

# KEEPING

January- March 2018

# UP



Awareness | Acceptance | Inclusion



## World Down Syndrome Day Celebration

Did you know World Down Syndrome Day is a global awareness day that was established by Down Syndrome International in 2006 and has been formally recognized by the United Nations since 2012? The date (3/21) is significant because of its relationship to Trisomy 21. People and organizations all over the world use this day as an opportunity to participate in fun activities, spread awareness, and celebrate their loved ones with Down syndrome.

**The 2018 World Down Syndrome Day Celebration will be held on Sunday, March 18, 2018 at The Athletic Club of Columbus.** The day will kick off with a special luncheon to honor the recipients of our DSACO Post-Secondary Scholarship (information below). The festivities will continue into the afternoon with games, crafts, bowling and a special magic show in the gym.

Be sure to stick around for the **Proud to Be Me Fashion Show**, a one-of-a-kind fashion show held in collaboration with Ohio State's Students Supporting People with Down Syndrome (SSPDS) group. This show features models of all ages with Down syndrome from across our service area in Central and Southern Ohio. Models are encouraged to apply at [dsaco.net](http://dsaco.net) by January 30th.

*To register for the celebration or for more information about how to be a model in the Fashion Show, please visit [dsaco.net](http://dsaco.net) or call 614.263.6020.*

### Inside this Issue:

- ★ DSACO in the Community
- ★ Scholarship Highlights
- ★ Winter & Spring Programming
- ★ Dancing with Our Stars Gala Information
- ★ Resource & Activity Groups
- ★ Medically Speaking by Dr. Stephanie Santoro

### Stay Connected with DSACO

 DSACO: Down Syndrome Association of Central Ohio

 @DSACO\_Cbus

 @DSACO\_Cbus

Keeping Up is a publication of the Down Syndrome Association of Central Ohio (DSACO).

## Post-Secondary Scholarship Program

With more than \$100,000 awarded since the inception of this program in 2004, the Post-Secondary Scholarship (formerly known as The Family Scholarship) is available to self-advocates or individuals who have a family member with Down syndrome. The applicant must be a high school graduate and reside in one of the 23 counties in DSACO's service area.

All applicants must be accepted into an accredited technical school, university, or college and enrolled in a field of study that will empower them to make a positive impact in the lives of people with Down syndrome.

The 2018 Post-Secondary Scholarship guidelines and application are available on the DSACO website. Completed applications must be submitted to the DSACO Office no later than 5:00 p.m. on Friday, February 16, 2018. (Continued on Page 7)



## 3-2-1 Update

Kari Jones with New Parent Program Coordinator, Carey Eash at DSACO's New Parent Brunch on November 4, 2017.

The results of the Membership Survey are in! We can't thank you enough for your feedback. While we have followed up with some members individually, we are excited to share what we're working on based on what you had to say:

3) One of the key messages we heard was regarding **accessibility** to DSACO's programs and offerings. We will continue to expand our reach of programs to make them more local. We'll also provide **more webinars** and **recorded sessions** for families who live far away or have busy schedules. In addition, we will offer programs with **Spanish** interpreters whenever possible. Look for the following icons in our newsletters, emails, and on our website that indicate how you can access our program offerings!



2) We heard your requests to learn more about **research opportunities** such as online questionnaires and in-person clinical visits. As a result, we've created a new page on our website—[dsaco.net/research-opportunities](http://dsaco.net/research-opportunities) and an email list that will announce new research opportunities as we hear about them.

1) At DSACO we know that it's important to serve your **whole** family. You echoed that sentiment in your survey feedback with requests for programs to manage **caregiver stress** and gain **coping skills**. While we have made efforts in that direction through our newly formed SIBS group, we want to do more for parents, too. With that in mind, we are excited to announce our first **Couples Retreat** this April (*more information on pg. 6*). This retreat will be a way to take care of the most amazing advocate who gives so much: You!

President and CEO

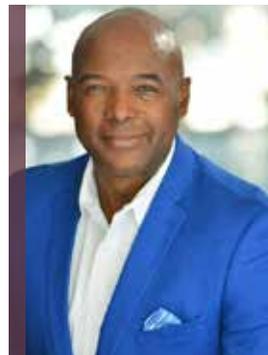
Down Syndrome Association of Central Ohio (DSACO)

## DSACO Welcomes New Board Members: Kevin & Bill



**KEVIN MCCARTY** became involved with DSACO in 2009, shortly after his son, Mack, was born. Kevin is a state certified real estate appraiser and licensed real estate agent. He recently began his own company, KTM Appraisal Services, LLC.

Kevin and his wife, Lisa, live in Grove City with their two young children Anna, age 6, and Mack, age 8. They also have three grown children, Chelsea, Connor, and Tyler. Understanding the great value of DSACO, Kevin hopes to bring a parent perspective to the board and continue to educate, advocate, and bring awareness to the Central Ohio community.



**BILL GREEN** currently serves as head of male mentoring programs at the Academy of Urban Scholars in Columbus, Ohio. He recently left his position as Vice President of Operations for the Columbus Division of the Kroger Company to pursue his desire to be more hands on in serving the community. Prior to his departure, Bill had served the company since 2000 in store,

district and division operational leadership in Columbus, Cincinnati and Atlanta, Georgia. Bill came to Kroger as a corporate attorney in the legal department after practicing law for regional law firms in Louisville and Lexington, Kentucky.

His heart for the community led him to serve as a volunteer for Junior Achievement of America, in Kentucky, Georgia, and Ohio. He has volunteered with the Boy Scouts of America starting BSA Troop 155 and serving as its first scoutmaster from 2009 to 2012.

He has been married to his wife Kristy for 23 years and currently reside in Columbus, Ohio. They have three children, Taylor, currently a senior at Tennessee State University, William IV who also attends Tennessee State, and Ethan who is currently a senior at Stephenson High School in Stone Mountain, Georgia.

# DSACO in the Community



(1) Program Coordinator, Rachel Berens, visited Fairfield County Board of DD on October 23rd for a county outreach visit. (2) Program Coordinator, Kim Baich, and DSACO Board Member, Dr. Stephanie Santoro, put together a Parent Panel at Ohio State on November 14th. (3) DSACO visited Freedom Trails Elementary School on December 6, 2017 to pick up a donation of homemade onesies and bibs for DSACO's New Parent Welcome Packages. (4) Program Director, Marge Barnheiser, visited with Madison County Board of DD for a county outreach visit on November 27th.

## DSACO Calendars For Sale!

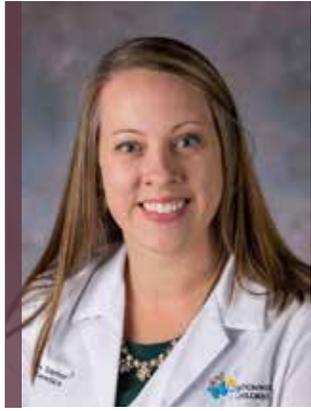
It's not too late to purchase your 2018 Faces in the Community calendar!

Visit [www.dsaco.net/calendar](http://www.dsaco.net/calendar) or the DSACO office to purchase yours. Calendars are \$10/each and can be shipped to you for an additional fee.

Thank you to all the families that submitted photos for the 2018 calendar! We had such an impressive response for photos that not all photos could be selected.



# Medically Speaking: by Dr. Stephanie Santoro



As mentioned in previous newsletters, one aspect of Down syndrome which has been an area of high need is adult health care. Although some papers have suggested various health supervision screens, no evidence-based guidelines have been available. Further, the most recent adult guidelines were published in 1999! The American Academy of Pediatrics created similar health supervision guidelines for children and teens years ago, but this has never been done for adults. To address this need, members of the Down Syndrome Medical Interest Group created a working group and began collaborating to work toward creation of health supervision guidelines for adults with Down syndrome. After years of 10+ physicians working together, we published the first manuscript in November 2017: “Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines.”

The goal of this first manuscript was to evaluate the medical literature to determine if evidence-based guidelines can be created. We identified and reviewed articles in a standardized manner using criteria from the United States Preventive Service Task Force. We performed detailed literature searches on specific conditions including: thyroid disease, cervical spine disease, hearing impairment, overweight-obesity, sleep apnea, congenital heart disease, and osteopenia-osteoporosis. The article has a paragraph summarizing the published literature regarding each of these conditions. Grading the evidence, we found that the number of participating adults and the design of clinical studies varied by condition and were often inadequate for answering all of our key questions. Many of the studies focused on a group of adults with Down syndrome, but most did not control for other variables or even compare to people with Down syndrome without the condition.

**TABLE 4** Articles used for data extraction by condition

	Publications (N) dates	Subjects (N)	Age range	Source of subjects	Methods	Study designs
Thyroid dysfunction	(19) 1977–2015	DS = 1,426; ID CTR = 68; PD CTR = 82; CTR = 103	17–76 yr	Community homes, clinics, residential facility	(Thyroid function tests) TBG, thyroid antibodies	Cohort/case series (14), case-control (5)
Cervical spine disease	(16) 1985–2014	DS = 1,561; CTR = 308	18–70 yr	Community and residential	(ADI, disc/bone height); plain films	Cohort/case series (13), case-control (3)
Hearing impairment	(10) 1981–2011	DS = 1,201; CTR = 1,461	15–80 yr+	Clinic or center based	pure tone audiometry, sound field testing, speech audiometry, ABR, tympanogram, bone/air conduction	Cohort/case series (6), case-control (3), epidemiologic (1)
Overweight-obesity	(5) 1992–2011	DS = 1,495; ID CTR = 6,095	15–76 yr	Family or community homes	(BMI) calculated	Cohort/case series (2), case-control (3)
Congenital heart disease	(4) 1999–2013	DS = 10,334; CTR = 69,705	18–68 yr	Residential facilities, hospitals	Echocardiogram	Cohort/case series (3), case-control (1)
Sleep apnea	(4) 2002–2013	DS = 71; CTR = 48	14–56 yr	Clinic	(AHI) Laboratory based PSG	Cohort/case series (3), case-control (1)
Osteopenia-osteoporosis	(8) 1999–2008	DS = 406; CTR = 186	18–60 yr+	Community and clinics	(BMD or BMM) DEXA	Case-control (6), chart review (2)

ABR, auditory brainstem response; ADI, atlas-dens interval; AHI, apnea-hypopnea index; BMD, bone mineral density; BMI, body mass index; BMM, bone mass measurement; CTR, control (typical); DS, Down syndrome; ID, Intellectual disability; PD, Psychiatric disease; PSG, polysomnography; TBG, thyroxine-binding globulin.

Unfortunately, we found a lack of basic research in adults with Down syndrome needed to guide creation of evidence-based decision-making for these seven topics. Overall, in order to develop an evidence-based clinical guideline, more high-quality, clinical research is needed to expand our knowledge-base.

Article: Capone GT, Chicoine B, Bulova P, et al. Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines. *Am J Med Genet Part A*. 2018;176A:116–133. <https://doi.org/10.1002/ajmg.a.38512>

★ Interested in learning more about **research opportunities** such as online questionnaires and in-person clinical visits? Dr. Stephanie Santoro and many researchers across the country need your help! Please visit a new page on our website—[dsaco.net/research-opportunities](https://dsaco.net/research-opportunities) to see a listing of available research opportunities.

# Available Scholarships for DSACO Families

DSACO is pleased to offer 7 different scholarships in 2018; Recreation, Ann Barbour Music & Performing Arts, Education, Conference, Post-Secondary and two new scholarships; HealthCare Coordination and Research Participation. Most scholarships are limited to \$200.00 per individual with the Conference Scholarship to \$400.00 per family annually. While specific guideline criteria is outlined for each opportunity, all scholarships are open to families in DSACO's 23-county service area.

The **Recreation Scholarship** is most often used by our adults and kids to participate in tennis, gymnastics and soccer. They also enjoy baseball with the Miracle League and basketball at their various community centers. Swimming and horseback riding lessons are two other favorites with our families. Our adults particularly like to use this scholarship for Personal Trainers.

The **Ann Barbour Music & Performing Arts Scholarship** is available for all types of dance, voice and instrumental instruction. Performing arts and theater classes would also qualify.

Education expenses such as private tutoring, auditing college courses, purchase of educational electronic applications, and DSACO's Summer Learning Academy tuition are a few of the possibilities that are covered by the **Education Scholarship**.

The **Post-Secondary Scholarship** is a competitive scholarship available as a college scholarship to self-advocates or individuals with a family member with Down syndrome. The scholarships are awarded at DSACO's World Down Syndrome Day event in March. Applications are available on our website and will be accepted through February 16, 2018.

The newest scholarships available are the HealthCare Coordination and Research Participation Scholarships. **DSACO's HealthCare Coordination Scholarship** program provides financial assistance to individuals with Down syndrome and their immediate family members to participate in a program supported by Quantum Health CarePartner. CarePartner's professionally trained Care Coordinators help navigate the complexities of healthcare, which leads to better health outcomes that reduce costs for families. Examples of areas where they can provide support are claims issues, billing and negotiations, insurance appeals, pharmacy issues, insurance policy comparisons and many others.

The **Research Participation Scholarship** is designed to assist members who wish to participate in local or regional research studies that relate to improving the lives of those with Down syndrome. Registration through DS-Connect® is a requirement for receiving funds for this scholarship. If not yet registered, please go to [dsconnect.nih.gov](http://dsconnect.nih.gov).

In 2017, more than 117 scholarships were awarded to individuals with Down syndrome and their families. We are looking forward to many more participants in 2018! If you are interested, DSACO can provide names of instructors and locations that other members have recommended.

All scholarship guidelines and applications can be found at [dsaco.net/scholarships](http://dsaco.net/scholarships) or email [info@dsaco.net](mailto:info@dsaco.net) for additional information.

"My family is grateful for the scholarship opportunities offered by DSACO. My son Alex loves his dance classes at Diversion Dance Collective. While dance has offered him an outlet for gross motor work and self-expression, and allows him to participate in an inclusive activity, it is an expensive hobby. We have utilized both the Recreation Scholarship and the Ann Barbour Music & Performing Arts Scholarship to help offset the cost of his dance tuition." Jen Franklin Kearns, parent of Alex.

“DSACO scholarships have encouraged us to seek out opportunities for Avery to participate in programs that can help her develop intellectually, physically, and socially. I think that these experiences have been important for Avery's quality of life and development, but I also think that they are meaningful because they often offer inclusive and diverse experiences for others. Chris Knoester, parent of Avery.”



# Programming for Families

## Guardianship and Estate Planning

Saturday, March 3, 2018 | 9:00 - 10:30 a.m.

DSACO Office | 510 E. North Broadway | Columbus, OH

Fee: \$10 | Includes a light breakfast



Attorney and DSACO parent, Derek Graham, Esq., will provide an overview of guardianship and estate planning, with a focus on information important to people with disabilities and their families.

He will cover the following topics:

- When guardianship is necessary
- The various types of guardianship
- Alternatives to guardianship
- Eligibility requirements for public assistance benefits
- Recommended components of a Will
- The various types of disability (special needs) trusts
- How trusts help maintain eligibility benefits

*Registration will open in February. For more information, visit [dsaco.net](http://dsaco.net).*

## Potty Training

Saturday, April 14, 2018 | 9:00 - 11:00 a.m.

DSACO Office | 510 E. North Broadway | Columbus, OH

Fee: \$10 | Includes a light breakfast



Find out if your child is developmentally and physically ready for toilet training and what methods are most successful. Emily Carruthers from The Center for Cognitive and Behavioral Therapy will provide helpful tips and share her proven methodology. Whether you have tried and failed or are planning to begin the toilet training process, this workshop will give you the help you need to make the process successful and less stressful. Learn how to tell if your child is ready, how to train for daytime and night time control, when and what to use as incentives and rewards, and much more.

*Registration will open in February.*

*For more information, please visit [dsaco.net](http://dsaco.net) or call 614.263.6020.*

## DSACO Couples Retreat

Saturday, April 21, 2018

Deer Creek State Park & Conference Center | 22300 State Park Rd #20 | Mt. Sterling, OH 43143

Fee: \$75 per couple

Time to line-up Grandma & Grandpa! We'll have great speakers during the day and drinks, dinner and conversation at night. There will also be free time to enjoy the indoor pool, take a walk or just relax and connect. You deserve this so mark your calendars!

A block of rooms have been reserved for those who want to spend the night. To book, please call Deer Creek Lodge & Conference Center at 740.869.2020. Room rates are \$105. **More details and registration will be available in early February.**

## DSACO Sibs Group

Bi-weekly Mondays | April 2 - May 7

6:00 - 7:30 p.m. | DSACO Office

510 E. North Broadway | Columbus, OH

Fee: \$10

After a successful launch in the fall, we are so excited to bring you a spring session of the DSACO sibs group!

Led by facilitators Malerie Torres, MA, RDT and Michelle (Truby) Long, MOT, OTR/L, this group welcomes sibs ages 6-12 who are interested in meeting, sharing experiences, and having fun! Each meeting features fun activities and a discussion component which center around a selected topic. Topics which may be addressed include self-esteem, coping skills, conflict resolution, and self-advocacy.

One sib who participated in the fall session stated that she "learned what standing up for myself was like." Our goal is to facilitate a welcoming environment where sibs feel comfortable and confident sharing and learning from one another.

*Registration will open in March. To be placed on a waitlist, email Rachel at [rberens@dsaco.net](mailto:rberens@dsaco.net).*



# Programming for Families

## Meet Your Local Fire Fighters!

### Free Family Event

We've had so much fun at our visits at local fire stations that we've decided to keep going! Throughout 2018, we'll continue to schedule visits and meet the brave folks who help us during our biggest time of need. These firefighters and EMTs are excited to meet our families! Bring the family and take a firehouse tour including a close-up look at a fire truck. Learn how to help your family navigate emergency situations and be prepared in the event of a fire. All ages welcome to attend!

- **Sunday, January 28, 2018 | 2:00 - 3:00 p.m.**  
Plain Township Fire Department  
9500 Johnstown Road | New Albany, OH 43054
- **Sunday, February 11, 2018 | 2:00 - 3:00 p.m.**  
Logan Fire Department  
155 E. Main Street | Logan, OH 43138
- **Sunday, March 4, 2018 | 2:00 - 3:00 p.m.**  
Major General Oscar Fire Station #271  
16300 County Home Road | Marysville, OH 43040

*Register at [dsaco.net](http://dsaco.net) or by calling 614.263.6020.*



## The Facts of Life and More

Saturday, March 10, 2018

1:00 - 3:30 p.m. | DSACO Office

510 E. North Broadway | Columbus, OH

Fee: \$10

Did you know that the groundwork for our children's sense of sexuality is laid at a very young age? Do you have questions about puberty and the sexuality and relationship concerns that accompany it? Learn "The Facts of Life and More" with Leslie Walker-Hirsch, internationally recognized speaker, educational consultant, and author of *The Facts of Life and More: Sexuality and Intimacy for People with Developmental Disabilities*. Leslie will answer your questions and talk about the best ways to approach and teach sexuality. Topics covered will include: major influences on sexuality, how age-peer friendships affect social development, understanding of social boundaries, and the Circles curriculum to teach social awareness/safety (now an app!).

This session is open to parents of any age child, teen or adult, older siblings and professionals who work with those with developmental disabilities. Often these trusted individuals receive little or no training regarding sexuality-related issues. Please extend an invitation to providers, educators, social workers, and anyone who works with teens or adults in our community.

*Register at [dsaco.net](http://dsaco.net) or by calling 614.263.6020.*

## Post-Secondary Scholarship Program (continued from Page 1)

The Post-Secondary Scholarship application can be hand-delivered or mailed to:

**DSACO**

**ATTN: Post-Secondary Scholarship Committee**

**510 East North Broadway**

**Columbus, Ohio 43214**

or faxed to **614.263.6094**.

Scholarship recipients will be awarded and recognized at DSACO's World Down Syndrome Day Celebration on March 18, 2018.

**Contact the DSACO office at 614.263.6020 or email [rberens@dsaco.net](mailto:rberens@dsaco.net) for more information.**



**The 2017 Post-Secondary Scholarship Recipients**

Ashley Hughes, Jaela Wollenburg, Taylor Lambert, Quin Winklefoos, and Megan Ryan

# Programming for Individuals with Down Syndrome

## IMPACT Safety Class for Teens and Adults

Saturday, February 10, 2018 | 9:00 - 11:30 a.m.

DSACO Office

510 E. North Broadway | Columbus, OH

Fee: \$10

*Open to persons aged 14+. Space is limited to 14 participants*

IMPACT Safety has a history of successfully teaching personal safety and self-protection skills to people with cognitive, physical, or emotional disabilities.

Through IMPACT workshops, teens and adults are offered a safe and secure environment for “learning by doing” through role-play and positive examples. The workshops are taught by an instructor team that is trained and skilled in working with people of all ages and abilities.

DSACO has offered this workshop in the past and believes it to be an important tool for all of our teens and adults as they navigate the transition of living and working in the community. Feedback from previous participants has been overwhelmingly positive, so we would love to have you join us!

*Register at [dsaco.net](http://dsaco.net) or by calling 614.263.6020.*

## “It’s My Turn” Training

Saturday, January 13, 2018

9:00 a.m. - 3:30 p.m. | DSACO Office

510 E. North Broadway | Columbus, OH

Fee: \$10 | Includes a light breakfast and lunch

Developed by The Ohio Coalition for the Education of Children with Disabilities, the mission of the It’s My Turn training is to help make the transition process from school into life easier for students and to help them become better self-advocates. Using an interactive self-determination curriculum, students learn about themselves by:

- Developing a personal profile which helps them become more aware of their choices and abilities.
- Exploring options best suited to the student based on his/her own personal needs and interests.
- Setting goals and learning the steps he/she must take to reach them.

This workshop is open to middle school and high school students. The focus of the workshop is employability, with students learning more about their choices and increasing their self-esteem by realizing what they are capable of accomplishing. Parents are invited to attend the last 30 minutes of the workshop to celebrate the achievements of the day.

*Register at [dsaco.net](http://dsaco.net) or by calling 614.263.6020. Space is limited, so don’t delay!*

## Show Me the Money Webinar

Monday, January 22, 2018 | 12:00 p.m.



The membership survey results are in and as a response to the feedback, DSACO is hosting a webinar to share information and answer your questions about all of our scholarship programs. We have a quite a few of them and some are fairly new. All are designed to be of benefit to our families so our hope is that you and your family take advantage of them! Please join us!

*Registration is available at [dsaco.net](http://dsaco.net) or by calling 614.263.6020, and is required so we can send the webinar link.*

## Relationships & Dating

Saturday, March 10, 2018

9:00 a.m. - 12:00 p.m. | DSACO Office

510 E. North Broadway | Columbus, OH

Fee: \$10

Join the Living Happy & Healthy group for this session with internationally recognized speaker, educational consultant, and author, Leslie Walker-Hirsch. Learn about safe and healthy relationships, building friendships, relationships at work, dating and more. There will plenty of role playing in this session so be ready to “act” the part while you learn to identify and develop your circle of friends!



*Register at [dsaco.net](http://dsaco.net) or by calling 614.263.6020.*

# Programming for Individuals with Down Syndrome



## Living Happy & Healthy

**Saturdays: February 24, March 3, March 10**

**9:00 a.m. - 1:00 p.m.**

**DSACO Office | 510 E. North Broadway | Columbus, OH**

**Fee: \$50 | Includes lunch | ages 16+**

A healthy lifestyle is more than eating right or getting exercise. It's about knowing who you are and what you need to be your "best" person. DSACO is launching a program this spring that will focus on healthy choices and discovering what each individual needs to live a happy life. It is designed to help people with disabilities develop confidence and skills to stay on a journey towards a healthy and happy lifestyle.

There are many techniques to live a healthy lifestyle. Most importantly, these techniques must be unique to each individual, providing purpose, meaning and happiness in life. This involves learning about the importance of self care, connection to community, building and keeping healthy relationships, and learning how to stay mentally and emotionally healthy. Living Happy & Healthy is a fun and educational way for teens and adults to try new experiences and start on a journey to better overall health. A support system will also be established so that everyone shares the love and experiences the rewards of each person's success.

DSACO is launching this program for teens and adults with three (3) half-day trainings followed by six (6) community outings. These outings will vary in location and will last approximately 2-3 hours. Locations and times are yet to be determined and will be based on the program participants' interests. The program is built to be fun while discovering many different activities, making new friends, and sharing stories of success.

**Register at [dsaco.net](http://dsaco.net) or by calling 614.263.6020. Space is limited, so please register early.**

## P.A.L.S. Expansion

**Tuesdays, March 6 - April 24 | 6:30 - 8:00 p.m.**

**DSACO Office & Cornerstone Deli**

**Fee: \$10 for 6 or 8 week session**

P.A.L.S. is back and better than ever! This spring, we will be launching an 8 week session that will incorporate technology and Next Chapter Book Club. The core sessions will run as they have in the past, with licensed social worker Nichele Lyndes facilitating the sessions and addressing topics such as dating and relationships, self-esteem, and stress management. Some sessions will be held at the DSACO Office, and others will be held at Cornerstone Deli (3296 N. High St., Columbus, OH 43202).

Two fun and interactive "bonus" sessions will be added in April! The first bonus session will feature a special guest from the Nisonger Center and will be dedicated towards technology skills. This session will cover topics ranging from cell phone usage to safe practices when using social media. DSACO will provide tablets to those who need them for this session.

The second bonus session will introduce participants to Next Chapter Book Clubs. Trained facilitators will ensure that each participant, regardless of reading level, feels welcomed and included in the reading process. Jillian Ober, Program Manager of Social Programs at the Nisonger Center, will be on site to answer questions and share information about additional opportunities for participation in book clubs.

This program is available to transition-age individuals with Down syndrome (ages 14-23). Participants can opt to participate in just the typical six week session of P.A.L.S. or the full eight week package!

**Registration will open in February. For more information, visit [dsaco.net](http://dsaco.net).**



# Programming for Individuals with Down Syndrome

## Couch to 5K Running Club Begins Monday, March 19, 2018

Nine weeks can go by quickly - especially when you are training with our friends from 2FGR in preparation for the 2018 Run for Down Syndrome. It may still be cold and even snowing but the training will begin on Monday, March 19th. A lap or two around the lake at Antrim Park with a few die-hard friends will warm your heart! The 5K Running Club is for anyone but we are especially looking for self-advocates and their friends! In years past, this group has formed some very close bonds. Running (or walking) together is a great way to make friends and encourage the development of healthy habits.

The Run for Down Syndrome will take place on Thursday, May 17, 2018. It's hard work but also fun and rewarding!

**Contact Marge Barnheiser at [mbarnheiser@dsaco.net](mailto:mbarnheiser@dsaco.net) for more information.**



## Save the Date for iCan Bike Camps



DSACO is excited to host two iCan Bike Camps this coming summer.

**June 4 - June 8, 2018**

Worthington Kilbourne High School

**June 11 - June 15, 2018**

Grove City High School Rec Center

Participants ages 8+ go from adapted roller bikes to two-wheelers in just 5 days! Last year's camps boasted an impressive 84% success rate.

**Registration for this program will open in March.**

**If you'd like to be placed on a waitlist, please email Rachel Berens at [rberens@dsaco.net](mailto:rberens@dsaco.net).**

## Advocate with us in Washington

The NDSS Buddy Walk® on Washington is a unique advocacy experience being held on Tuesday and Wednesday, April 10 and 11, 2018. The two-day advocacy conference brings the Down syndrome community together to advocate for legislative priorities that impact the lives of people with Down syndrome and their families. No previous advocacy experience is required! Training and talking points are provided as part of the conference. If you have ever wanted to experience advocacy at its best, this is it! Join us!

DSACO supports our families in this effort through our Conference Scholarship program. We are especially interested in supporting any self-advocates who would like to attend.

**Contact Marge Barnheiser at [mbarnheiser@dsaco.net](mailto:mbarnheiser@dsaco.net) or 614.263.6020 for more information.**



# Nuestro Rinconcito



En cada columna de “Nuestro Rinconcito” tratamos de algo que tiene que ver con nuestros hijos que tienen el síndrome de Down. Para esta edición una mamá ha mandado la pregunta siguiente:

¿Hay algún lugar o algún programa de ayuda en casa que puede ayudar a mi hija a aprender a hacer por sí misma cosas como el aseo personal. Mi hija no está haciendo lo que debe a estas alturas y creo que necesito

ayuda. Yo siempre ando corriendo (muy ocupada) y no tengo el tiempo para dedicarle a ella y yo solo puedo guiarla. También, me falta paciencia y muchas veces termino haciendo las cosas por ella. Es muy difícil porque tengo otro hijo pequeño en casa que también necesita de mí.

Yo creo que todos nosotros los padres de hijos con síndrome de Down podemos identificarnos con tu pregunta. Ya que la mayoría de los niños con síndrome de Down aprenden mucho más lentamente que los otros niños entonces precisan mucho más de nuestro tiempo...¡y nuestra paciencia!

Pero, sí, puedes y debes buscar ayuda en la casa ya que beneficiará a tu hija y a ti también. Si no tienes un Waiver, pero tu hija tiene Medicaid, hay varias agencias que pueden mandar terapeutas ocupacionales, fisioterapeutas, terapeutas de lenguaje, y asistentes de salud a tu casa. Los servicios tienen que tomar lugar en tu casa. Si tú (o Uds. que están leyendo esta columna) estás interesada en obtener estos servicios valiosos, debes contactarme y yo puedo mandarte la información sobre estas agencias para que recibas sus servicios. Si tienes Medicaid, estos servicios son gratuitos, pero cada agencia acepta solamente ciertos tipos de Medicaid. Por ejemplo, hay una agencia que acepta solamente Medicaid Aetna, Medicaid Molina, o Medicaid tradicional. Si tu hija no tiene el tipo de Medicaid que acepta tu agencia preferida, si deseas, la agencia puede ayudarte a cambiar al tipo de Medicaid que acepta la agencia.

Estas agencias deciden si tu hijo(a) calificaría para estos servicios viendo cada caso individualmente. No solamente depende del tipo de Medicaid que tiene tu hijo(a), sino también la situación económica de la familia. Si tienes más necesidades económicas,

es más probable que tu hijo(a) recibirá estos servicios. El programa es parte de Healthchek, que es parte de Medicaid. Sirve niños de menos de 21 años.

Adicionalmente, TODOS Uds. que están leyendo esta columna deben apuntarse a la lista de espera para un Waiver. La lista de espera es larga—pueden pasar muchos años hasta que le toque a tu hijo(a). Hay varias categorías de Waiver, y ninguna depende de los ingresos familiares. Solo dependen de cuánto dinero está a nombre de tu hijo(a)—que nunca puede ser mucho (para mantener su elegibilidad para Medicaid).

En la mayoría de los casos, cuando uno tiene un Waiver, es de por vida. Paga por cuidadores que pueden cuidar a tu hijo(a) en casa o pueden llevarle dondequiera...al cine, al parque, al doctor, a la peluquería, etc., etc. También, paga por terapias, equipos especiales que necesite tu hijo(a), programas para después de graduación de la secundaria, transporte, un montón de cosas. También, la persona puede ayudar a, por ejemplo, lavar y planchar la ropa de tu hijo(a). Claro, depende del tipo de Waiver que recibas, pero cualquier tipo Waiver es mejor que ninguno.

Si quieren ponerse en la lista de espera, por favor, escríbanme y les mando la solicitud. La planilla es corta y sencilla. Tengan en cuenta que toda esta información supone que sigan viviendo en Ohio. Si tienen servicios (o un Waiver) aquí en Ohio y se mudan a otro estado normalmente perderás todo y tendrás que empezar de nuevo.

Concluyo diciendo que no debes sentirte culpable por no poder “hacerlo todo” y ser “la madre perfecta”. No es fácil criar a un(a) niño(a) con una discapacidad...y ¡estamos haciendo mucho mejor trabajo de lo que creemos! Y...¡allí afuera sí existe ayuda!

- Arlene Raya

[araya@dsaco.net](mailto:araya@dsaco.net)

Facebook: Mamás Latinas de D.S.A.C.O



The Latino Holiday Party took place on Sunday, December 17, 2017 at the DSACO Office. The party had a piñata, face painting and Santa stopped by for a visit, too!

# Upcoming Fundraising Events

## 2018 Dancing with Our Stars Gala

The Dancing with Our Stars Gala is an inspiring evening devoted to raising funds and awareness for the Down Syndrome Association of Central Ohio.

Experience a gala like no other, featuring choreographed dances performed by 36 adults with Down syndrome. Guests will not only enjoy the performance, but delightful hors d'oeuvres, dinner and dancing. Guests will also have the opportunity to participate in a dance lesson hosted by Arthur Murray Dance Studio before the program.

The funds raised benefit DSACO's Medical Edge - our medical outreach program to help ensure every family receiving a Down syndrome diagnosis receives current and up-to-date information and resources.

The event begins at 6:00 p.m. with cocktail hour, and dinner and the program will begin at 7:00 p.m. Valet parking will be provided for all attendees. The night will also feature a silent auction, photo booth, wine pull and gift card grab. Don't miss out on this fun and memorable night!

## 2018 Guest of Honor



**Dr. Stephanie Santoro**  
*Clinical Geneticist*  
Nationwide Children's Hospital  
*Assistant Professor of Pediatrics*  
The Ohio State University

At this year's Dancing with Our Stars Gala, our Guest of Honor will be Dr. Stephanie Santoro. Each year DSACO honors an individual who is making a huge impact in the Down syndrome and disability community—and we feel that Dr. Santoro is an excellent addition to our roster of Honorees.

In addition to her professional roles, Dr. Santoro works hard to ensure that families are supported and informed throughout their journey after receiving a Down syndrome diagnosis. Through her role as Chair of DSACO's Medical Advisory Committee, she has led efforts to create systematic, intentional changes within Central Ohio's health care systems to create a more positive experience for families. We look forward to celebrating Dr. Santoro, and our other stars at the Gala!



PRESENTED BY: 

**Saturday, February 3, 2018**

**Renaissance Columbus Downtown Hotel**

**50 N. Third Street | Columbus, OH 43215**

### Registration Pricing:

*(All registrations include valet parking and dinner)*

\$75/person or a table of ten until January 5, 2018

\$85/person or a table of ten after January 5, 2018

*To purchase seats, please visit [dsaco.net/gala](http://dsaco.net/gala).*



A block of rooms has been reserved for Dancing with Our Stars Gala guests for \$119 for a King or Queen/Queen room. Please call 877-901-6632 and reference the Down Syndrome Association of Central Ohio Dancing with Our Stars Gala when making your reservation. This room block will be available until January 13, 2018.

# Resource & Activity Groups

---

## M.O.M.S. Resource Groups (Mothers Offering Mothers Support)

*DSACO Moms have the opportunity to share stories, needs, concerns and ideas*

---

### POWELL

Join us the second Tuesday of the month at 7:00 p.m.  
Gallo's | 240 N. Liberty Street, Powell

#### Group Contacts:

Susie Jones      susiejones429@yahoo.com  
Kim Vega        kimvega@gmail.com  
617.512.3392

### WESTERVILLE

Join us the first Thursday of the month at 6:30 p.m.

**January 4** - Max & Erma's | 790 N. State Street, Westerville

**February 1** - Mellow Mushroom | 2170 Polaris Pky, Westerville

**March 1** - Wine Bistro | 925 N. State Street, Westerville

#### Group Contact:

Mandy Peterson      mandy\_6862@yahoo.com  
740.501.8206

### NORTHWEST

Join us the third Tuesday of the month at 6:30 p.m.

Max & Erma's | 4279 Cemetery Road, Hilliard

#### Group Contact:

Liz Loehrer      douearit@gmail.com  
614.208.8426

### CENTRAL

Join us the third Thursday of the month at 6:30 p.m.  
City Tavern | 697 N. 4th Street, Columbus

#### Group Contact:

Angela Buddendeck      cookieparty@yahoo.com  
937.313.1306

### SOUTHEAST

Join us the second Wednesday of the month at 6:30 p.m.

Shades on the Canal | 19 S. High Street, Canal Winchester

#### Group Contact:

Courtney Frost      bcfrost816@yahoo.com  
614.307.0232

### CHILLICOTHE

Due to lack of attendance, we are reevaluating this group.  
If you have any ideas, please contact Rachel Berens at  
rberens@dsaco.net.

## D.A.D.S. Group

*Dads get a chance to get to know each other and learn a bit from one another in a social setting. The mission of D.A.D.S. is to assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome.*

---

### JANUARY 8, 2018 | 6:00 p.m.

Gallo's | 5019 Olentangy River Road, Columbus

#### Group Contact:

Nathan Vega      nathanvega@gmail.com

### FEBRUARY 5, 2018 | 6:00 p.m.

Location to be determined

*To be added to the D.A.D.S. Group email list, please contact Rachel Berens at rberens@dsaco.net or 614.263.6020.*

### MARCH 5, 2018 | 6:00 p.m.

Location to be determined

# Resource & Activity Groups

---

## Little Buddies Parent Resource Group

*Parents of infants and toddlers ages 0-4 with Down syndrome welcome. Refreshments and childcare will be provided.*

---

Join us on the 4th Monday of the month from 6:30 - 8:30 p.m.

**Location unless otherwise indicated:**

Worthington United Methodist Church  
600 High Street, Worthington

**Group Contacts:**

April Horne	aprilhorne624@gmail.com 740.360.7093
Angela Buddendeck	cookieparty@yahoo.com 937.313.1306

**JANUARY 22, 2018**

Social

**FEBRUARY 26, 2018**

CarePartner Program

**MARCH 26, 2018**

Topic to be determined

## Southeast Play Group

*Children ages 8 and under with Down syndrome and siblings are welcome to attend.*

---

Join us on the third Saturday of the month.

**JANUARY 20, 2018 | 11:00 a.m. - TBD**

Winter Carnival, Fairfield County Library Northwest Branch  
2855 Helena Drive, Carroll, OH 43112

Join us for games, fun activities and a prize wheel!

**RSVP to Renee by January 16, 2018.**

**FEBRUARY 17, 2018 | 1:30 - 3:30 p.m.**

AHA Children's Museum  
313 S. Broad Street, Lancaster, OH 43130  
Admission free for DSACO members 8 and under.

**RSVP to Renee by February 13, 2018.**

**NO MEETING IN MARCH**

See you at DSACO's World Down Syndrome Day Celebration on March 18, 2018 at The Athletic Club of Columbus.

**Please register online at [dsaco.net](http://dsaco.net).**

**Group Contact:**

Renee Wolfe	reneewolfe0812@gmail.com 740.412.0765
-------------	--

## Weekend Play Group

*Infants, toddlers & preschoolers with Down syndrome and siblings are welcome to attend.*

---

Join us on the 2nd Saturday of the month from 10:00 a.m.-noon

**Location unless otherwise indicated:**

Advent Lutheran Church  
3660 Kenny Road, Columbus

**Group Contacts:**

Dawn Thornton	dawnrthornton@gmail.com 614.893.1808
Dave & Jen Snyder	dtsnyder@gmail.com 614.893.3941

**JANUARY 13, 2018**

**FEBRUARY 10, 2018 | 10:00 a.m. - 1:00 p.m.**

Easter Seals | 3830 Trueman Ct, Hilliard

**MARCH 10, 2018**

# Resource & Activity Groups

## School-aged Social Group

*Social group for school-aged kids with Down syndrome, ages 5-12 years old.*

**SUNDAY, JANUARY 21, 2018 | 2:00 - 4:00 p.m.**

St. Brigid of Kildare Church - Hendrick's Hall  
7179 Avery Road, Dublin, OH 43017

Join us for an afternoon of fun including games, activities and snacks. Children with Down syndrome and their siblings ages 5-12 are welcome to enjoy this event.

**RSVP to Andrea by January 14, 2018.**

**Group Contact:**

Andrea Bartosch      andreabartosch@live.com  
614.395.1095



## Adult Stamping Club

*This social group works on paper crafting skills to create one-of-a-kind greeting cards to give to family and friends.*

Join us on the first Wednesday of the month from 6 - 8 p.m.

**Location unless otherwise indicated:**

Urban Coffee Meeting Room  
7838 Olentangy River Road, Columbus

**Group Contact:**

Sue Leppert      sdlbuckeye@aol.com  
614.354.0658

*RSVP to Sue Leppert no later than a week prior to each session.*

**JANUARY 10, 2018**

**FEBRUARY 7, 2018**

**MARCH 7, 2018**



**510 E. NORTH BROADWAY, 4TH FLOOR | COLUMBUS, OH 43214 | 614.263.6020 | DSACO.NET**

Kari Jones	President and CEO	kjones@dsaco.net
Marge Barnheiser	Program Director	mbarnheiser@dsaco.net
Evanthia Brillhart	Event Manager	ebrillhart@dsaco.net
Rachel Berens	Program Coordinator	rberens@dsaco.net
Kim Baich	Program Coordinator	kbaich@dsaco.net
Carey Eash	Program Coordinator	ceash@dsaco.net
Arlene Raya	Program Coordinator	areya@dsaco.net
Barbara Leman	Office Manager	bleman@dsaco.net

*KEEPING UP is a publication of the Down Syndrome Association of Central Ohio (DSACO), reporting items of interest relating to Down syndrome. DSACO does not promote or recommend therapy, treatment, institution, or professional system. Any editorials are the opinion of one person and not meant to represent the exclusive opinion of DSACO. DSACO is a 510(c)(3) nonprofit organization. Contributions are fully tax-deductible.*

Return Service Requested



The mission of the Down Syndrome Association of Central Ohio is to support families, promote community involvement and encourage a lifetime of opportunities for people with Down syndrome. Our vision is for people with Down syndrome to achieve their fullest potential in an accepting and inclusive community.

## Upcoming Events

### JANUARY

#### It's My Turn Training

Saturday, January 13 | 9:00 a.m.-3:30 p.m.  
DSACO Office

#### Show Me the Money Webinar

Monday, January 22 | 12:00 p.m.

#### Fire Safety Event - Plain Township

Sunday, January 28 | 2:00 - 3:00 p.m.  
Plain Township Fire Department

### FEBRUARY

#### Dancing with Our Stars Gala

Saturday, February 3 | 6:00 p.m.  
Renaissance Columbus Downtown Hotel

#### IMPACT Safety Class for Teens & Adults

Saturday, February 10 | 9:00 - 11:30 a.m.  
DSACO Office

### FEBRUARY CONTINUED

#### Fire Safety Event - Logan

Sunday, February 11 | 2:00 - 3:00 p.m.  
Logan Fire Department

#### Living Happy & Healthy

Saturday, February 24 | 9:00 a.m.-1:00 p.m.  
DSACO Office

### MARCH

#### Living Happy & Healthy

Saturday, March 3 | 9:00 a.m.-1:00 p.m.  
DSACO Office

#### Guardianship & Estate Planning

Saturday, March 3 | 9:00 - 10:30 a.m.  
DSACO Office

#### Fire Safety Event - Marysville

Sunday, March 4 | 2:00 - 3:00 p.m.  
Major General Oscar Fire Station #271

### MARCH CONTINUED

#### P.A.L.S. Expansion Begins

Tuesday, March 6 | 6:30 -8:00 p.m.  
DSACO Office

#### Living Happy & Healthy

Saturday, March 10 | 9:00 a.m.-1:00 p.m.  
DSACO Office

#### The Facts of Life and More

Saturday, March 10 | 1:00 - 3:30 p.m.  
DSACO Office

#### Post-Secondary Scholarship Luncheon

Sunday, March 18 | 12:00 - 2:00 p.m.  
The Athletic Club of Columbus

#### World Down Syndrome Day Celebration

Sunday, March 18 | 2:00 - 5:00 p.m.  
The Athletic Club of Columbus

#### Couch to 5K Training Begins

Monday, March 19 | 6:00 p.m.  
Antrim Park