



Treasure Valley Down Syndrome Association Newsletter

August 2005



Make steps for a brighter tomorrow by taking part in the Buddy Walk!

The 3rd Annual Treasure Valley Buddy Walk will be taking place on Saturday, October 8th at Capitol Park, which is located at 6th and Jefferson (across from the Capitol Building) in Boise.

Schedule of the Day Events:

Pre-Registration/Registration

Pre-registration is available online at www.idahodownsyndrome.org or you can mail in the enclosed form by September 8th. On-site registration will be available before the walk from 10:00 – 10:50 AM. Pre-registration packets will also be able for pick up at this time.

The Buddy Walk

At 11:00 AM, Individuals with Down syndrome, families and friends walk a one-mile course from Capitol Park to Julia Davis Park and then enjoy a BBQ, games and music to promote inclusion and awareness of Down syndrome.

Fun in the Park

Relax and have fun in the park with games, food, music and more from 11:30 – 2:30 PM.

I hope to you see there!

Sincerely,

George Taylor
Buddy Walk Chairman

Register Online!
It's quick. It's easy
No stamps necessary.
Register today!
www.idahodownsyndrome.org

Growing Up and Growing Older (With Grooves)

By Dianna Brown

Once again the National Down Syndrome Congress convention was an inspiration and high point of our year. Held in Anaheim we were able to spend a couple of days at Disneyland. Melissa and Matt went to their own workshops which included Tennis, Body Movement, Personal Safety including some self defense moves, Self Advocacy, Dance, Signing and song, and of course the annual Talent Show. Matt even spoke to the group during open mike time. (A little scary!)

I attended the pre-conference workshop entitled *Growing Up and Growing Older*. Given by Dennis McGuire, Ph.D., Director of Psychosocial Services, The Adult Down Syndrome Center of Lutheran General Hospital in Chicago, it turned out to be a hilarious and informative time. He spoke on everything from self-talk to Alzheimer's. New research on Alzheimer's leans toward the belief that not all people with Down syndrome will have Alzheimer's. Definitely Alzheimer's is incorrectly the diagnosis in many of our younger people.

I do not like to stereotype our kids by saying "they all do this or that," but there are some unique experiences that we parents talk about usually finding out that we are not the only ones with a child who 'does that'. The Down syndrome clinic in Chicago has seen thousands over the years. Dr. McGuire carefully laid out what he called our children's *grooves*. He said "you don't try to take the grooves away; you just teach appropriate ways to use their grooves". From the wandering when they are young to being neat-nicks when they are older, to writing stacks of letters and lists, he had us in stitches because we all could relate.

As I sat there the first 2 hours, he described Matt to a T. Then I could not believe he knew Melissa so well. When he started describing some of the things Mike used to do I was no longer skeptical. Our kids do have some behaviors that are more frequently characteristic of someone with DS. He said these behaviors can be real positives and gave many examples of how *grooves* have helped people with Down syndrome cope.

In order to describe some *grooves* he said they are thinking of writing a book called, *if people with Down syndrome ruled the world*. I think he was joking, but here are some statements it would contain.

If people with Down syndrome ruled the world:

No one would be in a hurry.

Lunch would be a 12:00 and Dinner at 6:00.

Everyone would be on time. No more waiting at the Doctor's office.

There would be lists for every day's activities.

Everything would have its place, especially in bedrooms, even if that place were on the floor.

Everyone would self-talk or have imaginary friends.

(He said something like this.) The words "We'll make a program" would be avoided at all costs in every meeting. And if it was mentioned by any school personnel, they would have to be separated from their peers while a program was put into place.
Et Cetera! Et Cetera!

There is an excellent article in the new *Down Syndrome News* by Dr. McGuire on self talk. He encouraged us at the convention to allow self talk but teach our kids where it should be done. He said there are many professionals out there who are still diagnosing our kids with mental health issues if they self talk. He explained that it is a necessary part of life for them to work out problems, plan their day, etc. He said we should be aware that if self talk changes or stops it may be a signal that something is wrong. Dr McGuire encouraged us to listen to the self talk to see if anything is happening at school or at work, because it is when their speech is the most clear. The pressure to make someone understand is off, so the speech improves. He said don't try to eliminate self-talk or other *grooves* because (tongue in cheek) "You don't mess with Mother Nature. It is part of their genetics."

Upcoming Conferences/Workshops

1. IPUL Upcoming Workshops For Southwest Idaho for 2005

Please register with the IPUL office or for more information, call 342-5884 or 1-800 242-IPUL (4785)

| Location | Date | Time | Title |
|---------------|------------|---------------------|-------------------------------------|
| Emmett | 8/18/2005 | 6:00 PM - 8:00 PM | Is Your Child a Target of Bullying? |
| Shoshone | 9/17/2005 | 10:30 AM - 12:30 PM | Guardianship and Other Options |
| Shoshone | 9/17/2005 | 1:00 PM - 3:00 PM | Success with IEP |
| Boise | 9/21/2005 | 11:00 AM - 1:00 PM | Guardianship and Other Options |
| McCall | 10/1/2005 | 10:00 AM - Noon | Understanding ADHD |
| Meridian | 10/3/2005 | 7:00 PM - 9:00 PM | Success with IEP |
| Eagle | 11/08/2005 | 6:00 PM - 8:00 PM | Solving the Employment Puzzle |
| Mountain Home | 11/16/2005 | 5:00 PM - 7:00 PM | No Child Left Behind |
| Boise | 12/07/05 | 6:00 PM - 8:00 PM | No Child Left Behind |

Health Helps

Down Syndrome Healthcare Guidelines

*Based on 1999 Down Syndrome Health Care Guidelines**

Neonatal (Birth-1 Month)

- Review parental concerns. Chromosomal karyotype; genetic counseling, if necessary.
- If vomiting or absence of stools, check for gastrointestinal tract blockage (duodenal web or atresia or Hirschsprung disease).
- Evaluation by a pediatric cardiologist including echocardiogram. Subacute bacterial endocarditis prophylaxis - SBE, in susceptible children with cardiac disease.
- Exam for plethora, thrombocytopenia.
- Review feeding history to ensure adequate caloric intake.
- Thyroid function test - check on results of state-mandated screening at birth.
- 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) and refer for enrollment in local program.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

Infant (1-12 Months)

- General neurological, neuromotor and musculoskeletal examination.
- TSH and T4-Thyroid Function Test (6 & 12 months).
- Evaluation by pediatric cardiologist including echocardiogram (if not done at birth). Consider progressive pulmonary hypertension if VSD or atrioventricular septal defect and little or no symptoms of heart failure.
- Subacute bacterial endocarditis prophylaxis-SBE (as indicated).
- 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 already, or if suspicious).
- Ear, nose and throat exam (as needed), especially if suspicious of otitis media.
- Well-balanced, high-fiber diet.
- Vision exam (by 6 months and annually; earlier if nystagmus, strabismus or indications of poor vision).
- Discuss Early Intervention and refer for enrollment in local program.
- Application for Supplemental Security Income (SSI), depending on family income.
- Consider estate planning and custody arrangements; continue family support.

For the complete Health Care Guidelines for Individuals with Down Syndrome, visit the Information and Resources section of the NDSS Web site. Growth charts are also available on the web site.

* "Health Care Guidelines For Individuals With Down Syndrome: 1999 Revision" (Down Syndrome Preventive Medical Check List) is published in **Down Syndrome Quarterly** (Volume 4, Number 3, September, 1999, pp. 1-16) and is reprinted with permission of the editor. Information concerning publication policy or subscriptions may be obtained by contacting Dr. Samuel J. Thios, Editor, Denison University, Granville, OH 43023; e-mail: thios@denison.edu. Granville, OH 43023 (email: thios@denison.edu).

2005 TVDSA BUDDY WALK™ REGISTRATION FORM

Fill out form completely. Required fields are marked with an asterisk (*). Mail completed form with payment to the address below. Make checks payable to "TVDSA". **DO NOT SEND CASH**
Pre-Registration must be postmarked by September 8th 2005

*Walker's Name _____
 *Street Address _____
 *City _____ *State _____ *Zip _____
 *Daytime Phone _____
 *E-Mail Address _____
 Team Name _____

Mail forms and payment to:

 TVDSA
 c/o George Taylor
 426 S. Silver Bow Ave
 Eagle, ID 83616

Please notify me of future events Total # of Walkers _____

- Individual Registration – \$10 ea X _____ = \$ _____
- Family Registration (Up to 2 adults & 3 children) – \$25 = \$ _____
- Additional Children 13 and Under – \$5 X _____ = \$ _____
- Team Registration (Up to 4 Team Members) – \$30 = \$ _____
- Additional Team Members – \$8 X _____ = \$ _____

TOTAL PAID: \$ _____

| | | | |
|--|-----------|-----------|----------|
| T-Shirts: (indicate size and quantity) | | | |
| Adults: | S _____ | Children: | XS _____ |
| | M _____ | | S _____ |
| | L _____ | | M _____ |
| | XL _____ | | L _____ |
| | XXL _____ | | |

Waiver: In consideration of me and/or my minor child being permitted to participate in the Buddy Walk, I hereby— for myself, my heirs and personal representatives— assume any and all risks which might be associated with the event. I further waive, release, discharge and covenant not to sue the National Down Syndrome Society or the Treasure Valley Down Syndrome Association, its officers, employees, sponsors, organizers, volunteers or other representatives or their successors and assigns, for any and all injuries or damages of any kind whatsoever suffered by myself and/or my minor child as a result of taking part in the events and any related activities. I also authorize the use by NDSS or Treasure Valley Down Syndrome Association of any photo, film or videotape taken of me or my minor child at the event for any purpose.

Signature _____ Date _____

THIS REGISTRATION IS NOT VALID UNLESS SIGNED

Meeting Schedule and Place

The following meetings and topics are scheduled for the fall and spring: Childcare is provided. We hope to see many of you there. The meetings are the second Tuesday of the month.

MEETING PLACE: Boise First Community Center 3852 N Eagle Rd Boise ID

- Sept 13, 2005 IQ Testing, determining your child's learning style
- Oct 11, 2005 L.E.A.F. (Language Learning Enrichment Advisors & Facilitators)
- Nov 15, 2005 Alternative Therapies
- Jan 10, 2006 Topic to be decided
- Feb 21, 2006 Nutrition (Dietician)
- Mar 14, 2006 Dentist
- Apr 11, 2006 Public Education
- May 9, 2006 Developmental Pediatrician
- June 2006 Annual Picnic –date to be decided



Annual Membership Dues

It's time to remind you to send in your Treasure Valley Down Syndrome Association memberships. At only \$10 per family, it's just about the best deal around.

Name: _____

Address: _____

Email: _____

Phone: _____ Membership or Donation: _____

Make checks payable to TVDSA and mail your tax deductible donation to:

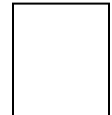
TVDSA , c/o Lynda Wells, Treasurer, 11190 Camas, Boise ID 83709

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Amy Wall: Vice President, 375-5405, TAWall1@msn.com
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Lynda Wells: Treasurer, 323-8669, lyndawells@yahoo.com
Dianna Brown: Membership organizer, 459-1189, upaboutdown2@aol.com
Judy Halverson: Contact Chairperson, 327-0541, rdhalverso@aol.com
Melody Witte: Buddy Walk organizer, 938-0255, melodywitte@bitSMART.net
George Taylor: Buddy Walk organizer/Webmaster, 938-4565, gwtaylor@mpccorp.com
Tonya Maestretti: Friend of the Board, 378-9912, tkmaestretti@hotmail.com
Michelle Laughenberger: Friend of the Board, 853-7702
Alice Antonioli: Friend of the Board, 322-5420, gburington@msn.com
Crystal Stark: Friend of the Board, 938-8010, crystal_stark@yahoo.com

Visit our website at www.idahodownsyndrome.org

Treasure Valley Down Syndrome Association
PO Box 153
Greenleaf, ID 83626



*Next Meeting
Tuesday September 13th*

