motor capabilities, is far more common in individuals with Down syndrome than the general population. However, not all individuals with Down syndrome will develop Alzheimer's disease, and even those showing Alzheimer's-type symptoms may not have Alzheimer's disease since other conditions can mimic the symptoms. The presence of extra genetic material found among persons with Down syndrome may lead to abnormalities in the immune system and a higher susceptibility to certain illnesses, such as Alzheimer's, leukemia, seizures, cataracts, breathing problems, and heart conditions.



How common is Alzheimer's disease in individuals with Down syndrome?

People with Down syndrome also experience premature aging. That is, they show physical changes related to aging about 20 to 30 years ahead of people of the same age in the general population. As a result, Alzheimer's disease is far more common in people with Down syndrome than in the regular population. Estimates vary, but a reasonable conclusion is that 25 percent or more of individuals with Down syndrome over age 35 show clinical signs and symptoms of Alzheimer's-type dementia. The percentage increases with age. In the general population, Alzheimer's disease does not usually develop before age 50, and the highest incidence (in people over age 65) is between five and 10 percent. The incidence of Alzheimer's disease in the Down syndrome population is estimated to be three to five times greater than in the general population, and oftentimes, symptoms begin much earlier.

What are the symptoms of Alzheimer's disease?

Early symptoms include loss of memory and logical thinking, personality change, decline in daily living skills, new onset of seizures, changes in coordination and gait, and loss of continence in bladder and bowel habits.

Many people confuse Alzheimer's disease with dementia. What's the difference? Alzheimer's is a disease; dementia is a group of symptoms that include loss of memory, thinking, and reasoning skills. However, dementia isn't always caused by Alzheimer's disease; it can result from other conditions as well. Although some memory changes may be age-related, memory problems that interfere with daily life are not. According to experts, common early signs of Alzheimer's disease or other dementias include:

* Memory loss. Although older memories might seem unaffected, people with dementia might forget recent experiences or important dates or events that interferes with daily life. Anyone can forget some details from a recent event or conversation or recall them later. People with dementia might forget the entire thing.

* Repetition. People with dementia may repeat stories, sometimes word for word. They may keep asking the same questions, no

Topic: Sensory Processing in Young Children

Melissa Bandy, IdahoSTARS Statewide Project Director, spoke about Sensory Processing in young children. While defining the Vestibular System, Proprioceptive System and the Tactile System, she outlined the components of Sensory Processing that each system shares.

These include:

- Sensory Registration: "Someone just touched my arm."
- Orientation: "Where is that person that just touched my arm?"
- Interpretation: "I think that means they want to fight (or play, etc.)"
- Organization of a Response: "If they want to fight, I should fight back."
- Execution of a Response: (Pushing, hitting, etc. may take place.)

Handouts included "Self Regulating" Calming and Alerting Techniques for the following categories:

- Visual
- Auditory
- Vestibular
- Tactile
- Gustatory/Oral
- Proprioceptive

Handouts are still available and will be brought to the March Parent meeting. Please contact [Kelly Zimmerman](#) if you want a copy and cannot attend the next meeting.

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

matter how many times they're answered.

* Language problems. We all struggle to remember a word occasionally. People with dementia can have profound problems remembering even basic words. Their way of speaking may become contorted and hard to follow.

* Personality changes. People with dementia may have sudden mood swings. They might become emotional - upset or angry - for no particular reason. They might become withdrawn or stop doing things they usually enjoy. They could become uncharacteristically suspicious of family members -- or trusting of telemarketers.

* Disorientation and confusion. People with dementia may get lost in places they know very well, like their own neighborhoods. They may have trouble completing basic and familiar tasks, like cooking dinner or shaving.

* Lack of hygiene. Sometimes this is the most obvious sign of Alzheimer's disease. People who have dressed smartly every day of their lives might start wearing stained clothing or stop bathing.

* Odd behavior. We all misplace our keys from time to time. People with Alzheimer's disease and other dementias are prone to placing objects in odd and wholly inappropriate places. They might put a toothbrush in the fridge or milk in the cabinet under the sink.

If your loved one is exhibiting any of these Alzheimer's warning signs, don't panic. Having these symptoms doesn't mean that your loved one necessarily has Alzheimer's disease. But you need to schedule an appointment with the doctor for an evaluation.

How is a final diagnosis made?

Alzheimer's disease is difficult to diagnose. It is important to be certain Alzheimer's-type symptoms do not arise from other conditions, namely thyroid disorders, clinical depression, brain tumor, recurrent brain strokes, metabolic imbalances and various neurological conditions.

The diagnosis of Alzheimer's disease is made on the basis of clinical history, showing a slow, steady decrease in cognitive function and a variety of laboratory tests which provide contributory evidence, including electroencephalogram, brain stem auditory evoked response, computerized transaxial tomography and magnetic resonance imaging, among other tests and measurements.

Is there a baseline test that can be repeated at intervals to determine specific decrease in cognitive function?

Psychologists often use questionnaires answered by family members, companions or caretakers that assist in the early detection of dementia. It is recommended that individuals with Down syndrome be tested at age 30 to provide a baseline reading, and periodically thereafter. If the tests show deterioration, further tests must be made to rule out conditions that present similar or overlapping symptoms.

Calendar of Events

February 3rd:

Disability Advocacy
Day at the State Capitol
8:00am-3:00pm

February 8th:

IPUL Support Group
6:00pm-8:00pm
Casual Q&A on the
Children's Medicaid
Benefit Redesign
Contact: [Angela Lindig](#)

February 9-11th:

[PEAK Conference](#),
Denver, Colorado

February 11th:

Lil' Buddies Playgroup
with Music Makes
Connections!
3:00pm-5:00pm at
Caleb's house in Eagle
Contact: [Kristie Yerger](#)

February 11th:

AIM/Cool Club
4:00pm-6:00pm
Community Service
Project: Valentine's for
the Cancer Patients at
St. Luke's.
Contact: [Molly Benton](#)
or [Freddie Gallas](#)

February 11th:

Sibshop
10:00am-2:00pm
See additional
information below or
call: 433-8845

February 13th:

ELKS Education Training:
Social Stories.
7:00pm-8:30pm
Free but pre-registration
required.
Call: 706-5549

February 16th:

Best Buds (Elementary)
Gathering
6:00pm-7:30pm at
Planet Kid at the Wings
Center in Boise
Contact: [Kristie Yerger](#)

February 21st:

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

February 27th:

Lil' Buddies Playgroup
10:00am-12:00pm
at Allison's house in
Boise
Contact: [Kristie Yerger](#)

What information has research yielded about a link between Alzheimer's disease and Down syndrome?

Current research shows that the extra "gene dosage" caused by the abnormal third chromosome of Down syndrome may be a factor in the development of Alzheimer's disease. The early aging of the Down syndrome brain may also be a factor.

A number of centers are testing therapies in Down syndrome that appear to benefit patients with Alzheimer's disease in the general population.

Conclusion: The sooner Alzheimer's disease is diagnosed, the sooner you can get treatment. Alzheimer's disease isn't curable, but it is treatable. Drugs can help slow down the progression of Alzheimer's symptoms for a limited time. Your loved one may also be eligible for clinical trials, in which new, cutting-edge Alzheimer's treatments are available.

The sooner Alzheimer's disease is diagnosed, the sooner you can plan for it. Accepting that a loved one has Alzheimer's is terribly difficult. But the sooner you do, the better off you are. The earlier you catch it, the more time you'll have to learn about the condition and prepare for what's ahead.

For your loved one's sake -- and for your own -- don't ignore the possible warnings signs of Alzheimer's disease. Don't wait until there's a crisis before you see a doctor. If you have any concerns about your loved one's memory or behavior, schedule an evaluation now.

Sources: NDSS and WebMD

Please mark your calendars to join
Treasure Valley Down Syndrome Association
in celebrating
World Down Syndrome Day
March 21st (3-21), 2012



Details COMING SOON!!!

February 29-March 3rd:

[Down Syndrome Affiliates in Action Conference](#)
Washington D.C.

March 10th:

Sibshop
10:00am-2:00pm
See additional information below or call: 433-8845

March 21st:

World Down Syndrome Day

April 5th:

ELKS Education Training:
Potty Training
7:00pm-8:30pm
Free but pre-registration required. Call: 706-5549

April 27-28th:

[r.i.s.e. Conference](#)
Portland, Oregon

July 19-22nd:

[NDSC Annual Convention](#)
Washington D.C.

Lil' Buddies

February Playgroups

Saturday, February 11th:

Music Makes Connections will be joining us for an hour music therapy session!
3:00pm-5:00pm at
Caleb's house: 478 E. Stonewater Ct in Eagle

Monday, Monday 27th:

10:00am-12:00pm at
Allison's house: 3750 S. Maple Grove in Boise

Happy Birthday to

Josiah & Westin!

If your Lil' Buddy has a February or March 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](#)

ATLANTO-AXIAL INSTABILITY AMONG PEOPLE WITH DOWN SYNDROME:

Notes for parents & care-givers

Dr Jennifer Dennis, Director of Information & Research, Down Syndrome Medical Interest Group

Revised July 2001

WHAT IS ATLANTO-AXIAL INSTABILITY?

In people with Down syndrome the ligaments which normally hold the joints stable can be very slack. This can lead to an unusually wide range of movement at some joints - much greater than in the general population. As well as affecting the ordinary limb joints this can affect the stability of one of the joints in the neck - the atlanto-axial joint. This joint is the highest joint in the spinal column and it lies just at the base of the skull. There is movement at this joint whenever you nod or shake your head (see diagrams).

The lower diagram shows in the middle picture that when the atlas and axis vertebrae are firmly bound to each other both move together when the neck bends forward. The diagram on the right shows the situation when the ligaments binding the joint are slack. Here the atlas moves forward, but fails to carry the axis with it.

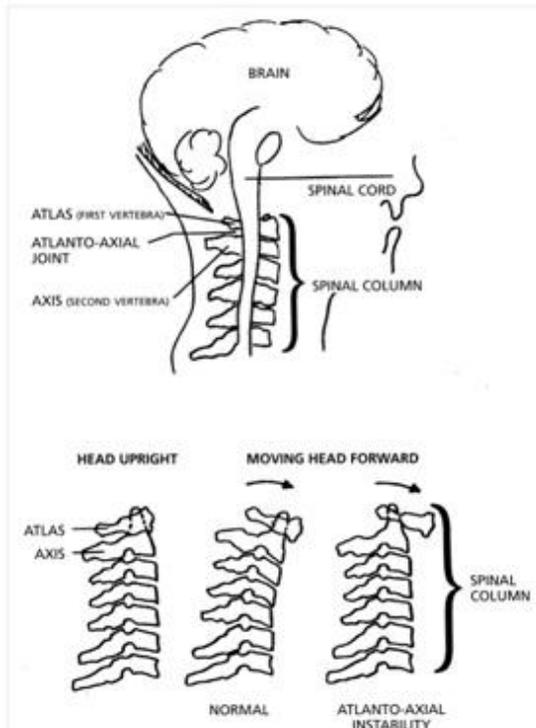
In some people with Down syndrome in addition to a slack ligament the actual bones of the atlanto-axial joint may be poorly developed. Theoretically these differences could make the joint more likely to dislocate than in people without Down syndrome.

CAN ATLANTO-AXIAL INSTABILITY CAUSE PROBLEMS IN PEOPLE WITH DOWN SYNDROME?

The spinal cord which carries all the nerve messages from the brain to the rest of the body passes very close to the atlanto-axial joint. Bruising of the spinal cord can happen to anyone with or without Down Syndrome. This can either happen suddenly as a result of a sudden shift within the joint or more gradually because of a day-to-day pressure on the spinal cord as the neck moves.

Because of the changes within the joint in some people with Down syndrome the following questions arise:

- Are people with Down syndrome more at risk than the rest of the population for whiplash type injuries and possibly



Best Buds (Elementary Group)

February Gathering:
Thursday, February 16th
6:00pm-7:30pm
at Planet Kid
at the Wings Center
1875 Century Way, Boise

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

Don't forget your socks!!

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

Cool Club & AIM

Our next gathering is

Saturday, February 11th
from 4:00pm-6:00pm
at
the Gallas' House
11368 Greenhurst Rd.
Nampa, ID

Activity: Community Service:
Making Valentine's for the children with cancer at St. Luke's Hospital

We will provide the craft supplies to make the valentines. Please bring a finger food to share.

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

D.A.D.S. Group

There will be NO February Gathering of the TVDSA D.A.D.S. group.

- some sporting injuries? Such injuries could lead to paralysis.
- Are people with Down syndrome more at risk than the rest of the population for difficulties which can arise as a result of chronic pressure on the spinal cord in the neck?
 - If there is an increased risk of either of the above can we predict which people with Down syndrome are most likely to be affected?
 - Can we do anything to prevent sudden injuries or the more slowly developing long-term effects of atlanto-axial instability?

We are not sure of all the answers to these questions, which is why doctors may vary in the advice they give.

WHAT SPORTING ACTIVITIES CAN PEOPLE WITH DOWN SYNDROME TAKE PART IN?

It is clear that very few sporting injuries have ever been recorded in people with Down syndrome which could have been caused by atlanto-axial instability. In fact the injuries recorded would have been just as likely to occur in an ordinary person as a result of a similar fall or accident.

Sports such as jumping on a trampoline, diving and boxing do carry an element of risk for anyone, not just for people with Down syndrome. People can accidentally fall onto their head in many sports.

People with Down syndrome may be less at risk because many are less vigorous in their activities than their peers without Down syndrome. On the other hand they may be more at risk in some activities because they tend to be less well coordinated. These two may well balance each other out.

Doctors are often asked whether simple forward rolls or supervised bouncing up and down on a mini-trampoline in a nursery school are particularly dangerous for children with Down syndrome. The answer is that there is no good evidence that they should be so. The same applies to the early stages of horse riding. At a more advanced stage in all these pursuits a greater element of risk is inevitable for everyone, whether with or without Down syndrome.

ARE THERE ARE OTHER ACTIVITIES WHICH MAY BE DANGEROUS? CAN ANY PRECAUTIONS BE TAKEN?

It is possible that because of a tendency to instability in the neck region some people with Down syndrome may have an increased risk of whip-lash injury following road traffic accidents. We are not sure about this but at the moment it seems sensible to recommend that head-rests are always in place when a person with Down syndrome is travelling. Similarly after a road traffic accident it is important to alert helpers to the fact that a person with Down syndrome may be more likely to have sustained a neck injury than another person.

Another point to be aware of is that doctors will need to take special care when giving the sort of anesthetic that involves passing a tube down the windpipe and achieving a neck position that can strain or cause joint dislocation. There is virtually no risk of this if the anesthetist and recovery room staff are alerted beforehand to the fact that the person has Down syndrome.

SIBSHOPS

Sibshops is a program designed for brothers and sisters of kids with special needs.

We are happy to announce two separate Sibshop dates hosted by the Idaho Federation of Families. Sibshops will be held at the Children's Home Society and is open to brothers and sisters, ages 7-14, of children with special needs.

We will feature a combination of fun, information, surprises, and great discussion for everyone who attends.

February 11th:
10:00am-2:00pm

March 10th:
10:00am-2:00pm

Cost: \$5.00 (Meal Provided)
Children's Home Society
704 N 7th Street
Boise, ID 83702
Call 433-8845 to Register today!

Conferences, Workshops and Webinars

Idaho Parents Unlimited (IPUL) Parent Support Group
6:00pm-8:00pm
500 S. 8th Street, Boise

Topic: Casual Q&A on the Children's Medicaid Benefit Redesign

For more information, contact [Angela Lindig](#)

PEAK 2012 Conference on Inclusive Education

February 9-11, 2012
Denver, Colorado

Upcoming PEAK Webinars
FREE

Preparing for the IEP
February 16th 6:30-7:30pm

CAN WE PREDICT WHICH PEOPLE ARE LIKELY TO HAVE PROBLEMS DUE TO ATLANTO-AXIAL INSTABILITY?

What should care-givers look out for in everyday life?

Sudden neck dislocation is very rare in people with Down syndrome but probably occurs more often than in other people. We do know however that mild symptoms occur in most people before dislocation occurs, so it is important to be on the lookout for these.

These same symptoms may also be present in older people who don't have a major dislocation but have chronic problems due to pressure on the spinal cord. These symptoms should alert you that some compression may be occurring. **Look out for:**

- Pain at a spot near the hard bump behind the ear.
- A stiff neck which doesn't get better quickly.
- Alteration in the way a person walks so that he/she appears less good on his/her feet.
- Deterioration in a person's ability to manipulate things with his/her hands.
- Incontinence developing in a person who has previously had no problems.

If any of these occur the person should be seen by a doctor. If the onset of symptoms is sudden an emergency appointment is needed.

Are routine neck x-rays helpful?

The question which has caused the greatest confusion with regard to atlanto-axial instability is whether or not people should have neck x-rays to find out if the joint is unstable. We now know that neck x-rays taken in the routine manner followed in most x-ray departments are unlikely to be reliable in identifying instability. Some people who initially appear to have instability as shown by a neck x-ray can show no evidence of instability if re-x-rayed one week later. Equally people whose neck x-ray appears entirely normal can show apparent evidence of x-ray instability one week later. On the basis of these findings there appears to be no useful information gained by carrying out such an x-ray.

X-rays can be taken in research conditions where results are known to be consistent from week to week. Even then, if instability is shown, we do not know if it is these people who are most at risk of sustaining a sudden dislocation-type injury at some time in the future. In fact we have evidence of the reverse, namely of people with no x-ray evidence of instability who subsequently sustain a neck dislocation.

What advice should be followed about x-rays?

In 1986 the Chief Medical Officer (CMO) of the then DHSS issued guidance, in the form of a letter to all doctors - CMO (86)9 - about atlanto-axial instability in people with Down syndrome. One of the recommendations was that where vigorous sporting activity was envisaged the individual should first have their neck x-rayed in order to establish whether any instability was present. Since that time evidence has accumulated which indicates that neck x-rays do not reliably predict those at risk of compression of the spinal cord. In particular, cases of spinal cord compression have occurred in

Accommodations and Modifications to Curriculum

February 28th 5:30-8:30pm

Content of the IEP

March 1st 6:30-7:30pm

Un Instrumento para Realizar las Posibilidades

March 5, 12:00-1:00pm

Implementation and Follow up of the IEP

March 15th 6:30-7:30pm

2012 Elks Education Training Opportunities

FREE!

However, registration is required ahead of time, as class is limited to 20 participants.

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

Learn how to write and implement social stories into your child's daily routine. A social story is a short visual (words and/or pictures) story that helps teach appropriate social cues as well as give more detail to a child who might have a difficult time learning from traditional teaching methods. For example: wait in line, brush your teeth, raise your hand before talking, and say "please" and "thank you."

***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

Down Syndrome Affiliates In Action Conference

February 29-March 3rd Washington D.C.

people with apparently normal spinal cord x-rays.

The Standing Medical Advisory Committee to the CMO has now concluded that radiological examination is not a useful predictor of the risk of atlanto-axial dislocation and accordingly the CMO wrote to all doctors on 28 October 1995 withdrawing CMO (86)9. The American Academy of Pediatrics has also concluded that x-rays are not useful predictors of risk. Unfortunately however the Special Olympic Committee continues to demand neck x-rays before allowing people with Down syndrome to compete in Special Olympic events.

WHAT TREATMENT IS AVAILABLE?

A doctor suspecting that atlanto-axial instability may be present and causing problems in a person with Down syndrome will probably refer that person to either an orthopedic surgeon or a neuro-surgeon. If instability or dislocation is confirmed and it is thought to be causing problems an operation can be done to stabilize the upper part of the spinal column. The operation is delicate and not without risk, particularly in younger children, but it can be 100% successful in treating the problem.

Children with dislocation have also been successfully treated by traction - which eases the pressure in the neck and allows the joint to get back in place - followed by immobilization of the neck until the joint has firmed up again.

A PERSONAL VIEW

My own view is that there are two issues at the present time which are more important than whether or not we should be taking x-rays. We have to try to increase awareness among parents, care-givers and professionals of some possible risk situations where non-restrictive precautions can be taken to reduce the chance of neck injury. We also need to increase awareness of the symptoms of atlanto-axial dislocation and of the early signs of chronic pressure on the spinal cord. If we succeed in this, people are more likely to consult a doctor before any permanent damage ensues. Both of these issues have been discussed. Life for everyone is not without risk. It is for the individual to decide what 'risks' are acceptable for their children or for themselves. We all have to compromise our day-to-day lives as we balance freedom to take part in and enjoy life's activities against the risk of possible injury.

[Wrightslaw Special Education Law and Advocacy Trainings](#)

currently offering 12 trainings in 2012, in various U.S. locations

The closest training is: April 26th, Denver CO

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

Respect, Inspire, Support and Educate 23rd Annual Parent Conference April 27-28th Portland, Oregon

Northwest Down Syndrome Association (NWDSA) [All Born "In" Conference](#) April 28th Portland, OR

[National Down Syndrome Congress Annual Convention](#)

July 19-22 Washington DC Registration is Now Open!

TVDSA Scholarship Information

Are you considering attending an upcoming workshop or conference?

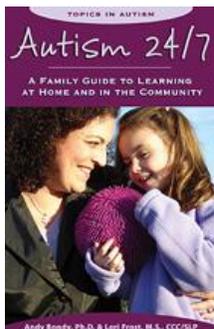
Did you know that TVDSA supports members in gathering information at local and national conferences and/or workshops?

The TVDSA Scholarship program is NOT income based, so everyone is eligible.

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

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

From the TVDSA Lending Library
by Mary Anne Murphy



Autism 24/7

by **Andy Bondy, Ph.D. and Lori Frost, M.S.,
CCC/SLP**

Some children with Down syndrome also, eventually, receive a diagnosis of autism. While such a diagnosis may feel overwhelming, this book is not. Instead, this book is short, to the point, easy to read, replete with examples and focused on teaching the steps for reaching goals. This book, *Autism 24/7*, provides outstanding guidance for families trying to help their son or daughter achieve goals. Once goals are set, parents and teachers can use this guide to walk through the steps of reaching those goals. I also recommend this book for families whose child has not ever been diagnosed with autism but has not been very successful learning new skills at home or in school.

This book is available in 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](#).



TREASURE VALLEY
DOWN SYNDROME
ASSOCIATION

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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!](#)

