

# **TVDSA Newsletter**

In this Issue

September is dedicated to adults with Down syndrome. Today's adults have paved the way for our youth in showing the community there really are no limits. However, as adults live longer lives than ever before, more unknowns surround us. Two very informative, but lengthy articles we want to share this month can be found by clicking the links below:

- Health Issues for Adults with Down Syndrome
- Alzheimer's and Down Syndrome

Monthly and archived TVDSA newsletters are available on our website at:

www.idahodownsynd rome.org for viewing and sharing. Notifications will be sent out when the newsletter has been posted each month. Newsletter Editor: Celena Auger

September 2012

# 10th Annual TVDSA Buddy Walk

Saturday, October 13th 11:00am-2:00pm

# **Online Registration CLOSES SOON!**

Online Registration will close at Midnight, **Tues.**, **Sept. 4**th. <u>Pre-registration Cost</u>: \$15 for adults; \$7 for 12 and under

Registration includes a t-shirt, lunch, entertainment, children's goodie bags and games, and more!

On-site registration opens at 9:00am at Capitol Park in Boise On-Site Registration Costs: \$17 for adults; \$8 for 12 and under (size & color of t-shirt not guaranteed)

Our <u>Big Raffle Item</u> this year: 4 Round Trip Tickets on Southwest Airlines

Raffle Tickets will be \$5.00 each or 5 for \$20.00

PLUS: the Silent Auction Table will be back this year!

For the first time, credit cards will be taken at On-Site Registration, the Information Booth/Merchandise Table and the Silent Auction Table.

# Thank you to our current 2012 Sponsors:













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# An Extra Chromosome, but the Gift of Serenity By: George F. Will, Washington Post Writers Group

When Jonathan Frederick Will was born 40 years ago — on May 4, 1972, his father's 31st birthday — the life expectancy for people with Down syndrome was about 20 years.

The day after Jon was born, a doctor told Jon's parents that the first question for them was whether they intended to take Jon home from the hospital. Nonplussed, they said they thought that is what parents do with newborns. Not doing so was, however, still considered an acceptable choice for parents who might prefer to institutionalize or put up for adoption children thought to have necessarily bleak futures.

Continued on Pg 3

### September 8th:

### Lil' Buddie's Playgroup

3:00pm-5:00pm

At Nathaniel's house in Nampa Contact: Kristie Yerger

### September 11th:

#### **TVDSA Parent Meeting**

7:00pm-9:00pm Topic: Alzheimer's Disease At A New Leaf Contact: Erin Rosenkoetter

#### September 12th:

### **Buddy Walk Committee**

**Meeting** at 7:00pm at Maui Wowi, Meridian

Contact: Melody Witte

#### September 12th:

## **IPUL Parent Support Meeting**

6:00pm-8:00pm

Topic: Success with the IEP Contact: <a href="mailto:parent@ipul.com">parent@ipul.com</a>

#### September 13th:

#### Best Buds Gathering at

6:00pm-7:30pm at Shankz Blacklight Miniature Golf in Meridian Contact: <u>Kristie Yerger</u>

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# September 14th:

#### IPUL Webinar - Free 10:00am-11:30am

Topic: Success with the IEP Contact: parent@ipul.com

#### September 15th:

AIM & Cool Club – BSU Game Watching Party at 1:30pm at

the Gallas' house. Contact: <u>Freddie Gallas</u>

## September 15th:

The Southeast Idaho Down Syndrome Association Buddy Walk\_At Brooklyn's Playground at OK Ward Park, 9:30am-Noon, Pocatello, ID

### September 17th:

#### **Buddy Walk Committee**

Meeting at 7:00pm at Maui Wowi,

Meridian

Contact: Melody Witte

#### September 18th:

### TVDSA Board Meeting

7:00pm-9:00pm at Bowl of Heaven in Eagle Contact: <u>Paul Auger</u>

#### September 24th:

### Lil' Buddie's Playgroup

10:00am-12:00pm At Caleb's house in Eagle Contact: <u>Kristie Yerger</u>

### September 25th:

#### D.A.D.S. Meeting

6:30pm-8:30pm at Fuddruckers in Meridian

Contact: Gus Olmos

### September 25th:

### Buddy Walk Committee

Meeting at 7:00pm at Maui Wowi,

Meridian

Contact: Melody Witte

# **Exercise for People with Down Syndrome**By: Adult Down Syndrome Clinic, Park Ridge, IL

## Why exercise?

There are many benefits to exercising. However, two of them have little benefit in people with Down syndrome. Coronary artery disease (heart attacks) and hypertension (high blood pressure) are relatively rare in people with DS so exercise has little benefit (hard to significantly reduce what is already so rare).

However, exercise does have several benefits for people with Down syndrome:

- help with weight control
- improve mood/help reduce psychological stress
- improve energy level
- improve sleep
- prevent diabetes mellitus or improve control of diabetes
- it is fun and can be a wonderful form of recreation and social activity

How much should a person with Down syndrome exercise?

While this hasn't been well studied in people with DS, at least 3 times a week

30 minutes per day is the general recommendation. However, for weight loss, daily exercise is a good idea. It can be exercise even if it doesn't look like exercise.

We found in a study that our patients who were closer to their ideal body weight didn't have to be exercising in the traditional sense but had access to recreation opportunities. The key seemed to be getting off the couch and being active. Go to a museum, do gardening, go downtown and take in the sights, etc.

Here is an additional article on: Overweight Prevalence in Persons with Down Syndrome:

http://www.advocatehealth.com/luth/documents/downsyndrome/ovrwtprv.pdf

Get started. Make it a family event. Have fun.

We start exercise for lots of reasons. We usually continue to exercise because it is fun.

# **Five Principles of Self-Determination**

# FREEDOM:

To decide how one wants to live his or her life

### **AUTHORITY:**

Over a targeted amount of dollars

# SUPPORT:

To organize resources in ways that are life enhancing and meaningful to the individual

# **RESPONSIBILITY:**

For the wise use of public dollars and the recognition of the contribution individuals with disabilities can make to their communities

# **CONFIRMATION:**

Of the important role that individuals with disabilities must play in the newly designed system

Source: Thomas Nerney and The Center for Self-Determination www.centerforself-determination.com

# **An Extra Chromosome** (continued from page 1)

Down syndrome is a congenital condition resulting from a chromosomal defect — an extra 21st chromosome. It causes varying degrees of mental disabilities and some physical abnormalities, including small stature, a single crease across the center of the palms, flatness of the back of the head, a configuration of the tongue that impedes articulation, and a slight upward slant of the eyes. In 1972, people with Down syndrome were still commonly called Mongoloids.

Now they are called American citizens, about 400,000 of them, and their life expectancy is now 60. Much has improved. But there has been moral regression, too.

Jon was born just 19 years after James Watson and Francis Crick published their discoveries concerning the structure of DNA, discoveries that would enhance understanding of the structure of Jon, whose every cell is imprinted with Down syndrome. Jon was born just as prenatal genetic testing, which can detect Down syndrome, was becoming common. And Jon was born eight months before Roe v. Wade inaugurated this era of the casual destruction of pre-born babies.

This era has coincided, not just coincidentally, with the full garish flowering of the baby boomers' vast sense of entitlement, which encompasses an entitlement to exemption from nature's mishaps, and to a perfect baby. So today science enables what the ethos ratifies, the choice of killing children with Down syndrome before birth. That is what happens to 90 percent of those whose parents have prenatal testing.

Which is unfortunate, and not just for them. Judging by Jon, the world would be improved by more people with Down syndrome, who are quite nice, as humans go. It is said we are all born brave, trusting and greedy, and remain greedy. People with Down syndrome must remain brave in order to navigate society's complexities. They have no choice but to be trusting because, with limited understanding, and limited abilities to communicate, they, like Blanche DuBois in "A Streetcar Named Desire," always depend on the kindness of strangers. Judging by Jon's experience, they almost always receive it.

Two things that have enhanced Jon's life are the Washington subway system, which opened in 1976, and the Washington Nationals baseball team, which arrived in 2005. He navigates the subway expertly, riding it to the Nationals ballpark, where he enters the clubhouse a few hours before game time and does a chore or two. The players, who have climbed to the pinnacle of a steep athletic pyramid, know that although hard work got them there, they have extraordinary aptitudes because they are winners of life's lottery. Major leaguers, all of whom understand what it is to be gifted, have been uniformly and extraordinarily welcoming to Jon, who is not.

Except he is, in a way. He has the gift of serenity, in this sense:

The oldest of four siblings, he has seen two brothers and a sister surpass him in size, and acquire cars and college educations. He, however, with an underdeveloped entitlement mentality, has been equable about life's sometimes careless allocation of equity. Perhaps this is partly because, given the nature of Down syndrome, neither he nor his parents have any tormenting sense of what might have been.

This year Jon will spend his birthday where every year he spends 81 spring, summer and autumn days and evenings, at Nationals Park, in his seat behind the home team's dugout. The Phillies will be in town, and Jon will be wishing them ruination, just another man, beer in hand, among equals in the republic of baseball.



# **Social Groups** Page

# **TVDSA General Meeting:**

When: Tuesday, September 11th from 7:00pm-9:00pm

Where: At A New Leaf, 2456 N. Stokesberry Pl. in Meridian

**Speaker:** Arlene Cossairt Topic: A Parent's Journey into the World of Alzheimer's Disease Research in Down Syndrome

There will also be time for social networking and to peruse the Library.

Childcare will be available. For more information, contact: Erin Rosenkoetter

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

When: Tuesday, September 25th from 6:30pm-8:30pm

Where: Fuddruckers on Eagle Rd and Ustick in Meridian

Topic: Dads introduction to the IEP Process. We will discuss the basics, how to become more involved with our child's education and the annual IEP process.

For more information about **D.A.D.S.** please contact Gus <u>Olmos</u>

# **Lil' Buddies Update:**

September Play dates:

Lil' Buddies will play Saturday, September 8th Caleb's house at 478 E. from 3:00pm-5:00pm at Stonewater Ct in Eagle. Nathaniel's House at 2468 W. Lincoln Ave in Nampa.

And Monday, September 24th from 10:00am -12:00pm at Need more information on Lil'Buddies Playaroup? Interested in helping organize the monthly gatherings? Please contact Kristie Yerger.

# **Best Buds (Elementary) Update:**

September Outing:

Best Buds will meet on Thursday, September 13th at 6:00pm-7:30pm at Shankz Blacklight Miniature Golf in Meridian, located at 82 F. Fairview, TVDSA will pay admission for each person with Down syndrome.

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),

September Gathering:

BSU Football Party at the Gallas' house, September 15th at

11368 Greenhurst Rd. in Nampa at 1:30pm. The game starts at 2:00pm.

Wear your BSU shirt, bring your favorite football watching snack and come watch the game with your friends.

For more information about **AIM** contact: Freddie Gallas.

For more information about Cool Club please contact: Kristie Yerger



# **Calling All Performers:**

Elevated Dance Project Verge dancers will be back to perform at the 10th Annual TVDSA Buddy Walk, October 13th AND they need individuals with Down syndrome to join them on stage!

Practices will be held at the EDP Studio: 1396 E. Iron Eagle Drive, Suite 300 in Eagle on Tuesdays, September 4th, 11th, 18th, 25th, and October 2nd from 4:30pm-5:30pm and a dress rehearsal the week prior to the performance (TBA) at the Julia Davis Bandshell.

We ask that the dancers be at least 8 years of age due to the need to memorize the routine.

If you, or an individual with Down syndrome you know, would enjoy dancing on stage, please contact: Celena Auger.

# Conferences, Workshops, Webinars & TVDSA Scholarship Information

Idaho Parents Unlimited (IPUL) Parent Support Group

September 12<sup>th</sup>

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

Topic: Success with the IEP workshop

Bring your questions and concerns and leave with proper support, preparation and information to successfully access Special Education for your child.

FREE! Please RSVP. Childcare available upon request.

For more information, parent@ipul.com

### IPUL Webinar:

Not able to attend the Parent Workshop?

Success with the IEP
Free Webinar
September 14th
10:00am-11:30am

Register <u>online</u> today!

The Southeast Idaho Down
Syndrome Association
Buddy Walk

#### September 15th

9:30am-Noon At Brooklyn's Playground at OK Ward Park Pocatello, ID

Getting Started: Developing
College Opportunities for
Students with Intellectual
Disabilities

Webinar: September 17th

Step UP for Down
Syndrome Celebration
September 22<sup>nd</sup>:

10:00am Mirabeau Point Park, Spokane Valley, WA

### r.i.s.e conference

7<sup>th</sup> Annual Building Futures Secondary Transition to College and Employment

October 22<sup>nd</sup>-23<sup>rd</sup>
Portland, OR

Idaho Partnership Conference on Human Services

Restore \* Rebuild \* Renew Strategies for Success

November 1-2<sup>nd</sup>
Riverside Hotel, Boise, ID

### r.i.s.e conference

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

January 18<sup>th</sup> & 19<sup>th</sup>, 2013 Portland, OR

ID Miss Amazing Pageant February 8-9th, 2013 Boise, ID

### **TVDSA Scholarships**

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 <u>Scholarship application</u> for the guidelines and how to apply today.

# **Art Contest**

Be the one to design the logo for Idaho's Statewide Self-Advocacy conference in May 2013
"The Possibilities of All Abilities"
Go to: Idaho Council on
Developmental Disabilities for more information. Artwork due by
Sept. 28th

# **Treasure Valley Family Signing:**

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

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."

# **Join the Celebration while Supporting TVDSA**



The PGA Tour will return to Boise for the 23<sup>rd</sup> annual Albertson's Boise Open presented by Kraft, **September 10-16, 2012** at Hillcrest Country Club. Thanks to Sara Lee TICKETS Fore CHARITY program, 100% of the ticket price will go directly to Treasure Valley Down Syndrome Association.

Order your tickets and support a worthy cause today, by visiting and selecting TVDSA:
www.albertsonsboiseopen.com



Sam's mannerisms of saying "Hi" to everyone, hugging often, smiling and laughing through even the worst of times, his purity and innocence and his lack of worry, anxiety, stress and doubt seem like something we should all strive for....We have so much to learn from these individuals if we allow ourselves to see.

~ Susan Mayer



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 at the Buddy Walk or at the November TVDSA Meeting.

# Did you miss the pre-order?

No problem, you can still get them at the Buddy Walk or November meeting.

# **Shop With Scrip and Give Back To TVDSA**

Purchase Gift Cards for school supplies, clothing, dining, gas, groceries, entertainment, home décor and more, and a percentage 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!

# **GoodSearch and TVDSA**

Please register for GoodSearch, powered by Yahoo at 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 through GoodSearch a donation is made to TVDSA.

# From the TVDSA Lending Library:

The Guide to Good Health for Teens and Adults with Down Syndrome

by: Brian Chicoine and **Dennis McGuire** 

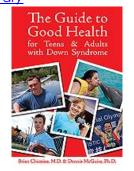
Ten years ago the authors of this book, Drs. Chicoine and McGuire, founded the Adult Down Syndrome Clinic in Chicago. In this book they share all they know and understand about helping adults with Down syndrome have the healthiest lives possible. Not only do the authors address diagnosis, treatment and prevention the TVDSA library.

of common health issues, they also address mental and emotional health issues as well as sexuality, abuse prevention and end-of-life decisions. The authors understand that health problems may be difficult to diagnose in individuals with Down syndrome, and they provide help in correctly "reading" health distress signals. This book will help the reader promote a healthy lifestyle for a loved one with Down syndrome.

This book is available from

Members may reserve it by contacting the librarian at library@idahodown syndrome.org.

For a complete list of the books/DVDs available through TVDSA, please check out our Lending Library



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: <u>Lucy Olmos</u>

Marketing: <u>Jason Woodward</u>

Fundraising & Membership: Malu Mulholland

Vice President and Programs Chair: Kristie Yerger

Secretary: Audrey Byrum

Buddy Walk Chair: Melody Witte Buddy Walk Chair: George Taylor