



# FAMILY CONNECTION

Winter 2020 Newsletter

## WASHINGTON UNIVERSITY RESEARCH STUDY – LOOKING FOR ADULT PARTICIPANTS

Washington University School of Medicine, along with the University of Pittsburgh Medical Center, the University of Wisconsin–Madison, and the University of Cambridge in England, are conducting a research study called Neurodegeneration in Aging Down Syndrome (NiAD). The study will be conducted over a 4-year period and involves both cognitive testing and scans of the brain via MRI and PET.



There is evidence to suggest that there is a higher risk of developing Alzheimer's disease and dementia among individuals with Down syndrome. Amyloid plaques, a protein that accumulates outside of nerve cells, are found in the brains of people with Alzheimer's disease and are thought to play a significant role in the development of symptoms. The gene that makes the amyloid protein is on the 21st chromosome, and since individuals with Down syndrome have an extra copy of the 21st chromosome, it is thought that there may be an increased risk of developing amyloid plaque deposits. These deposits can begin to develop in the brain many years before any memory loss or changes in functioning occur.

The research study is seeking participants who have Down syndrome and are 25+ years old. If selected, they could be compensated up to \$1,100. For additional information, you can contact the Down Syndrome Association of Greater St. Louis Adult Service Coordinator, Makini Anwisye, or contact Elizabeth Westerhaus MA in the Department of Neurology at Washington University directly.

Makini@dsagsl.org or 314.961.2504 | elizabethwesterhaus@wustl.edu or 314.747.1125

If you'd like to learn more, please join us on March 31 at the DSAGSL Office from 6:00-7:30pm. Guest speakers Elizabeth Westerhaus MA, and Dr. Ances from the Department of Neurology at Washington University will be sharing information about the research being conducted regarding the connection between Down syndrome and Alzheimer's disease. RSVP to Makini@dsagsl.org.

# A MESSAGE FROM ERIN

Hello friends!

I am buzzing with excitement! 2020 at the DSAGSL is promising to be one of our most exciting yet and I can't wait to share what we have in store. The DSAGSL is hard at work on our three year strategic plan which will guide the organization's direction and activities through the end of 2023. With the guidance of an amazing consultant, we are asking ourselves big questions about who we are, who we serve, and how we serve our community best. I hope you will join us at our Annual Celebration where we will give you a sneak peek at our goals and hopefully inspire you to get involved! The Annual Celebration will be held on Thursday, March 12th at 5pm at the Hilton in Frontenac. All are welcome!

In addition, we are expanding our employment programming and social enterprise to help more individuals with Down syndrome achieve their goals, increasing our stellar family support services to adults and aging families, starting our new African American meet ups and growing our Latinx network, partnering with our community groups to hold World Down Syndrome Day activities across the region, and are in full planning mode for our diamond anniversary golf tournament and one-of-a-kind Step Up for Down Syndrome / Run for 21 event.

There is much more to be excited about inside the pages of this newsletter. We hope you save the date for all of these events and start your Step Up Team today (did you know you can earn free tickets to a Cards v Cubs game through your fundraising?!). We look forward to seeing you. As always, I am always just an email or phone call away. I love hearing from community members about ideas, needs, questions, and even concerns. We are here to serve you! Thank you for all you do to keep the DSAGSL growing so we serve you better!

Sincerely,



Erin Suelmann  
Executive Director



**THE MISSION** of the Down Syndrome Association of Greater St. Louis is to benefit the lives of people with Down syndrome and their families through individual and family support, education, public awareness, and advocacy.

#### CONTACT US

8531 Page Ave, Suite 120. St. Louis, MO 63114  
314-961-2504 - [info@dsagsl.org](mailto:info@dsagsl.org)

## BOARD

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# CONGRATULATIONS TO OUR GRADUATING INTERNS!

It was bitter-sweet celebrating the 10 Self-Advocates that graduated from the DSAGSL internship program in 2019! We will miss having them in the office on a weekly basis, but are so excited for the opportunities ahead of them!

One of our graduates, Scott, now works part time at his dream job in a music store. One graduate, Paula, now works at US Bank, and another graduate, Jennifer, works at an elementary school in the cafeteria. Lindsey also graduated from the internship program, and now she works a paid position in the DSAGSL office. All of the graduates have also joined the DSAGSL Helping Hands program and continue to support the organization as advocates and volunteers.

After completing the internship program at DSAGSL, these graduates are able to add several skills to their resumes, such as sorting items, working on mailings, customer service, and appropriate workplace behavior.

Each intern has their unique personality, interests, and set of talents, but all of them have so much to offer the workplace and would make a great addition to any team! We are so proud of all of their accomplishments and continue to be here as a support in their job-searching efforts.

Are you interested in hiring someone with Down syndrome? Contact Employment Coordinator Andi McCormick at 314.961.2504 or [Andi@dsagsl.org](mailto:Andi@dsagsl.org) for more information.

Are you interested in an internship with DSAGSL? Are you a Self-Advocate that wants to volunteer with DSAGSL as part of our Helping Hands program? Contact Adult Services Coordinator Makini Anwisyie at 314.961.2504 or [Makini@dsagsl.org](mailto:Makini@dsagsl.org).

# RESOURCE CORNER

## I/DD HELP LINE

Although case management has ended in the state of Missouri for individuals with Intellectual/ Developmental Disabilities (I/DD) who are not covered by Medicaid, an alternative service does exist to ensure information about resources and programs is still accessible to everyone.

IDDHHelp can be used to obtain information and resources that assist individuals with I/DD and their families. The service areas covered are St. Charles County, St. Louis City, and St. Louis County.

**IDD HELP LINE - 1.877.256.2202**

## FREE DENTAL CARE

Individuals with Down syndrome of any age in which dental care presents a financial hardship to the family are eligible for free dental care on the first Thursday of the month at Sunset Hills Dental Group with Dr. Julia Hotz-Sudekum.

Dr. Sudekum is the parent of a 10-year-old boy with Down syndrome and has many years of experience working with patients with different abilities. She has enjoyed working as a dentist with Sunset Hills Dental Group since 2001.

## VIDEO WORKSHOP SERIES ON DSAGSL.ORG

DSAGSL will be creating workshop videos once each month on various topics such as health and wellness, education, and medical research. Some will feature guest speakers who are experts in their field. Videos will be posted on the 21st of each month on our YouTube channel and our Facebook page, and will be archived on our website so they can be watched at the viewers' convenience!

**DSAGSL.ORG/RESOURCES/VIDEO-SERIES - 314.961.2504**

## CARRIED WITH LOVE

Carried with Love is a small non-profit organization serving the Metro St. Louis area. They provide baby and toddler carriers for children with special needs. In order to be eligible, children must be living in the St. Louis metro area (Missouri side ONLY), and participating in services through First Steps or Early Childhood Special Education. Applications are now being accepted online and are reviewed on an on going basis.

**CARRIEDWITHLOVE.ORG | FACEBOOK.COM/CARRIEDWITHLOVESTL**

## THE ARYA FOUNDATION

The Arya Foundation provides need-based adaptive equipment for children with special needs in St. Louis. Children are eligible for equipment based on specific criteria and requests can only be funded up to \$1,000. Please contact DSAGSL with questions or if you need a referral.

**THEARYAFUNDATION.ORG**

# ADULT SERVICES TOOLKIT- RESOURCES FOR ADULTS WITH DOWN SYNDROME

DSAGSL was grateful to receive a grant from the St. Charles Developmental Disabilities Resource Board (DDRDB) to conduct an assessment of our community's needs related to aging and Down syndrome.

The goal of the assessment was to identify the needs of aging adults with Down syndrome in our service area through distribution of a survey to their caregivers, and subsequently use the results from this survey to inform future DSAGSL adult programming.

In addition to the needs assessment, the St. Charles DDRDB grant partially funded the development of the DSAGSL Adult Services Toolkit. This living document is an online resource guide for caregivers of adult and aging individuals with Down syndrome.

We find this toolkit to be helpful in that it is ever-evolving, just like the available resources are. Our hope is that caregivers can refer back to it as needed to find current resources related to aging and Down syndrome.

Visit [www.dsagsl.org/resources/for-families](http://www.dsagsl.org/resources/for-families) to access the toolkit.

## CENSUS 2020- MAKE SURE YOU'RE COUNTED

The census is right around the corner and only happens every 10 years. Every home will receive an invitation to participate on April 1, 2020, and it's important your family is counted. The census data impacts a lot of funding decisions, such as how much state and local governments receive for Medicaid, housing vouchers, Supplemental Nutrition Assistance Program (SNAP), and education programs. These programs impact people with disabilities and their families. Make sure your family is counted in the census so that your family is counted when making those funding decisions.

Census data impacts funding for crucial programs like Medicaid, but it also determines the number of representatives each state gets in the House of Representatives. By March 31, 2021, the Census Bureau will have collected and compiled all of the data that was reported and send states redistricting counts. This is used to redraw federal and state legislative districts based on population changes.

It's incredibly important that people with disabilities and their families are counted in the Census 2020. Once the invitation arrives, you can respond with information for your home online, by phone, or by mail. Look for your invitation and don't miss the deadline! Everyone matters. Everyone should be counted. Everyone deserves a voice.

*This information was gathered from the National Down Syndrome Congress and The Arc websites.  
[www.thearc.org](http://www.thearc.org) and [www.ndsccenter.org](http://www.ndsccenter.org)*

# SAVE THE DATE

## DINE & DONATE AT PASTA HOUSE

10% of sales are donated - must present flyer  
Tuesday, February 25 | All Day  
Several Pasta House Locations  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## TECHNOLOGY WORKSHOP

Friday, February 28 | 6:30pm-8:30pm  
DSAGSL Office  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## ANNUAL CELEBRATION

Thursday, March 12 | 5:00pm-7:00pm  
Hilton St. Louis Frontenac  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## WORLD DOWN SYNDROME DAY CELEBRATION

Saturday, March 21  
Various activities, locations, & times  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## ROCK 21 CONCERT

Saturday, March 28 | 12:00pm-3:00pm  
Tin Roof St. Louis  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## FIT STEPS EXERCISE GROUP

1st & 3rd Saturdays of the month | 9:00am-10:00am  
Anytime Fitness in Ballwin  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## FAMILY & COMMUNITY WORKSHOP

Research on Down syndrome & Alzheimer's disease  
Tuesday, March 31 | 6:00pm-7:30pm  
DSAGSL Office  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## CAREGIVER RESOURCE NETWORK

Monthly Meetings are the last Tuesday of each month  
6:00pm-7:30pm | DSAGSL Office  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## FAMILY PICNIC AND PHOTOGRAPHY EVENT

Sunday, April 24 | 11:00am-2:00pm  
Faust Park  
[dsagsl.org/calendar](https://dsagsl.org/calendar)

## BIRDIES & BASS GOLF TOURNAMENT

Monday, May 4 | starting at 8:00am  
Persimmon Woods Golf Club  
[dsagsl.org/events/golf](https://dsagsl.org/events/golf)

## STEP UP FOR DOWN SYNDROME & RUN FOR 21

Sunday, June 7 | 8:00am-12:30pm  
Forest Park  
[dsagsl.org/events/step-up](https://dsagsl.org/events/step-up)

## FESTABILITY

Saturday, July 25 | 11:00am-6:00pm  
Missouri History Museum  
[dsagsl.org/events/step-up](https://dsagsl.org/events/step-up)



# ANNUAL CELEBRATION

**THURSDAY, MARCH 12, 2020 | 5:00-7:00 | HILTON ST. LOUIS FRONTENAC | 1335 S LINDBERGH BLVD**

We hope you will join us for a special happy hour celebration as we recognize & honor our donors, volunteers, and all those who have contributed to the growth and success of DSAGSL over the last year. We will also be introducing and voting in new board members, as well as sharing some exciting plans for 2020 and beyond! We are very excited to share with you some of the strategic planning process, and we will be looking for feedback about the work that's been done so far.

Join us for drinks, appetizers, and some special announcements. RSVP to [rsvp@dsagsl.org](mailto:rsvp@dsagsl.org).

Childcare not provided, however children are welcome.

# WORLD DOWN SYNDROME DAY

**SATURDAY, MARCH 21, 2020**

There are so many ways to celebrate on World Down Syndrome Day!

**10:00-4:00** | Visit the Diamond Family, where guest jewelers from the DSAGSL community will be helping in the store, and 10% of purchases will be donated back to DSAGSL!

**1:00-3:00** | The Young Friends Board is throwing a World Down Syndrome Day celebration! Details have yet to be confirmed, but stay tuned for more information on this exciting event!

**10:00-12:00** | The Heartland DSA Community Group is having a celebration and recognition brunch at the Osage Centre in Cape Girardeau! RSVP to [heartland\\_cg@dsagsl.org](mailto:heartland_cg@dsagsl.org).

**2:00-4:00** | The Southern Illinois Community Group is having a celebration at Nu Bowl Lanes in Mt. Vernon! Wear your blue and yellow and don't forget your crazy socks!

Join us for any of these awesome events! You can also start your own awareness event, fundraiser, or celebration! Need ideas? Check out our webpage [dsagsl.org/programs/advocacy-awareness](http://dsagsl.org/programs/advocacy-awareness) or contact Community Engagement Coordinator Abigail Beckord at [abigail@dsagsl.org](mailto:abigail@dsagsl.org)

# THANK YOU 2019 STEP UP TEAMS

21 Cubed  
ADAPT Steps Up  
Abeo's Equestrians  
Abigail's Angels  
Abigail's Sassy Squad  
Adam Kloppenburg's Krew  
Alexander's Allstars  
Alyson's All Stars  
Amazing Amelia  
Andrew's A-Team  
Andrew's Buddies  
Andrew's buds for SUDS  
Arc Advocates  
Armando's Army  
Asher  
Aspen's Tribe  
Aspen's Tribe  
Ava's Buddies  
Avery's Army  
Bailee's brigade  
Bayer  
Be Abe's Superhero  
Big Walt's Warriors  
Big Walt's Warriors  
Blake's Bunch  
Bradens buddies  
Bret's Best Buddies  
Brian's Buddies  
Brinick's Buddies  
Bruno Loves Julie  
Can You Dig It!  
Carly's Crusaders  
Carly's Crusaders  
"Chase"ing a Miracle  
Chloe's Crew  
Cole's Crew  
Conover's Crew  
Cooper's Crew  
Cupcake's Crew  
Dakotas Dream Team  
Dancing Stars Queen  
Delaney's Dream Team  
Delta Gamma-SLU  
Dominic's Downright Perfect  
Drew's Crew  
Drew's Pack  
Edgewell Personal Care  
Eli's Buddies  
Elijah's Warriors  
Ella's Love  
Ellie Marie's Entourage  
Ellie's Entourage  
Emma's Empire  
Emma's Entourage  
Evangeline League

Evelyn's Entourage  
Evie's Entourage  
Extra Special x2- Nobles Family  
Extraordinary Evelyn & Company  
Ezra's Elites  
Gettin' DOWN With Harrison  
Go Diego Go  
Go Go Chloe  
Harper's Homies  
Hawthorn Elementary  
Henry's Heroes  
I LOVE LUCY  
In Their Shoes  
Isaac's Idols  
J.W. Terrill Steps Up  
Jacob's Journey  
Jamieron's Journey  
Jaycee's Joyful Crew  
Jaylen's Crew  
Jessica Jansen's Best Buddies  
John-John's Joy  
Jordan's crew  
Joseph & Friends  
Joseph's Joyful Supporters  
Joshua's Journey  
Journey's Journey  
Kasey Tatorpop  
Kayleigh's Krew  
Kyle's Crew  
Kyle's Kin  
Landon's Buddies  
Liam's Lookouts  
Liam's Lopers  
Liam's Lucky Charms  
Livi Lovers  
Lucy's Squad  
Luke's Crew  
Maddie Lou's Pit Crew  
Maddie Mouse  
Malcolm's Journey  
Mallory Grace's Gang  
Mary Cate's Marchers  
Mason's Minions  
Matty G's gang  
Maya Mia  
Maya's Mob  
McKayla's Buddies  
Mighty Little Warrior  
Nathan's Band  
Nolyn Nation  
Pfizer DisAbilities Team  
Princess Olivia's Court  
Queen Elizabeth  
ROSS IS BOSS  
Raylan's Renegades

Remington's Rebels  
Riley's Rockstars  
Robyn's Rowdys  
Roman's Soldiers  
Sassmasters  
Selah's Super Squad  
Selah's Super Squad  
Shane's Monkey Men  
Shea's Superhero Squad  
Show Mo Love  
Sloane's Squad  
Sophia's Grace  
Speed Os  
St. Louis Children's Hospital-  
Genetics  
St. Louis Life  
Step Up & Boogie Down  
Step Up for Joy  
Stevie's Superheroes  
Sweet Smile Sean  
TEAM JIMMY  
TJ's Troops  
Team Aiden  
Team DSA  
Team EXTRAordinary  
Team Easton  
Team Henry  
Team Hollywood  
Team Jackson  
Team Kayla  
Team Levi  
Team Lexi  
Team Louie  
Team Mac  
Team Mueller Prost  
Team Ordia  
Team Pierce  
Team Vinnie  
Team Wells Fargo Advisors  
The Bea Team  
The Crazy Lions  
The Cricket Crew  
The InVINCEibles  
Tommy's Troops  
TreNiyah's Troopers  
Tristan's Trilogy  
Tristans trotters  
Tucker's Truckers  
Westhoff Lions  
Working Wonders 4 Downs  
Wyatt's Warriors  
Young Friends of the DSA  
Z-breezy  
Zowie's Zoo  
Zoë's Outstanding Entourage



# RUN FOR 21

**SUNDAY, JUNE 7TH | 8:00AM | FOREST PARK**

The Run for 21 (formerly Relay and Run for 21) celebrates the amazing lives of people with Down syndrome. The race was moved to June to coincide with our largest celebration of the year – Step Up for Down Syndrome.

This 5k (plus a little extra!) is a 3.21 mile certified race through beautiful Forest Park. Race amenities include a race shirt, finisher medal, and one entry into the Step Up celebration. We encourage runners to start a Step Up for Down Syndrome Team and raise additional funds beyond their race registration to earn more Step Up t-shirts for family and friends.

**Learn more at [dsagsl.org/events/run-for-21](https://dsagsl.org/events/run-for-21).**



# STEP UP FOR DOWN SYNDROME

**SUNDAY, JUNE 7TH | 8:30AM – 12:30PM | 9:30 AWARENESS WALK | FOREST PARK**

Step Up for Down Syndrome is our largest celebration and fundraising event of the year! Donations from this event allow us to provide vital and life-changing programming to over 1,800 individuals with Down syndrome and their families!

Participants of Step Up for Down Syndrome start a team and raise money to earn amazing prizes, like Walk in the Park Cardinals Tickets! Then, everyone gathers together on the first Sunday in June at Forest Park for a huge celebration and awareness walk.

Music, games, food, bounce houses, face painting, rock-climbing wall, crafts, and a petting zoo are just some of the fun that awaits you and your family!

**Learn more and sign up your team today by visiting [dsagsl.org/events/step-up](https://dsagsl.org/events/step-up).**



# GET INVOLVED WITH DSAGSL

## FOLLOW US ON SOCIAL MEDIA

### FACEBOOK.COM/DSAGSL

Did you know that the Down Syndrome Association of Greater St. Louis is active on Facebook and other social media platforms? Find out about events, programs, research, advocacy, and so much more through our Facebook page. We also have different groups who have common interests.

**The Sharing Our Strategies** group is for parents and caregivers to share information, ask each other questions, and connect.

[www.facebook.com/groups/DSAGSLSharingOurStrategies](http://www.facebook.com/groups/DSAGSLSharingOurStrategies)

**The Ready 2 Work** group is for self-advocates that are looking for opportunities for employment training and who are actively looking for a job.

[www.facebook.com/groups/DSAGSLReady2Work](http://www.facebook.com/groups/DSAGSLReady2Work)

**The Down Syndrome Education Specialist** group is for education professionals who want to stay connected with each other and learn strategies for building meaningful educational experiences for students with Down syndrome.

[www.facebook.com/groups/1646889945457015](http://www.facebook.com/groups/1646889945457015)

Let's connect! Visit us on Facebook, Twitter, Instagram, and YouTube today!!

**YOU CAN FIND US ON INSTAGRAM & TWITTER AT @DSAGSL**

## AMAZON SMILES

### SMILE.AMAZON.COM

Do you shop on Amazon.com? Did you know you can select DSAGSL as your charity of choice and for every purchase you make, a donation is made to the organization? It's true! DSAGSL received over \$250 last year!! Just make sure to shop through **smile.amazon.com** to ensure your donation makes it to the Down Syndrome Association of Greater St. Louis.

## VOLUNTEER OPPORTUNITIES

### NEW FAMILY BRUNCH

Saturday, April 4, 2020 from 9:00am-12:00pm  
Jewish Community Center

### BRIDIES AND BASS GOLF TOURNAMENT

Monday, May 4, 2020 from 8:00am-11:00am  
Persimmon Woods Golf Club

### STEP UP FOR DOWN SYNDROME

Sunday, June 7, 2020 from 7:00am-1:00pm  
Forest Park

### INTERESTED IN VOLUNTEERING?

Visit our website to fill out the registration form, or contact Volunteer Manager Abigail Beckord at [abigail@dsagsl.org](mailto:abigail@dsagsl.org) or 314.961.2504.

## DSAGSL VEHICLE DONATION PROGRAM

### WWW.DSAGSL.ORG/VEHICLE-DONATION

Want to get rid of an old vehicle but don't want to deal with selling it... fixing it... or junking it? Donate it to DSAGSL! The donation process is safe and simple, and will benefit the lives of 1,800+ individuals with Down syndrome! Find out more about donating your unwanted car, boat, motorcycle or RV... whether it runs, or not! Visit [www.dsagsl.org/vehicle-donation](http://www.dsagsl.org/vehicle-donation)

## SIGN UP TO RECEIVE OUR EMAILS

### DSAGSL.ORG/SIGN-UP

All you have to do is visit our website and fill out the registration form!

## OTHER WAYS TO GET INVOLVED

### DSAGSL.ORG/GET-INVOLVED

Make a donation, set up a third party fundraiser, or collect items for DSAGSL through a donation drive! Questions? Email [abigail@dsagsl.org](mailto:abigail@dsagsl.org)

# COMMUNITY GROUPS

DSAGSL Community Groups provide information, resources and/or emotional support for parents and friends of individuals with Down syndrome. Each group has its own personality and may be based on location, culture, native language and/or the age group(s) they serve. Each community group is open to all interested DSAGSL members. Contact the groups below for more information about their respective events, or contact Abigail Beckord, Community Engagement Manager at the DSAGSL, if you have any questions or would like information about starting a group!

## MISSOURI

### **DADS APPRECIATING DOWN SYNDROME (DADS)**

Serving Greater St. Louis

Contact: Tony Sorocko | (314)393-8548

dadsstl@outlook.com | www.dadsstl.org

Facebook: www.facebook.com/groups/270173929671043

### **DOWN SYNDROME AND AUTISM (DS/ASD) COMMUNITY GROUP**

Serving Greater St. Louis

Contact: Christy Klaus | (314)961-2504 ext 2

christy@dsagsl.org | www.dsagsl.org

### **DOWN SYNDROME COMMUNITY GROUP OF UPSTATE MISSOURI**

Serving Kirksville, Brookfield and surrounding areas

Contact: Becky Pike | (660)651-5139

kirksville\_cg@dsagsl.org | www.facebook.com/dscnemo

### **HEARTLAND COMMUNITY GROUP**

Serving Southeast Missouri and Southern Illinois

Meetings are 2nd Sat. of each month 10am-12pm at the Cape

Girardeau Public Library, Penzel Conf. Rm

Contact: Claire Watson | (573)334-5685

heartland\_cg@dsagsl.org | www.facebook.com/HeartlandDSA

### **NORTH COUNTY/NORTH CITY COMMUNITY GROUP**

Serving North St. Louis County and St. Louis City

Contact: Sergei Marchenko | (773)817-7054 | north\_cg@dsagsl.org

### **ST. CHARLES COUNTY COMMUNITY GROUP**

Serving St. Charles, West County, & surrounding areas

*This community group is looking for new leadership*

Contact Abigail at DSAGSL more information | abigail@dsagsl.org

Facebook: www.facebook.com/stcdsgrp

### **SOUTH COUNTY MOMS GROUP**

Serving Kirkwood/Webster/South County and surrounding areas

Contact: Stephanie Holmes | (314)495-8388

Contact 2: Cheri Nienhaus | (618)570-8485

kirkwood\_cg@dsagsl.com

www.facebook.com/groups/kirkwoodwebsterdsmoms

## ILLINOIS

### **METRO EAST DOWN SYNDROME ALLIANCE**

Serving Belleville, O'Fallon, Shiloh and surrounding areas

Contact: Bob Lutz | (314)458-6918

Contact 2: Amanda Lutz | (618)789-3664

medsa\_cg@dsagsl.org | www.facebook.com/MetroEastDSA

### **SOUTHERN ILLINOIS COMMUNITY GROUP**

Serving Carbondale, Creal Springs, and surrounding areas

Contact: Samantha Dudley | Soil\_cg@dsagsl.org

www.facebook.com/SIDownSyndromeSupportGroup

## OTHER DOWN SYNDROME ASSOCIATIONS AND GROUPS

### **DOWN SYNDROME GUILD OF CENTRAL MISSOURI**

Serving Columbia, Jefferson City, Central Missouri and surrounding areas

Contact: Jessica Fahey | Program Coordinator | 913-384-4848

www.kcdsg.org/dsg-central-missouri.php

### **RIVERBEND DOWN SYNDROME ASSOCIATION**

Serving Southwest Illinois

Contact: secretary@riverbendds.org

www.riverbendds.org

### **DOWN COUNTRY**

Serving Hannibal, Quincy and surrounding areas

Contact: info@upatdowncountry.com | 217-617-3568

www.upatdowncountry.com | www.facebook.com/UpatDownCountry

### **DOWN SYNDROME GROUP OF THE OZARKS**

Serving Springfield, MO and surrounding areas

Contact: (417)885-9905 or (888)655-5173

info@ozarksdsg.org | www.ozarksdsg.org

### **LINCOLN LAND DOWN SYNDROME SOCIETY**

Serving Springfield, IL and surrounding areas

Contact: (217)415-8716 | lldss@comcast.net

www.lldss.org | www.facebook.com/

LincolnLandDownSyndromeSociety

### **CENTRAL ILLINOIS DOWN SYNDROME ORGANIZATION**

Serving McLean county, Bloomington/Normal and surrounding towns

Contact: (309)452-3264 | info@cidso.org | www.cidso.org

### **DOWN SYNDROME SUPPORT GROUP | BLESSING HOSPITAL**

11th Street Auditorium at Blessing Hospital | Quincy, IL 62305

Meetings: Every last Monday of the month at 6:30pm

Contact: 217-223-8400 ext 4190

### **HEART OF ILLINOIS DOWN SYNDROME ASSOCIATION**

325 E. Queenwood Rd. | Morton, IL 61550

Contact: (309)712-4852 | info@hoidsa.org

www.hoidsa.org | www.facebook.com/HOIDS

### **NEW COMMUNITY GROUP**

Community groups are sometimes based on geographic location and sometimes based on other commonalities, such as an additional diagnosis, similar age group, or cultural background. Each community group has a unique identity and is open to all DSAGSL members who are interested.

We have heard from members that there are families interested in creating an African American community group. Please contact Makini Anwise if you are interested in a leadership role, attending an event, or learning more. Makini@dsagsl.org or 314.961.2504 x7

# DSAGSL | IN ACTION



## *21 Suns All Abilities Yoga*

The 3rd Annual 21 Suns All Abilities Yoga event hosted 114 yogis in the beautiful World's Fair Pavilion in Forest Park and raised nearly \$8,000!

## *Parent and Family Workshop*

75 parents and caregivers attended the two-part Parent and Family Workshop in the fall of 2019. The first session was all about toilet training and the second session was about strategies for challenging behaviors.

## *Celebration Baskets*

21 new families were welcomed to the DSAGSL community in the fall, bringing the total for the year to 55. Each family receives a packet of information and resources, along with a celebration basket with gifts for their new family member!



## *Pop Up Snack Shop*

Our little shop isn't so little anymore! The Snack Shop employs 13 self-advocates learning on-the-job skills, and the shop "popped up" 15 times in the fall for a total of 22 pop-ups for the year!



## *21 Club Bowling Tournament*

72 bowlers competed in the first ever 21 Club Bowling Tournament! Trophies were awarded for 1st, 2nd, and 3rd place teams and individuals! Together, we raised \$2,800 and had a whole lot of cosmic-bowling fun!

## *Rock 21 Music Program*

27 rockers participated in the Rock 21 fall session and learned how to be part of a rock band. They took to the stage in November to perform at the Tin Roof in downtown St. Louis!

## *Holiday Party*

400 DSAGSL community members gathered to celebrate the holidays in December, and 30 awesome volunteers helped make the day a success! Attendees enjoyed cookies, music, dancing, crafts, Santa photos and lots of cheer!



# 2019 WALK IN THE PARK

We were stunned when the 2019 Walk in the Park event SOLD OUT! 2,300 community members gathered at Busch Stadium to walk the warning track before the game, and raise awareness for Down syndrome! A sea of green DSA shirts and foam fingers in the stands got plenty of air time on the jumbo screen, and 20 self-advocates took to the field during the opening ceremonies! The very best part of the whole day? A Cardinals WIN!

Your chance to earn Walk in the Park tickets to the 2020 events start now! The more money you raise for Step Up for Down Syndrome, the more ticket packages you earn for Walk in the Park! Visit [dsagsl.org/events/step-up](https://dsagsl.org/events/step-up) for more information!



# 2019 ANNUAL TRIVIA NIGHT

DSAGSL celebrated a decade of Trivia at our 10th Annual Trivia Night in November. Nearly 600 people participated, and 75 volunteers helped make the night spectacular. Together, we raised over \$55,000!!

Prizes were awarded to trivia players for best decade costume, local restaurants donated food for our VIP tables, and everyone enjoyed craft beer donated by Civil Life Brewing Company. A million thanks to all the players, sponsors, volunteers, and donors who made this night so incredible!!





# THANK YOU FOR YOUR SUPPORT!

## THIRD PARTY FUNDRAISERS

**BRENDA AND RANDY JOHNSON** - Scopus Sedge Fest Fundraiser benefiting Heartland Community Group

**DADS ST. LOUIS GROUP** - Puttin' for Down Syndrome Golf Tournament

**ST. MARY'S KNIGHTS OF COLUMBUS COUNCIL #3790-** Annual BBQ Fundraiser

**IREM ST. LOUIS** - 2019 Charity Donation

**KNIGHTS OF COLUMBUS, DE ANDREIS COUNCIL #800** - General Donation

**TAPPED ST. LOUIS** - Dine to Donate Event

**RBO PRINT LOGISTIX** - Down Syndrome Awareness Month "Genes Day" Fundraiser

**ARCHWAY OLDS CLUB, ST. LOUIS** - Club Fundraiser

**THE PAT CONNOLLY TAVERN** - Dine to Donate Music Night

**ZEE BEE MARKET** - Down Syndrome Awareness Month Give Back Fundraiser

**BELEZA SALON** - Down Syndrome Awareness Month Give Back Fundraiser

**KRISTI DENNER & MOD PIZZA** - Down Syndrome Awareness Month Give Back Fundraiser

**BUDDY BRIGADE** - Xander Davidson Lemonade Stand Fundraiser

**REINBERG FAMILY** - Albert & Hope Reinberg Lemonade Stand Fundraiser

**DIEHL FAMILY** - Ajla and Belma Diehl Book Fundraiser

**KIDS WHO KARE CAMP** - Camp Fundraiser

**SIGNATURE CONSULTANTS** - Annual Gift Card Fundraiser

**O SEW PERSONAL** - Quilting Donation for Celebration Baskets

**MCAULIFFE CHIROPRACTIC** - Pop Up Snack Shop Snack Drive

## GRANTS

**STATE FARM NEIGHBORHOOD ASSIST** - Pop Up Snack Shop

**ST. JOSEPH CATHOLIC CHURCH OF COTTLEVILLE** - New Family Support

**TRIO FOUNDATION** - Aging Support

**WAYNE C. KAUFMANN** - Employment Initiative & Capacity Building

# MEMORIAL TRIBUTES

**A LIFE THAT TOUCHES OTHERS GOES ON FOREVER -  
ALWAYS ON MY MIND AND FOREVER IN MY HEART**

**ELIZABETH "ELLE" DAVIS**

**DENNIS W. DIAZ**

**VIRGINIA EMMETT**

**VIRGINIA GIST**

**VIRGIL L. GOETTING**

**KATHLEEN A. KIRKSEY**

**SCOTT KUMMER**

**RAMONA LANDESS**

**EDWARD EUGENE MASCHEK**

**GREG OTT**

**HAZEL PARSONS**

**BETTY JANE SCHULTE**

**CLYDE RAY SHEPARD**

**KELLY HOGAN WEHRLE**

**TIMOTHY FRANK MCKINLEY**

## OTHER WAYS TO GIVE

### CALAMIA GIVING CIRCLE

Join the Calamia Giving Circle by making a gift of \$1,000 or more to the Down Syndrome Association of Greater St. Louis. In honor of your gift, a plaque will be hung on our Giving Circle Wall. It's donations like these that provide year-round services, supports, and programs for individuals with Down syndrome and their families in our community.



### ROSEMARIE BAUMGARTNER SOCIETY

When planning your estate and the legacy you'd like to leave, consider becoming a member of the DSAGSL Rosemarie Baumgartner Society. Gifts can be made from your IRA, will, or trust, and provide vital programs and supports for people with Down syndrome and their families now, and in the future.

Contact Executive Director, Erin Suelmann, for more information about the Calamia Giving Circle, the Rosemarie Baumgartner Society, or any other questions you may have about leaving a legacy gift to DSAGSL. 314.961.2504 or [Erin@dsagsl.org](mailto:Erin@dsagsl.org).



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[www.dsagsl.org](http://www.dsagsl.org)



## **BIRDIES & BASS FISHING DERBY & GOLF TOURNAMENT** **MONDAY, MAY 4, 2020 | PERSIMMON WOODS GOLF CLUB & LAKES**

*Join us for this one-of-a-kind event! During the fishing derby, anglers are paired with a self-advocate teammate and compete for heaviest catch, as well as earn strokes off of their golf score. Foursomes are filling up quickly. Register online today!*

[www.dsagsl.org/events/golf](http://www.dsagsl.org/events/golf)