

In this Issue

This month, you will find a couple of articles for parents – how to take care of yourselves and your marriage and how to advocate for your children. Included, you will find a link to watch the Today Show video clip from March 25th, announcing a teen from Oregon as the first American with Down syndrome to make it to the base camp of Mount Everest.

You will also meet Gus Olmos, who is currently overseeing the D.A.D.S. Social Group. Over the next several months we will be highlighting our social group volunteers that bring together the different subgroups of TVDSA. Get to know the leaders and why they do it.

To partake in any social activity, you do not have to be a member or join the subgroup, just come and meet new people and have a good time!

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

Taking Care of Your Marriage

Raising a child with a disability such as Down syndrome can be taxing on a marriage. In the book *Married with Special-Needs Children* by Laura E. Marshak, Ph.D. and Fran Pollock Prezant, M.Ed., CCC-SLP, one parent relates her philosophy of marriage: "I like to use a boat analogy when talking about marriage. The way I see it, you and your spouse start off kind of on these little rafts, drinking pina colodas out in Aruba and Jamaica. You don't realize that you have to get over that horizon eventually. And so you party and party without realizing that you need to build your boat up and go through a couple of storms to make it to the horizon. You have to prepare yourself for the future and start nurturing and caring about the boat. The advice I give to couples who sail into a storm and are fighting is: Don't whack at your boat in a storm. If you are in the middle of a crisis, don't take the very support you have and start whacking at it, because that is dumb. My husband and I are in a gorgeous boat right now and I appreciate that. One of us will steer. Me. And he is the guy back there making sure everybody is comfortable." The author points out the importance of viewing your marriage as larger than the two of you and her advice "not to hack at your boat in a storm" is an easy refrain to remember because it could not be truer. The book utilized interviews and surveys to gather information. Participant responses to the survey question "From your perspective, what aspects of living with a child with a disability are most stressful to you, your spouse, and your marriage?" were as follows (listed in order of descending frequency):

1. Stress over behavior and safety issues
2. Time demands
3. Total or near total responsibility by one parent
4. Concern over future of child
5. Education concerns and planning
6. Lack of opportunity to spend time with spouse
7. Lack of understanding of others
8. Financial issues
9. Inadequate help from family
10. Physical and emotional fatigue
11. Denial of children's problems by family and friends
12. Stress of child's lack of communication skills
13. Stress over lack of child's progress
14. Parental isolation
15. Limited socialization by child
16. Child care issues
17. Finding appropriate resources
18. Concern over child's physical and emotional health
19. Dividing time and attention between child and siblings
20. Stress over appropriate decisions
21. Parental disagreement
22. Envy of normal parenting situations
23. Fighting for services
24. Concerns about whether to have more children
25. Interference by relatives
26. Sacrificing careers
27. Trying to maintain parental social relationships
28. Feeling unappreciated or unsupported



Continued on Page 4

April 13th:

Lil' Buddies: 10:00am-12:00pm at Kaleidoscope Pediatric Therapy in Boise. Contact: [Jennifer Rice](#)

April 13th:

AIM 3:00pm-5:00pm at Ceramica in Boise. Limited space, reserve your spot with [Freddie Gallas](#)

April 16th:

TVDSA Board Meeting 7:00-9:30pm at A New Leaf Contact: [Paul Auger](#)

April 20th:

Home Depot Workshop 9:00am-12:00pm ALL AGES! Meridian, Free

April 22nd:

Lil' Buddies: 10:00am-11:30am at Charlotte's house in Boise. Contact: [Jennifer Rice](#)

April 23rd:

D.A.D.S. Meeting: 6:30pm-8:30pm at Fuddrucker's, Meridian Contact: [Gus Olmos](#)

April 25th:

Best Buds 5:30pm-7:00pm At Smart Art Crafts for Kids, in Boise. Contact: [Kristie Yerger](#)

April 27th:

Shine! Prom: 6:30pm-10:30pm Center at the Park, Meridian RSVP to [Joy](#) at 208-890-3133

May 21-23rd:

2013 Possibilities of All Abilities Conference, Boise

July 19-21st:

NDSC Conference Denver Co [Registration](#) NOW OPEN!

Are you interested in participating in one or more of the social groups? Unsure how to get started? You do NOT have to be a member of TVDSA or of the sub-group. Just come, meet new people, relax & have some fun!

Basic Blue Print for Advocating for Your Child with Special Needs By: Cynthia Falardeau

I am just a Mom. I never planned on being the parent of a special needs child. It was not a club I wanted to join. Frankly, it was not something I ever imagined could touch my well organized life.

You see, I always did things the "right way." I figured if I did, then nothing bad would ever happen to me.

But, everything changed when Wyatt was born. You see nothing was as I had planned. But I can tell you that our lives have been profoundly enriched by the gift of our son. It has not always been an easy road. Our son Wyatt brings joy to our lives. He is the light of our lives. I hope that by sharing the following ten points that we might be able to help other parents like Jim and me.

Learning to advocate for your child is an acquired skill. I can't say I have done it all perfectly. I can share what I have learned from the knocks and falls I have taken on the path to help our son overcome autism, apraxia and a limb difference.

Here are ten points I hope will help you or someone you love:

1. Take Care of Yourself:

It is exhausting to be a parent. It's even harder when you have special circumstances draining your energy. I know I was just trying to make sense of the cards I had been dealt. Then, when I anteed up my parents and friends never ending questions and concerns, I thought I was going to explode. You have to find time to just breathe and slowly accept the challenge you have been given. Find your release through a church, an exercise class or merely by sitting quietly in a chair for a set amount of time. You have to gather yourself up because your child and your husband or partner needs you.

2. Tie the Knot and Hold on Tight:

It is a journey. The road will be long but there will be plenty of rewards once you open yourself up to them. Someone once told me when Wyatt was a baby, "Knot the rope and hold on tight. You will swing back and forth, round and round but eventually, you will find your way to help your son. It

does not happen overnight." It's true. I know I have changed a lot during the past six and half years. My son's therapists have told me so! The path to acceptance is part of the way to helping your child. It takes time and a lot of hard work.

3. Create Your Team of Support:

There are people out there who want to help. Build your own team. I simply named mine, "Team Wyatt." I recruited the obvious: therapists, teachers, administrators, clergy, family, friends and anyone who I thought could help. Find a way to keep everyone informed and on the same page in planning for your child's therapy and educational regimen. Like any successful team, you need a game plan and a means to share and implement the plan. Talk to other parents to network and to get ideas. You will find there is help in many unexpected places. This team helps me plan, overcome issues and celebrate even the smallest milestones.

4. Stay Positive – Avoid Negative People:

You have to be a bit selfish to help your child. You will find there are plenty of other parents out there who have it worse than you do. There is a Blessing in learning about others' challenges that makes you grateful for your own problems. However, I think you have to be picky to sustain your own core foundation of positive energy to help your child. Parent support groups are wonderful, but you need to find the one that fits your personality. My heart would ache for many of the parents I met. I wanted to help them, but I knew I needed to help myself first. I sought the support of others who had similar temperaments and outlooks. Again, you need all of your energy to keep moving forward for the sake of your child.

5. Get Organized:

Create a binder or a set of files to help you keep track of insurance information, resources, IEPs (Individual Education Plans) and information you collect from other parents or resources. This includes having a note pad ready when you call

Basic Blue Print (continued from page 2)

or meet with other parents or professionals. Don't count on them to email you a recap of your meeting. Most people are busy and they are giving you what they can. Make it easy for them to help you by being organized. This includes writing down questions before you meet with doctors, therapists and teachers. I recommend creating an agenda before heading into a meeting. It helps everyone understand your concerns. It also helps you collect all of the information you are seeking.

6. One Plan Does Not Fit Every Child and Every Family:
Stay home or work? As a mother you can't win because someone always has an opinion about what you should be doing. Everyone is different. You have to decide what works for you and your family and don't let anyone make you feel bad about it. I know I have had another mother say to me, "Well I did not have the luxury of having a career." I can tell you that I have a career because I need to pay for \$20,000 in therapy and services not covered by insurance. I also knew that I could not go to the bathroom without my son melting down. I needed money for his therapy and I needed him to learn to be independent. It was very hard. I cried every day the first two years I went back to work. Wyatt is now in a general education classroom with pull-out support. He has academic goals. His behaviors remain in check. This would have never happened if I stayed home. Again, everyone is different; find what works for you, your child and your family.
7. Advocate Like Your Hair is On Fire:
Don't wait! Intervention is the key. You can find information on the internet to support any opinion, but one thing remains clear: early intervention brings results. As a mother you need to stick to your "gut feeling". I once worried constantly about what people thought. When my son was in the NICU something changed. My doctor said, "You are not trying to make friends. You are fighting for your child's life!" I have always remembered that, but there is a balance to blowing people out of the water and getting them to work with you. Go back to points three and four. The bottom line is that you can't wallow in what caused your child's difference, you don't have time. You have to make a plan and move forward. The clock is ticking.

I will tell you that our son went from being curled up in a ball on the floor crying, hiding and not talking at age

3 to entering Kindergarten and talking at 6. It can be done and you can make it happen!

8. Seek Out New Resources But Beware of the Snake Oil!
I know that I would do just about anything to get my son to talk, overcome his sensory issues and to even have a right hand. The reality is that there are plenty of people out there who will sell you anything to help you feel better. Unfortunately, many appear well intentioned but really do not have any science or fact to prove that their wonder product will deliver results. Do your research, consult professionals and follow your gut. Also remember that not every plan works for every child. Go back to point six!
9. Celebrate and Honor Your Child:
Anyone who knows me will tell you that I am crazy about taking photos and videos. I email my "Team Wyatt" several times a week. Why? Because I want to celebrate all that he is accomplishing and all that is possible. I truly believe that anything is possible through love and faith. When I celebrate I believe I unite my team and therefore further support my son. It has also led to a path of acceptance and peace. There are gifts in any situation. You just have to be open to them.
10. You're the Mom:
There is something very powerful about being a mother. You will recognize it when you develop "Mama Bear Syndrome." I will never forget the first time I felt the veins in my neck popping out during an IEP meeting. I felt like I was becoming the "Incredible Hulk." It bothered me immensely. I did not understand how I could be professional and composed during the most intense business presentations. However, when it came to my child, I was protecting my cub! You do need to find a balance and find your support team. Go back to points 3 and 4!

This list is just a basic blue print to help any special needs parent begin to advocate. As I have mentioned, it is a process. It begins with faith and love. You have to find a way to get people to work with you. Everyone wants to be on a winning team. Your ability to foster support for your child begins with you.

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Teen Makes Disability History at Mount Everest

An Oregon teen with Down syndrome is the first American with the chromosomal disorder to make it to the base camp of the world's tallest mountain. Watch the Today Show clip from March 25, 2013 [here](#).



TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

Social Groups Page

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

D.A.D.S. will be meeting at
Fuddruckers April 23rd
from 6:30pm-8:00pm.

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

Shine! Prom: Hollywood Stars – Everyone Shine

April 27th
from 6:30-10:30pm
at **Center at the Park**
1920 Records Avenue,
Meridian, ID

For high-school through adults
with developmental/intellectual
disabilities.

Music, dancing, refreshments,
pictures, and entertainment.
\$5.00 Entry fee, ADA friendly

RSVP: Joy at 208-890-3133 or
joy@camfam5.com

Dresses and men's dress attire
available at reduced price!

Lil' Buddies (age birth-5 years) Update:

April Gathering:

Lil' Buddies will have a play
date on **Saturday, April 13th**
at **Kaleidoscope Pediatric
Therapy**, located at 7211
Franklin Rd in Boise, from
10:00am-12:00pm.

This is NOT a group therapy
session, it is a play date at
a great facility!

Then **Monday, April 22nd**
come to **Charlotte's
house**, located at 12067
Goldenrod Ave, in Boise,

from **10:00am-11:30am**.

Need more information on
Lil' Buddies? Please
contact [Jennifer Rice](#)

Best Buds (Elementary) Update:

April Gathering:

Best Buds will be meeting
Thursday, April 25th at **Smart
Art Crafts for Kids**, located
at 6728 N. Glenwood Street
in Boise, from **5:30pm-
7:00pm**. Dinner will be

included. Each child with
Down syndrome will be
paid for by TVDSA, parents
are free. If siblings or
friends wish to attend and
decorate a craft, the cost
is \$5.00.



Need more information on
Best Buds? Please contact
[Kristie Yerger](#).

Cool Club (Jr./Sr. High)

April: There will be no
Cool Club Gathering this
month.

Are you interested in
organizing outings for Cool
Club? Contact: [Kristie Yerger](#)



Adults in Motion (AIM)

April Gathering:

Adults in Motion will be
meeting on **Saturday,
April 13th** from **3:00pm-
5:00pm** at **Ceramica**,
located at 1002 South
Vista Avenue in Boise.

Participants will paint a
piece of pottery of their
choice. They have cups,
bowls, small animals, and
more. TVDSA will cover
the studio fee for each
AIM member. There is

only room for 12
participants, so please call
Freddie Gallas (409-718-
0417) to reserve your spot
for this fun event!

For more information
about **AIM** contact:
[Freddie Gallas](#) or [Niculina
\(Nina\) Bistriceanu](#)

Get to know our Social Group Leaders:

Gus Olmos parent coordinator for D.A.D.S.:

To understand why I lead this group you need to understand the reason for the group. Dads Appreciating Down Syndrome, or D.A.D.S., is a committee or community group (within a local Down syndrome support organization) of fathers of children who happen to have Down syndrome. We hesitate to call ourselves a "support group," even though we do, in many ways support each other. The three foundational pillars of D.A.D.S. are Support, Action, and Fellowship.

I feel this is the basic foundation for why I lead this group. We all have one thing in common and it's great to share this same vision. I also enjoy meeting other dads and conversing with them at our meeting about topics that affect our lives and our children's lives. Currently we fellowship, but I envision doing more with support and action. I lend my time so that many can feel welcomed, and we can share stories and be supportive for each other.



Conferences, Workshops, Webinars & TVDSA Scholarship Information

Home Depot Workshop for Kids with Disabilities

April 20th, June 15th, August 17th & October 19th
from 9:00am-12:00pm
at the Meridian Home Depot:
1100 S. Progress Ave
Meridian

Free workshop is geared to provide a fun, quiet, low stress, warm and welcoming environment for kids with special needs of all ages and abilities. Various methods will be provided. Come to one or come to all.

Northwest Conference on Families Unlocking Doors: Effective Strategies for Engaging Families

April 11-13th
at the College of Idaho,
Caldwell [email](#)

[2013 Possibilities of All Abilities Conference](#)

May 21-23rd

Centre on the Grove, Boise

A conference for adults and transition-aged youth with disabilities. Cost: only \$50.00

[Registration](#) Open now –
closes April 19th

2013 NDSC Conference: "Causecation" **July 19-21st** Denver, Colorado

Registration opens in March!
convention.ndsccenter.org

[When Behavior Gets in the Way: Creating Caring Schools and Communities](#) **July 29-31st**

Manchester, NH

Boise Parks & Recreation's AdVenture Program Adaptive Recreation

A wide range of recreational, social and educational programs for youth and adults with disabilities. Scholarships available.

AdVenture offers classes, camps, outdoor trips, and recreation activities designed for people with a variety of disabilities including, but not limited to: orthopedic, spinal cord, neuromuscular, hearing and visual impairments as well as intellectual disabilities.

To learn more, please visit
www.cityofboise.org/AdaptiveRecreation, call 208-608-7680 (TTY 1-800-377-3529), e-mail
AdVentureProgram@cityofboise.org or like us on Facebook,
www.facebook.com/bprAdVentureProgram.

[Wrightslaw Conferences](#)

Special Education Law
and Advocacy

Various dates and locations
across the U.S.

[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.

Taking Care of Your Marriage (continued from Page 1)

29. Being overwhelmed
30. Letting go of dreams for self, child and family
31. Stress over child's frustration, suffering and "differentness"
32. Attitudes of employers about parents of children with disabilities
33. Spouse at different emotional stages
34. Parental health needs
35. Alternate lifestyle due to child's needs
36. Negative attitudes by professionals and public



Debbie Clark, LCSW, LMFT, of Children's Medical Center Down Syndrome Clinic has the following advice on keeping your marriage afloat:

- Work together as a team
- Negotiate and compromise with your spouse for time to be a couple and time for self.
- Plan some activities with your children where you can relate to each other as adults.
- Create time for romance.
- Lower housekeeping standards
- Relax your career and work standards
- Remember your courtship
- And last, but not least, maintain a sense of humor.

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.

Idaho Gives Day, May 2nd, 2013

Come one and all from near and far to the **1st Annual Idaho Gives Day** which TVDSA is joining. The date is **May 2nd** and you can join from anywhere. Tell your family and friends to join us in raising money for the TVDSA and awareness. All you have to do is go to <http://idahogives.razoo.com/story/Tvdsa> and donate to our group, fast, simple, safe and can be done from the comforts of home!

For more information, contact [Malu Mulholland](#)





TREASURE VALLEY
DOWN SYNDROME ASSOCIATION

PO Box 1404
Meridian, Idaho 83680
208-954-7448

We're on the Web!

See us at:

www.idahodownsyndrome.org

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

TVDSA 2013 Calendar Closeout Special



For \$15, the price of the
Calendar, you get a
Calendar **AND** a set of 11
unique TVDSA Note Cards!
(while supplies last)

You can order your
calendars [online](#) or email
[Kristie Yerger](mailto:Kristie.Yerger@idahodownsyndrome.org)

TVDSA needs your ideas.
We are looking for your fun and
interesting ideas for fundraising.
Have a favorite place to go or
eat - let us know.
All ideas are welcomed please
email Malu at
fundraising@idahodownsyndrome.com

Announcing the TVDSA Greeting and Note Cards!

TVDSA has greeting & note cards available to purchase.
The original calendar photo shoot pictures are now
greeting & note cards!

You can purchase a set of 11, with one of each of the
prints, or a set of 10, of a single print/month. Cost: \$7.00
per set.

To [view and order](#) the greeting/note cards visit our:
[website](#) or contact: [Kristie Yerger](mailto:Kristie.Yerger@idahodownsyndrome.org).



From the TVDSA Lending Library:

More Than a Mom
by: Heather Fawcett and
Amy Baskin

Parenting can be stressful enough, without
special needs. The authors of *More Than a
Mom* dive into every facet of a mother's
life to help her develop and maintain a
thriving and fulfilling life while raising a child
who does have special needs. The authors
provide the reader with loads of practical
suggestions. Every mom can find some
part of this book that addresses a
challenge she faces now.



More Than a Mom is available in the
TVDSA library. Members may reserve it by
contacting the librarian at
library@idahodownsyndrome.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: [Lucy Olmos](#)

Community Outreach Chair: [Erin Rosenkoetter](#)

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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](#)