

THE DSG News

PEOPLE WITH DOWN SYNDROME – VALUED AND INCLUDED

A P U B L I C A T I O N O F T H E D O W N S Y N D R O M E G U I L D O F D A L L A S

October 2016

Affiliate of the National
Down Syndrome Congress
and the National Down
Syndrome Society

Buddy Walk® Frequently Asked Questions



DOWN SYNDROME GUILD
OF DALLAS

Sunday, October 23, 2016
AT&T Plaza at Victory Park
2500 Victory Avenue
Dallas, TX 75219

11:00 am – 3:00 pm

Walk begins at 1:00 pm

Registration and giving now open at
<http://2016dsgbuddywalk.kintera.org>.

Make plans to lace up your favorite shoes, put the wagon in the car, and dress in your festively colored t-shirt as the Down Syndrome Guild of Dallas invites you to walk with us on Sunday, October 23, 2016. The Buddy Walk® is an emotional and powerful day for all of us as we celebrate the abilities of people with Down syndrome. With over 5,000 participants and new supporters added each year, we know you and your team are bound to have a few questions. While we've tried to answer our most frequently asked questions here, please feel free to contact the DSG office at

any time at 214.267.1374 or samantha@downsyndromedallas.org if you have any additional questions.

Q. Who has to register for the Buddy Walk®? **A. EVERY** participant, regardless of age, must register online or in person the day of the event and pay all necessary fees in order to participate and be eligible to receive a commemorative Buddy Walk® t-shirt (subject to availability). *Online registration closes at midnight on Friday, October 14, and early registration is highly encouraged.*

Q. When/where can I pick up my t-shirts? **A.** Team captains are responsible for picking up and distributing all commemorative Buddy Walk® t-shirts to their team members. Team captains must schedule a time between Saturday, October 15 - Thursday, October 20, by contacting Samantha at 214.267.1374 or samantha@downsyndromedallas.org to pick up t-shirts. Additional instructions will also be sent to all team captains via e-mail. *Please note that only registered participants raising or donating the appropriate fees are eligible to receive a t-shirt. All sizes will be pulled from our database, so please make sure all your team members have registered and entered in their sizes. No t-shirts for pre-registered participants will be*

available for pick up at the walk.

Q. Where can I park? Where can my team meet? **A.** A map of the event area, including parking and team tailgating, can be found at 2016dsgbuddywalk.kintera.org. All spaces are on a first come, first served basis. *Tents, chairs, and coolers are allowed in the team tailgate area; however, grills and open flames are not allowed.*

Q. Will food be available for purchase? **A:** Yes, we are pleased to offer participants expanded entertainment and new dining options this year. It'll be a culinary treat for everyone with a variety of tasty snacks and lunch options. Be sure to come hungry! A complete listing of dining options are available on our website at 2016dsgbuddywalk.kintera.org, and a portion of food truck sales will also be donated back to the DSG.

Invite everyone you know to join us on Sunday, October 23, at AT&T Plaza at Victory Park as we celebrate the Down syndrome community in North Texas. Make a direct impact in the lives of people with Down syndrome with your fundraising efforts at 2016dsgbuddywalk.kintera.org. It'll be a fun day as we show our support for each other with a bit of Texas spirit!

GREAT WAY TO HONOR LOVED ONES

Club 21

is a Down Syndrome Guild program to honor a loved one: matching the numeral of the important chromosome that affects our children.

A gift to the Down Syndrome Guild to honor loved ones is a tangible way to recognize their lives, celebrate holidays, birthdays, anniversaries, graduations, new homes, or any number of occasions.

A gift in honor of a friend or relative is a thoughtful and caring way to express sympathy while sharing concern for an important cause. Upon receiving a memorial or honorarium gift, the DSG will notify the family or individual of your thoughtfulness and send you, the donor, a letter of receipt.

Interested in making a *Club 21* donation? Contact Jennifer Ford at (214) 267-1374 ext. 1 or e-mail jennifer@downsyndromedallas.org.

Executive Director's Message *by Jennifer Ford*

The Buddy Walk® is an incredible day of celebration filled with shared fellowship and awareness for the Down syndrome community. However, its greatest impact is felt throughout the year as it funds the programs and activities of the Down Syndrome Guild of Dallas. Year after year, we continue to be amazed and inspired by the fun and creative ways our amazing teams raise funds that support our families throughout the year. Without your support, the organization could not continue providing accurate and current information, resources, and support for people with Down syndrome, their families, and the community. We greatly value your support and have included ten easy fundraising ideas that you can implement with your own team this year.

1. Utilize social media to share the link to your Buddy Walk® fundraising page
2. Implement an e-mail campaign to reach friends and family near and far with a request to sponsor your team for at least \$25
3. Post flyers at your school or local businesses you frequent
4. See if your company has a matching donation program or would host a casual day for a small donation
5. Have a garage sale
6. Host a neighborhood block or theme party to raise money
7. Ask a local eatery to share their profits for a day in honor of your Buddy Walk® team

8. Create a contest for raising money—football team offense vs. defense
9. Deliver a group of fake pink flamingos to a donor's yard. Leave a note explaining the cause and asking for a donation to "replant" the flamingos in the yard of the next "victim" the first donor designates
10. Give decorated jars to family and friends for their spare change over the next few weeks

If you have not created a Buddy Walk® team yet this year, it's not too late to register and begin fundraising. Online registration at 2016dsgbuddywalk.kintera.org closes **Friday, October 14**, at midnight. Day of registration is also available for additional fees. Each of you can make an impact by simply asking those around you to join us on **Sunday, October 23**, at AT&T Plaza at Victory Park for the 2016 Buddy Walk®.

Please remember that **EVERY participant regardless of age must register online or in person the day of the event in order to participate and be eligible to receive a commemorative Buddy Walk® t-shirt. If you need assistance with registering, please do not hesitate to contact us at (214) 267-1374, jennifer@downsyndromedallas.org, or samantha@downsyndromedallas.org.*

Instructor-Led Playgroup for Ages 0-4

Mondays, September 12 -
December 12, 2016
9:00 am - 10:00 am

Eagle's Wings Athletic Center
104 N Greenville Ave.
Allen, TX 75002

Join other families with children ages 0-4 with Down syndrome for an instructor-led playgroup that aims to promote motor and social skills. Siblings of any age are also welcome to attend. The class will be taught by Wendy McLean, PT, C/NDT. Wendy graduated from the Texas Tech University Health Sciences Center physical therapy program and has completed 227 hours of advanced holistic pediatric clinical training to earn her certification as a Neuro-Developmental Treatment

(NDT) therapist. Wendy has extensive experience helping children and adults with developmental and neurological challenges through early childhood intervention programs, schools, and outpatient clinic setting. She is a certified clinical instructor for PT students through the American Physical Therapy Association and has also been trained in the use of Adaptive Yoga, Emotional Regulation Techniques, and Infant Massage.

Participants must RSVP to Samantha Escherich at samantha@downsyndromedallas.org or (214) 267-1374 with parent name, child with Down syndrome name and age, and sibling name and age.

We Caught These Two Cuties Taking a Quick Break from Splashing at Our Summer Water Park Events



Cookies with Santa for Families with Children Ages 0-12

Saturday, December 10, 2016
10:00 am – 12:00 pm

Fellowship Bible Church
9330 N Central Expy
Dallas, TX 75231

The Down Syndrome Guild invites families of children with Down syndrome ages 0-12 to join us for cookies and pictures with Santa. Children will have the opportunity to decorate gingerbread man cookies and have their picture taken with Santa and Mrs. Claus. This holiday event is free of charge to all Down Syndrome Guild members and their *immediate* family. Space is limited, so participants *must RSVP* with the number of adults and children to Samantha Escherich at samantha@downsyndromedallas.org or (214) 267-1374 *no later than Friday, December 2, 2016.*

Imagine the Possibilities – NDSC Convention by The Urban Family

Inspiration, Encouragement, Information, Connections and Enjoyment. Our family experienced all of this, and more, at the National Down Syndrome Congress (NDSC) Convention in Orlando, FL.

Brandt (20) participated in the Youth and Adults sessions, beginning with a Kick-Off Party, which included introductions, ice breaker, and of course a dance party. He met many other self-advocate participants and learned from the self-advocates who led the sessions he attended, such as: ballroom dancing, cooking demonstration, and kickboxing! Each evening he joined the other attendees at a dance and concluded the conference with an act in the Talent Show along with his partner Bennett McKee, which brought the crowd to their feet dancing to Cotton Eyed Joe.

Katelyn (12) enjoyed the Brothers & Sisters sessions, meeting other siblings, and hearing from the siblings who led the sessions. They discussed what it is like to have a sibling with Down syndrome and some of her comments were: “People with Down syndrome can succeed in post secondary schools”, “Some of our siblings are able and others unable to live independently – for a variety of reasons”, “People with Down syndrome bring a wide range of skills to community activities”, and “Children with Down syndrome are visual learners.” She really enjoyed the outing with the other siblings to Wonder Works.

Bryan and I [Kari] went to several different workshops throughout the weekend, and I’ll share our “takeaways.”

Going to College: Postsecondary

Opportunities – There are around 250 colleges in 37 states that offer opportunities for individuals with intellectual disabilities. They vary in their format and levels of inclusion. www.thinkcollege.net offers a database of program offerings. Some financial aid is available for individuals pursuing postsecondary education opportunities as well.

Alzheimer’s Disease and Down syndrome – Nearly 100% of all people with Down syndrome develop the physiological markers for Alzheimer’s Disease (AD), although not all will develop the resulting conditions of dementia, etc. Also interesting, is that in 10% of the cells of all people with AD, Trisomy 21 is present. This correlation is very interesting to researchers and makes studying the causes, conditions, and treatments for AD closely tied to elements of Down syndrome. Doing tests and trials with individuals with Down syndrome could advance the research on AD much quicker than with the total population because of the consistency in frequency and the earlier onset of AD (sometimes becoming present in the 30’s and 40’s). The funding going into AD research is very significant because 40% of all people will eventually develop AD. This all

bodes well for the resulting knowledge and benefits that may be gained for research and medical applications for individuals with Down syndrome.

The Joy of Work: Finding a Job, Starting a Career – When doing job development, ask potential employers to consider how they could be more effective in their job, utilizing an assistant, and this could become a position for an individual with disabilities. Approach hiring manager, not the HR person – speak to the person closer to the actual work. Consider job coaches as job developers and refer to yourself as a career counselor/consultant (not a parent looking for a job for their children). “My name is ___ and my student/son/daughter is looking for work experience or a job in the area of ____.” If no success, “Do you have any ideas, contacts or leads?” and utilize your contacts to assist in developing other contacts. Utilize a team of people to help with ideas/job leads.

Eat Right, Future Bright – Energy and Vitamins – Some foods give energy and some give vitamins and consider food as “fuel”. ChooseMyPlate.gov is an online resource. The book *Thumbs Up/Thumbs Down* creates selective choice, empowering the individual to make their choice. Metabolism of an individual with Down syndrome is 10-15% lower than a typical person. Nutritional goals should be to manage the amount of food eaten and understand moderation, help



DOWN SYNDROME GUILD
OF DALLAS

GRUPO DE FAMILIAS UNIDAS

19 DE NOVIEMBRE

3-5 PM

REUNION DE

GRUPO DE

FAMILIAS

UNIDAS

**GRUPO DE
FAMILIAS UNIDAS**

Ven a conocer y
reunirte con otros
padres que tienen
hijos con
syndrome de Down

Las reuniones son
en Español!

Toda la familia es
bienvenida

Familias Hispanas
Unidas para ayudar
a nuestros hijos

**DOWN SYNDROME
GUILD OF DALLAS**

1702 N. Collins Blvd.
Suite 170
Richardson, TX 75080

19 de noviembre
de 2016

3-5 pm

understand the best types of food, and develop life-long self monitoring.

Postsecondary Education Outcomes

– Students shared their experiences with inclusive postsecondary schooling, which included auditing college courses and certificate programs. Outcomes have been tracked and results can be used to advocate for postsecondary opportunities. Schools/colleges which desire to create an inclusive postsecondary model program should apply for TPSID grants (50% of the time is working with/learning with students who are not disabled). Many of those providing support for these programs are students pursuing a degree in special education.

ABLE Act – A few states have developed savings programs for individuals with disabilities to be able to save and not affect their eligibility for SSI. This program was modeled after the 529 Plan. Contribution limits vary by state, as well as range of investment options, and the income earned is not taxed. There are a couple states which are “open” to anyone in the US to contribute – Ohio and Nebraska. The other states are limited to their residents.

Transition to Adulthood for Youth with Down syndrome – Create a one-page medical summary document with your child’s information and emergency contacts. Samples are available on the internet. Emergency

contact numbers should be loaded into phones on the Health App – Medical ID. Create a document/social story to know how to make medical appointments and a list of providers, location, and contact information. The presenters (which would be similar to a service provider of DARS services) performed interest inventories and situational work assessments. I plan to investigate further the services that DARS offers!

Comprehension Strategies – Reading A-Z offers fluency practice passages; Vocabulary A-Z available online; Vocabulary cartoons offer a graphic novel version of History texts. Activate Prior Knowledge – Think aloud “This story reminds me of the time . . . “ or “If you were in . . .”; Visualizing – making mental pictures “I can see . . . It looked like . . . I can imagine . . .” and Predict – talking out loud – model by thinking aloud, practicing on familiar stories. A reading tool is RAZ Reading Online.

Dating - Girlfriend/Boyfriend

– Consider developmental age vs. chronological age – teach to conservative norm. Dating – spending time together; Flirting – important part of the process – giving and reading signals. If the other person is not interested, stop flirting.

Holiday Treats for Teens Ages 13-17

Saturday, December 10, 2016
3:00 pm - 5:00 pm
Down Syndrome Guild

1702 N. Collins Blvd. Suite 170
Richardson, TX 75080

Teens ages 13-17 are invited to join peers for an afternoon of holiday treats, including a festive movie, holiday cookies, and hot cocoa. **Please RSVP with the name of the teen joining us to Samantha Escherich at samantha@downsyndromedallas.org or (214) 267-1374 no later than Friday, December 2, 2016.**

Game Night for Teens Ages 13-17

Saturday, November 19, 2016
6:30 pm - 8:30 pm
Down Syndrome Guild
1702 N. Collins Blvd. Suite 170
Richardson, TX 75080

Teens ages 13-17 are invited to join peers for a night full of fun, games, and snacks. Have your game face ready to learn and teach new and exciting games. If you don't love games but like hanging out with friends and munching on snacks, you are welcome too!

Please RSVP with the name of the teen joining us to Samantha Escherich at samantha@downsyndromedallas.org or (214) 267-1374 no later than Friday, November 11, 2016.

Employer Spotlight: Blake Pyron Blake's Snow Shack, Sanger, TX



Blake Pyron was born and raised in the small Texas town of Sanger where he was the varsity football captain, prom king and even Texas Citizen of the Year. But his inspiration story melted hearts around the world with the summer 2016 opening of "Blake's Snow Shack." At 20 years old, Blake became the youngest business owner in Sanger, and the first in the state of Texas with Down syndrome. The story of his snow cone stand made international news, appearing in the Huffington Post, A&E Latinoamerica, Unworthy, Reddit and even the Today Show Australia.

You may have even seen his logo on the Leavine Family Racing #95 NASCAR at Pocono Speedway. When asked why he chose this type of work, Blake indicated that "it's hot in Texas,

and everyone loves snow cones". Blake also stated that the best part of his job is seeing friends and meeting new people. "If you believe in your child, they will believe in themselves," says Blake's mother, Mary Ann. "1 in 5 Americans have a disability, but 5 in 5 Americans have potential."

Blake is a National Down Syndrome Ambassador and the 2016 Self Advocate Honorary Chair of the Dallas Buddy Walk®, where he will be serving his famous snow cones. Be sure to stop by and see Blake at the 2016 Buddy Walk® on Sunday, October 23 at AT&T Plaza at Victory Park for one of his favorite menu items, #84 Blake's Football number . purple / Gold .. A grape and banana snow cone.

2016 iCan Shine Bike Camp



The DSG hosted the 2016 iCan Shine Bike Camp at UTD in August with the support of over 60 volunteers. These volunteers work tirelessly throughout the week assisting riders physically and emotionally as they conquer their fears and gain the skills necessary to become life-long, independent riders. We cannot thank our volunteers enough for their continuous support of the iCan Bike program and would like to specifically recognize our friends at Jesuit College Preparatory for their service during Bike Camp and to the DSG throughout the year.

Dads' Night Out Steak 101 Class

Saturday, November 11, 2016
6:00 pm - 9:00 pm
Local Yocal Farm to Market
213 N Tennessee St.
McKinney, TX 75069

Love steak? Then join us for Steak 101 - an education in all things beefy with Local Yocal's highly entertaining owner, Matt Hamilton, in Historic Downtown McKinney. Steak 101 is divided into 3 segments: (1) Meat Industry Discussion, (2) The Beef Carcass and Steak Cuts, and (3) Grilling & Sampling! You'll get the inside story about beef; certification programs, meat grading, cattle raising, grilling, and much more. Learn about the difference between Wagyu vs. Angus, naturally-raised vs. grass-fed, and rare vs. ruined. Visit the cutting room to see what makes each steak special, and then enjoy a delicious tasting of 17+ fine beef cuts! Bring your appetite, and BYOB! Dads of individuals with Down syndrome of any age are welcome.

Space is limited and RSVP is required to Samantha Escherich at (214) 267-1374 or samantha@downsyndromedallas.org **no later than Monday, November 7, 2016.**

1702 N. COLLINS BLVD.
SUITE 170
RICHARDSON, TX 75080

Return Service Requested

(214) 267-1374

www.downsyndromedallas.org

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PRESIDENT: LYNN CAMPBELL

EXECUTIVE DIRECTOR: JENNIFER FORD

DIRECTOR OF PROGRAMMING: SAMANTHA ESCHERICH

DOWN SYNDROME CLINIC EVERY THURSDAY
AND FRIDAY AT CHILDREN'S MEDICAL CENTER.

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DOWN SYNDROME GUILD OF DALLAS



MISSION STATEMENT: THE DOWN SYNDROME GUILD OF DALLAS PROVIDES ACCURATE AND CURRENT INFORMATION, RESOURCES, AND SUPPORT FOR PEOPLE WITH DOWN SYNDROME, THEIR FAMILIES, AND THE COMMUNITY.

VISION STATEMENT: PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED.

ARE YOU MOVING? DON'T FORGET TO PROVIDE US WITH YOUR CHANGE OF ADDRESS BY CALLING THE OFFICE AT 214.267.1374 OR SEND US AN E-MAIL AT JENNIFER@DOWNSYNDROMEDALLAS.ORG.

Down Syndrome Guild Calendar of Events

October 1
Fall Conference

October 14
IMPCT Gala

October 23
Buddy Walk®