

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

November-December 2017

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

New Parent Meeting for Families with Children Ages 0-2 Years Old

Sunday, January 7, 2018

2:00 pm - 4:00 pm

Down Syndrome Guild of Dallas
1702 N. Collins Blvd. Suite 170
Richardson, TX 75080
DSG Member Cost: Free

The Joys and Challenges of Raising a Child with Ds Parent Panel

Join other new parents (*with children ages 0-2 with Down syndrome*) as we gather information, meet new friends, and share resources. Our panel of "experts" will share their personal experiences on the joys and challenges often associated with raising a child with

Down syndrome. There will be ample time for Q&A as well as opportunities to connect with other families. Light snacks and childcare will be provided

Childcare space is limited and registration is required. Online registration is now open at

www.downsyndromedallas.org/new-expectant-parents. Registration closes Tuesday, January 2, 2018. Have questions? Please contact Samantha Escherich at 214.267.1374 or samantha@downsyndromedallas.org.

Holiday and Year-End Giving

Whether you are searching for that perfect holiday gift or simply interested in making a year-end charitable contribution, a gift to the Down Syndrome Guild of Dallas is a wonderful way to give back to the community. Your tax deductible contribution will help support the mission of the Down Syndrome Guild by allowing us to continue providing accurate and current information, resources, and support for people with Down syndrome, their families, and the community.

To make a holiday or year-end contribution to the Down Syndrome Guild, please visit our website at www.downsyndromedallas.org and click the *Donate Now!* link in the upper right corner of your screen.

Please contact the DSG office at (214) 267-1374 or e-mail jennifer@downsyndromedallas.org if you have any questions or need assistance with your giving.

HERB'S PAINT & BODY
DOWN SYNDROME GUILD
GOLF CLASSIC

Mark Your
Calendar

Herb's

Enterprise English Golf BASF ABUELOS LKO KEITH M

Monday, May 21, 2018 • Dallas Athletic Club

**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.

In memory of Creola Phelps.

From: Jim, Chris, and James Taylor

In honor of the 50th wedding anniversary of Rita and Howard Wasserman.

From: Jamie Venise

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 or e-mail jennifer@downsyndromedallas.org.

President's Message *By Lynn Campbell*

As we say in Texas, “Happy Fall Y’all”! At least the temperatures are finally (kind of) starting to make it feel like fall. What a wonderful day it was on October 29th for the 2017 DSG Dallas Buddy Walk®. It was a beautiful day and so many of you participated. I always look forward to that day like no other and it leaves my heart full as I watch our community come together. I enjoy the Walk itself, of course. What I enjoy most is seeing my friends with Down syndrome and their families having a good time dancing, smiling, playing, climbing, eating and more. From first time participants to people who have been at every Walk since the first one and all those in between, the faces represented people connected to Down syndrome in a variety of ways. In addition to our members with Down syndrome, I saw, met or visited with siblings, parents, grandparents, aunts, uncles, cousins, therapists, school friends, co-workers, neighbors, and teachers. How cool is it for your Math teacher to come to your Buddy Walk®?

I want to take this opportunity to thank our sponsors, staff, Board Members and volunteers who stepped up with their time and talents to help the Buddy Walk® event run smoothly. It takes hours, days, weeks and months to plan for this day. Thank you to each of you who served to help make this incredible event happen.

Thank you to the individuals and teams who raised funds and walked with

us. You gave yourselves and asked for donations from your extended family, friends and places of work to collectively make a huge difference in our ability to serve the Down syndrome community. Each dollar collected goes to help us fulfill our mission to provide accurate and current information, resources and support to people with Down syndrome, their families and the community.

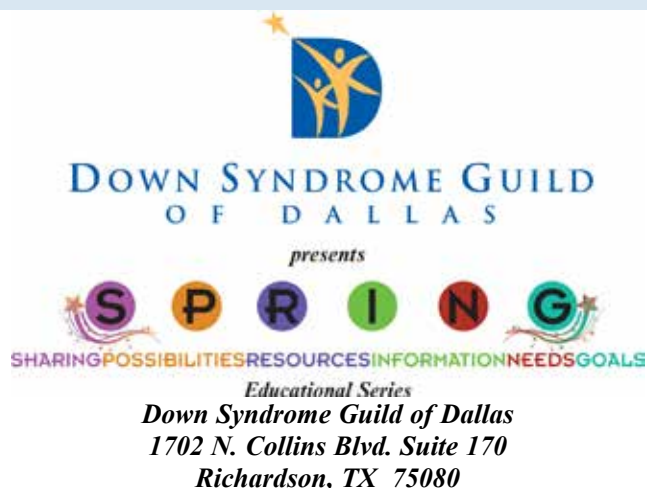
Each of you helps to make a difference in the lives of people with Down syndrome and their families. This is a community with heart that makes a significant, positive and lasting impact. Together we can continue to share our vision of *people with Down syndrome – valued and included*.

Please note the December and January activities mentioned in the newsletter that we have planned and register for and attend these fun events.

Last, we are excited about our SPRING 2018 Educational Series. Check out on our site www.downsyndromedallas.org the four Saturday morning sessions that are offered for **FREE** to our membership. The topics were chosen as a result of feedback from you, the members. You won’t want to miss these informative sessions.

Happy Thanksgiving! Happy Holidays! Happy New Year!

Lynn Campbell, DSG Board President



Saturday, January 27, 2018 - Contents of the IEP and the ARD Process

10:00 am - 12:00 pm

Speaker: Jim Wright, Region 10 Coordinator at Partners Resource Network - PATH Project

This workshop is designed to provide parents with practical working knowledge of the contents of an IEP as defined by IDEA. Through the process of writing an IEP, we will learn to set reasonable and measurable learning goals for a child with a disability and to state the individualized services that the school district will provide for that child. Additionally, this workshop will provide an overview of the ARD process so that parents will be prepared to participate at every stage of the process. Participants will gain an understanding of the ARD meeting agenda, as well as their procedural rights and responsibilities.

Saturday, February 17, 2018 - STAAR Testing

10:00 am - 1:00 pm

Speaker: Lorna Salgado, Special Populations Consultant, Region 10 ESC

In this session, participants will learn the differences between STAAR testing with accommodations and STAAR Alternate 2 testing. We will discuss the participation requirements for each, as well as how state testing decisions and scores affect the student in progressing to the next grade level/graduation. There will also be time to ask general questions about state testing for students with disabilities.

Saturday, April 14, 2018 – Planning for the Future, Everything You Need to Know about Special Needs Planning

10:00 am - 12:00 pm

Speaker: Tresi Moore Weeks, Attorney, Weeks Law Firm

Tresi explains the planning essentials involved with a special needs plan: Special Needs Trust, wills, life insurance and retirement beneficiary designations, powers of attorney, and life plan. She gives an overview on how each of the above areas relate to each other and how parents can provide for the care of their child after the parent has become incapacitated or passed away.

Saturday, May 5, 2018 – How to Develop Time and Money Skills Through Everyday Experiences

10:00 am - 12:00 pm

Speaker: Carla Austin, OTR

Everyday life experiences offer some of the best teachable moments for reinforcing math concepts needed to perform activities such as telling time and using money. People with Down syndrome can benefit from these life lessons throughout their school years extending into adulthood. Strategies will be discussed to introduce skills and offer repeated opportunities for practice. Practical suggestions, take home materials, and handouts will be provided which can be used at home and school by teachers and parents in home, school, and community settings. The goal of this session is to leave with "go to" materials and activities and to know how to incorporate them into daily routines.

Online registration is now open at <http://downsyndromedallas.org/spring-education-series>. There is no cost to attend; however, space is limited and attendees must register in advance. Childcare is NOT provided.

Performing Arts Class for Youth and Teens Ages 5-17

Thursdays, January 25, 2018 -
March 8, 2018
5:00 pm - 6:00 pm

North Texas Performing Arts
6121 W Park Blvd, Suite B216 (2nd
floor, near Dillard's)
Plano, TX 75093

DSG Member Cost: \$25

Musical productions are unique for uniting all art forms. Through the combination of drama, song, dance, and visual art, characters and stories come to life. Ending in a short showcase, this workshop aims to give students opportunities to learn the fundamentals of putting on a production. Students will create stories, develop characters, draw and paint backdrops, and sing and dance to a few musical numbers. Through the development of these skills and expressing creativity as a group, students further their development of social, communication, motor, and cognitive skills.

Space is limited and registration is required. Online registration is now open at www.downsyndrome.org. Registration closes Friday, January 12, 2018. Have questions? Please contact Samantha Escherich at 214.267.1374 or samantha@downsyndromedallas.org.

Please note that this event is valued at over \$125 per person and offered to DSG Members for a reduced rate of \$25 per person.

Ambassador Spotlight - Jude



Jude and his family have been breaking down barriers for people with Down syndrome since he was just a baby. His mom, Rachel, realized quickly that an extra chromosome did not define her child, his abilities, or his dreams. Now at the age of sixteen, Jude has proven to the world that people with Down syndrome should be treated with the same respect and equality as individuals without the condition.

Jude began modeling around the age of two and has continued to pursue his passion over the years. In 2016, Jude was sponsored by Global Disability Inclusion to take part in Fall New York Fashion Week (NYFW), making history as the first male model with Down syndrome to walk the runway at NYFW. "The whole point of his debut at NYFW was to show that people with disabilities should have the same opportunities as everyone else,

that they are equal, not 'special,'" Rachel stated. "Jude believes that. He knows that society's perception about his disability limits him more than the diagnosis itself ... He knows inside what he is capable of."

Back home in Plano, Jude enjoys being a typical, active teenager. His free time usually includes yoga, swimming, Legos, Minecraft, and quality time with his friends and family. The teen also



enjoys dancing with his competitive dance troop and participating in activities hosted by the Down Syndrome Guild of Dallas and his church youth group.

From advocating for his rights at school to making history at New York Fashion Week, Jude truly embodies the mission and vision of the Down Syndrome Guild of Dallas. His self-advocacy and determination are proving to the world that people with Down syndrome are valued and should be included in all aspects of life. We are certain that Jude will continue to soar and break barriers for people with Down syndrome, and the Down Syndrome Guild of Dallas is honored to recognize Jude as our Self Advocate Ambassador for November 2017.

Ambassador Spotlight - Aaron



Aaron is a cheerful and loveable three year old who loves playing with balls, splashing in the water, and Mickey Mouse. Aaron also adores his two older siblings, who continuously make him laugh and smile. Aaron's parent's, Heather and Kevin, describe the happy three year old as a blessing and have a passion for showing others how Down syndrome has positively impacted their lives.

Heather and Kevin are no strangers to the special needs community and met volunteering at Camp Summit, so they felt like a child with special needs was just in their plan. The family strives to educate their community about Down syndrome and share how Aaron has impacted their lives for the better. Aaron has a Facebook blog where the family shares their joys, challenges, and just everyday life with a toddler who happens to have Down syndrome.

Aaron's mom, Heather, describes Aaron's smile as contagious and says that "anyone who sees him cannot help but smile themselves".

In addition to the web, Aaron's joy sparks an emotion in almost everyone he meets in person as well. From the grocery store to the zoo, people are always stopping to comment on his cheerful disposition and smile. Heather and Kevin view this as a



great opportunity to spark a conversation about Down syndrome and help inform others. The family is also passionate about giving back to new parents and supporting other families the same ways others did for their family. They are active members of the Down Syndrome Guild of Dallas as well as some other local Down syndrome groups where they are able to simultaneously share their wisdom and experiences while gaining insight from other families as well.

The Down Syndrome Guild is so pleased to recognize Aaron as our Self Advocate Ambassador for December 2017 and look forward to watching him grow and continuing to share his positivity and joy with others.

Book Club for Adults Ages 18 and Older

Tuesdays, January 9, 2018 –
February 27, 2018
7:00 pm - 9:00 pm

Panera Bread
7839 Park Lane
Dallas, TX 75225
DSG Member Cost: \$25

Adults will gather with their peers to read a book, ask questions, and learn, all while enjoying social time together. Participants may choose to purchase their own dinner at the restaurant. We will enjoy the first part of our time socializing with friends and then the second half reading and sharing.

Space is limited and registration is required. Online registration is now open at www.downsyndromedallas.org/adults. Registration closes Friday, December 29, 2017. Have questions? Please contact Samantha Escherich at 214.267.1374 or samantha@downsyndromedallas.org.

Please note that this event is valued at over \$30 per person and offered to DSG Members for a reduced rate of \$25 per person.

Special Thanks to Our 2017 Corporate Sponsors

Title Sponsor:



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Angels of Care Pediatric

Home Health

The Ashford Rise School of Dallas

Ben E. Keith

Berry Family Services

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Monkey Mouths Pediatric

Speech Therapy

Neighborhood Credit Union

Xtra Love

Celebrating the 2017 Buddy Walk®



Thanks and gratitude to all who participated, volunteered, donated, and came out in support of the 16th Annual Down Syndrome Guild of Dallas Buddy Walk®!

First and foremost, thank you to all the Buddy Walk® Teams and individual donors. Our Team Captains work tirelessly to include their closest friends and family, and we could not be more appreciative of your support. The energy and enthusiasm that we see from our teams year after year is so inspiring. It's always so exciting to see the decorated strollers and wagons, creative t-shirt designs, and posters. Team tailgating also took on a whole new meaning this year, and the Plaza was filled with dancing and entertainment. Congratulations to our first, second, and third place teams Ty Wyl E Coyotes, Jesuit Football Offense and Defense, and Team Levi for your fundraising successes this year. Together these three teams raised over \$91,000 in support of the Buddy Walk®. You continue to amaze and inspire all of us with your dedication to the Buddy Walk® and the Down Syndrome Guild of Dallas!

Next, thank you to all of our corporate partners and sponsors listed on this page. Your participation illustrates your commitment to our community, programs, and people with Down syndrome.

Last, but certainly not least, the Buddy Walk® would not happen without our fantastic volunteers. Our volunteers assist us throughout our planning, but their services are critical on Buddy Walk® day. They unload trucks at 6:00 am, direct traffic, manage face painting and games on the Plaza, cheer on walkers, and perform tasks both big and small. Their helping hands are greatly appreciated as they work to make the day enjoyable for everyone.

While the Buddy Walk® is just one day, the success of the event is felt year round. With over \$276,000 raised to date, the DSG will be able to continue sponsoring events, hosting programs, and supporting education and medical research initiatives for our members. The Buddy Walk® also cultivates awareness with people who may not have had a direct connection with Down syndrome before but now recognize that people with Down syndrome are valued and included. Most importantly, the Buddy Walk® reminds us that we are members of a shared community - a group composed of those who understand how you feel, know what you may be experiencing, and may offer words of wisdom when needed. Together, we can make a difference in immeasurable ways!

Transition Clinic at Children's Health Dallas

By Joanna Spahis, RN, CNS, AGN-BC and Debbie Clark, LCSW

In May of 2014, after 21 years of providing care for children in the Down Syndrome Clinic at Children's Health, we saw the need for a specialized Transition Clinic. We realized that our patients were growing up, and needed to develop the necessary skills to transition from pediatric care to the adult world. Unfortunately, there is no Adult Down Syndrome Clinic in Dallas to which we can refer our young adults. Children's Health developed an organizational initiative to focus on successful transition for our patients to adult care. Our Transition Clinic utilizes a specific checklist to identify strengths and areas in need of growth. Upon completion of the checklist, the medical team, in partnership with the family and adolescent, can formulate goals to assist in achieving knowledge and skills for independence in adulthood.

In developing our checklist, we looked at examples from other Children's Health clinics as well as utilized goals from the "Got Transition" web site, www.gottransition.org. We talked to transition experts from other hospitals and consulted with experienced parents of adult children with DS. There are a few other transition clinics in the United States for adolescents with chronic illnesses and disabilities, but none except ours is only for adolescents with Down syndrome to our knowledge. We did a pilot (trial) study before opening the clinic program, to refine and expand our checklist. Currently, our Transition Clinic provides care for adolescents, age 15 to 18. Teens are seen yearly, and are ready to graduate to adult care at age 18.

The focus of our checklist is on several categories: medical needs, independence skills, self-care, and awareness of community resources.

- Medical needs would include awareness of Down syndrome, safe use of medications, and interacting with the medical team.

- Independence skills involve tasks such as understanding healthy vs. unhealthy foods, interacting appropriately with friends vs. strangers, and dressing properly for the weather. More advanced skills include using the 9-1-1 system and going out alone.

- Self-care skills include bathing and dressing independently, having a bedtime routine, and being able to prepare simple meals.

- Awareness of community resources includes obtaining a state ID, knowledge of Medicaid, Medicare, and Social Security programs, and consideration of adult guardianship and alternatives.

A key component of the transition checklist is being able to assess the teen's abilities and to individualize their goals. We help families identify adult primary care providers for their adult child once they are discharged from our pediatric DS clinic. We have received helpful feedback from some of the families, and their responses have been generally positive. As the clinic continues to evolve, we will try to incorporate suggestions from families whenever possible.

Reunion de Grupo de Familias Unidas

Sábado, del 20 de enero de 2018

3:00 pm - 5:00 pm

Down Syndrome Guild of Dallas

1702 N. Collins Blvd. Suite 170

Richardson, TX 75080

Costo para Miembros de

DSG: Gratis

- Ven a conocer y reunirte con otros padres que tienen hijos con síndrome de Down
- Las reuniones son en Español!
- Toda la familia es bienvenida
- Familias Hispánicas Unidas para ayudar a nuestros hijos

¿Tiene preguntas?

Comuníquese con Samantha

Escherich al 214.267.1374 o a

samantha@downsyndrome.org
dallas.org

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RICHARDSON, TX 75080

Return Service Requested

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WWW.FACEBOOK.COM/DALLASDSG

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.

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

CALL (214) 456-2357

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Down Syndrome Guild Calendar of Events



November

November 28 - Big D Gives on Giving Tuesday



December

December 9 - Cookies, Cocoa and Crafts with Santa for Families with Children Ages 0-12 Years Old

December 9 - Holiday Giving and Gifts Party for Self Advocates Ages 13+