



familyconnection

volume 2015: issue three

newsletter

DSAGSL Named *National Parent Group of the Year*



PhotocourtesyofNationalDownSyndromeCongress

Above: Erin Suelmann and Christy Klaus (center) with NDSC Executive Director David Tolleson and NDSC Board President Marilyn Tolbert, Ed.D.

In June, Erin and Christy attended the National Down Syndrome Congress Conference in Phoenix, Arizona. DSAGSL was named National Parent Group of the Year. The award was given in appreciation of the significant resources, both educational and social that the DSAGSL provides our members. Thank you to every one who contributed to our success. We are excited to keep excelling in the Down syndrome community.



The ballroom at the NDSC Conference.

DSAGSL
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2015-2016

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Volunteer & Event Manager

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Family Support Coordinator

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Office Information

8531 Page Ave., Suite 120
St. Louis, MO 63114
Phone: 314-961-2504
Fax: 314-989-1579
www.dsagsl.org
info@dsagsl.org

from the Executive Director

Dear Friends:

For anyone who was able to join us at our recent annual meeting, we were pleased to share the news of another successful year! We're thankful to our families, volunteers, donors and everyone else who continues to make DSAGSL better every day. We're also especially grateful for the recognition given to our organization. In June, we were privileged to be chosen as the National Parent Group of the Year by our friends at the National Down Syndrome Congress.



So yes, our past year has been a year of tremendous growth and some pretty awesome accolades. But after a year like we've had, I'm reminded of a simple truth: To whom much is given, much will be required.

At DSAGSL, we recognize that our families expect us to build on our success, to use donor dollars wisely, and to keep growing our voice in the community. Our staff is working on plans for our 40th Anniversary year in 2015-16, and we can't wait to have you join us!

In these pages, you'll see information about upcoming events such as Walk in the Park on September 26, fall programs, as well as plans for Down Syndrome Awareness Month in October including our 3rd annual DSAGSL Talent Show. You'll also see information about advocacy and employment, which will be major themes at DSAGSL this coming year, as well as several opportunities to educate yourself and those who are closest to your favorite person with Down syndrome.

As we get further into the year, you'll likely see more about our 40th Anniversary celebration. This presents us with a unique opportunity to show St. Louis how capable and valuable our members are. Regardless of how involved you have been lately, take the time to be a part of what we're doing in our 40th year. So many of you have given time and energy to make us what we are today. You deserve to see what you've built, and to continue reaping the benefits of what DSAGSL can do for you!

Again, we recognize that your support has given us more resources and opportunities to serve you than ever before. Not only do we understand what this requires of us, but we are ready to accept the challenge. We, as always, thank you for inspiring us daily and making what we do possible. We also expect to see you at an event or program this fall, and hope you'll join us in making our 40th year our best ever!

A handwritten signature in dark ink, appearing to read "Jeremie Ballinger". The signature is fluid and cursive, written over a light-colored background.

Jeremie Ballinger
Executive Director

The DSAGSL MISSION is to benefit the lives of people with Down syndrome and their families through individual and family support, education, public awareness, and advocacy.

communityGROUPS

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 based on location, culture, native language and the age group(s) they serve. Contact the groups below for more information about their respective events, or call 314.961.2504 if you belong to a group that would like to be a part of our community group network.

MISSOURI

Dual Diagnosis Autism Spectrum Disorder and Down Syndrome Support

CONTACT

jennifer.haughey@esmw.org
(314)432-6200

Facebook: facebook.com/LifeSkillsMO

Heartland Community Group

(Southeast Missouri and Southern Illinois)

CONTACT

heartlanddsa@msn.com
(573)334-5685

Facebook: facebook.com/HeartlandDSA

Central Missouri Down Syndrome Family Network

CONTACT

centralmodsfamilynetwork@gmail.com
(573)230-7230

Facebook: facebook.com/centralmodsfamilynetwork

Down Syndrome Group of the Lake of the Ozarks

(Camdenton, MO and surrounding areas)

CONTACT

dsgloz@hotmail.com
(573)374-8337

Kirkwood/Webster Community Group

CONTACT

joyce@objectnirvana.com/(314)822-2227;
dewdrop519@yahoo.com/(618)570-8485;
emily.ratliff@logan.edu/(636)236-5759

Dads Appreciating Down Syndrome (DADS)

CONTACT

dadsstl@dadsstl.org

Website: www.dadsstl.org

Facebook: facebook.com/pages/DADS-St-Louis-Chapter/134721146598480

North County Community Group

CONTACT

dsagsl.ncg@gmail.com
(314)305-2302

Facebook: facebook.com/pages/North-County-Down-Syndrome-Community-Group-STL/501592436546406?fref=ts

Saint Charles County Community Group

CONTACT

downsyndromestc@gmail.com
Facebook: facebook.com/stcdsgroup

Northern Missouri Community Group

CONTACT

beckyjpike@gmail.com, (660)627-7453;
kmccurry@highway.com, (660)258-7204

Facebook: www.facebook.com/pages/Down-Syndrome-Community-Group-of-Northern-Missouri/356892451086093

ILLINOIS

Metro East Down Syndrome Alliance

(Shiloh, Illinois and surrounding areas)

CONTACT

amb2728@gmail.com
(618)593-6169

Website: metroeastdsa.org
Facebook: facebook.com/groups/245883765486/

Southern Illinois Community Group

(Carbondale, Creal Springs, IL and surrounding areas)

CONTACT

jaakdander1@yahoo.com, (618)922-5846

Facebook: facebook.com/pages/Southern-Illinois-Down-Syndrome-Support-Group/10150122313390495

OTHER DOWN SYNDROME GROUPS

Riverbend Down Syndrome Association

(Southwest Illinois)

CONTACT

secretary@riverbendds.org
(618)667-8771

Website: www.riverbendds.org

Down Country

(Hannibal, Quincy and surrounding areas)

CONTACT

info@upatdowncountry.com
217-617-3568

Website: www.upatdowncountry.com

Facebook: facebook.com/UpatDownCountry

Down Syndrome Group of the Ozarks

(Springfield, MO and surrounding areas)

CONTACT

info@ozarksdsg.org
(417)885-9905 or (888)655-5173

Website: www.ozarksdsg.org

Lincoln Land Down Syndrome Society

(Springfield, IL and surrounding areas)

CONTACT

lldss@comcast.net
(217)741-1832

Website: www.lldss.org

Mineral Area Down Syndrome Group

CONTACT

bshelton@centralr3.org
(573)701-3576

If you know of an event, activity or social outing that might interest other families in the area, let us know! E-mail emily@dsagsl.org with all the info so we can share it with our community.

SHARE IT!

6.1.15 - 6.5.15 Lydia Cox Memorial Bike Camp

Sixty-two young people with Down syndrome and other disabilities learned to ride a two-wheel bike at our 9th annual Lydia Cox Memorial Bike Camp. For the first year, we were also able to hold a second week of camp in Edwardsville! This camp is made possible by the Lydia Faith Cox Memorial Foundation, Variety St. Louis, Maplewood Bikes, Helmets First, South Technical High School, Liberty Middle School and over 60 amazing volunteers.



6.7.15 Step Up for Down Syndrome

Kicking off DSAGSL's 40th Anniversary in style at Forest Park, Step Up for Down Syndrome teams participated in a one-mile walk to raise awareness and support for individuals with Down syndrome. Attendees also enjoyed a rock climbing wall, trackless train, bounce houses, live music, face painting, and more. Thank you to all volunteers and members who made the event possible.

8.7.15 - 8.8.15 Hockey Camp

Our 2nd annual Hockey Camp was held at Westminster Christian Academy in partnership with the AAA Blues, Total Hockey and St. Louis Blues Alumni. Athletes of all abilities learned hockey skills, rules and scrimmaged during this two-day camp. Thanks to all of the volunteers, parents and athletes who attended. Stay tuned for more athletic camps offered by the DSAGSL.



8.22.15 New Mother's Luncheon

The DSAGSL and Pujols Family Foundation were thrilled to welcome over 42 mothers and babies under three to our annual New Mother's Luncheon. This is always a special afternoon for everyone involved. Gillian Marchenko, mother to two children with Down syndrome and author of Sun Shine Down, graciously spoke to our group over a delightful lunch at J. Gilbert's restaurant.

8.31.15 Birdies and Bass Tournament

Our Birdies and Bass Tournament held at Persimmon Woods Golf Club kicked off bright and early with the "Bass" portion as self-advocates helped golfers fish to lower their golf score. After lunch, the "Birdies" portion started with golf and concluded with a live auction and dinner. Thank you to all volunteers, staff, and members for their continued support at this event.



dsagslBLOGSPOT highlights from stories featured in our blog

We love to feature our self-advocates, members and families in the blog on our website. Whether you want to share knowledge on a research topic, applaud achievements or share your stories...we want to hear them! If you are interested in submitting a piece, contact Emily at 314.961.2504 or emily@dsagsl.org.

Camp Barnabas

by Paige Brune

"When I was at Camp Barnabas, I conquered three fears.

One of the fears was swimming in the deep end of the pool, when I took a swim test for camp.

The camp was awesome, and I had a great time there. I met some new friends and my favorite thing to do was the wrap ups and lessons."

To read more of Paige's blog, visit dsagsl.org/campbarnabas.

Friendly Face

by Jasimine Johnson

"Hola! I am the first out of my family to graduate high school and attend college. I love animals, people, traveling and trying different things. My everyday hobbies are playing sports, writing, reading, working, singing and dancing.

I love meeting new people, however I am very shy. (Not sure how that works, but it does.) I have a smile that will brighten up your day and a heart to fill in the gaps. My dream in life is to become a manager of my own business."

To read more of Jasimine's blog, visit dsagsl.org/jasimine.

Sports Camp Experience

by Lindsey Hawkins

"Last week, I went to sports camp. Everyone came in on Sunday mid-afternoon and there were different groups. The theme for the week was Super Heroes.

On Tuesday, I caught a 6-inch bluegill on fishing day. Some other athletes got snapping turtles on their hooks that were so big.

We had to take off our shoes and socks and we ended up getting mud all over our legs and feet."

To read more of Lindsey's blog, visit dsagsl.org/sportscamp.

Dierbergs School of Cooking

by Megan Layton

"I participated in the School of Cooking at Dierbergs. There was a great turnout, 14 people attended. Dierbergs has had the cooking class for eight years. The class was hosted by Sally and Dennis.

We prepared and ate Italian tomato bruschetta, fresh and light caesar salad, chicken spedini, green beans with crisp crumb topping and a side of cheddar au gratin potatoes. For dessert, we had red velvet cupcakes with cream cheese frosting."

To read more of Megan's blog, visit dsagsl.org/cookingclass.

The following article was published by Mizzou News. Rights to the story are those of the University of Missouri.
The original article is located here: <http://bit.ly/1gmVhV8>.

Cause of Regression in Individuals with Down Syndrome Identified Individuals with regressive Down syndrome return to baseline functioning when treated for Catatonia **by Fran Webber**

COLUMBIA, Mo. – Down syndrome, the most common chromosomal disorder in America, can be complicated by significant deterioration in movement, speech and functioning in some adolescents and young adults. Physicians previously attributed this regression to depression or early-onset Alzheimer's, and it has not responded to treatments. Now, a researcher at the **University of Missouri** has found that Catatonia, a treatable disorder, may cause regression in patients with Down syndrome. Individuals with regressive Down syndrome who were treated for Catatonia showed improvement, the researcher found.

"Our findings are important for young people with Down syndrome, autism and probably other neurodevelopmental disorders," said Judith Miles, professor emerita in the MU School of Medicine and researcher with the MU Thompson Center for Autism and Neurodevelopmental Disorders. "Until recently, Catatonia was felt to be just a complication of schizophrenia; however, it now is known that Catatonia is a common neuropsychiatric disorder that complicates many types of brain disorders. Our recognition that Catatonia occurs in young adults and adolescents with Down syndrome means these individuals who before were relegated to lives of incapacity may now receive treatments that restore them to their usual levels of activity."

Those who care for individuals with regressive Down syndrome describe them as "zombie-like," Miles said. Symptoms of regression can include difficulty moving and sleeping, inability to perform activities of daily living, no longer talking, and a lack of interest in previously enjoyed activities.

In her study, Miles followed the cases of four patients with Down syndrome who were diagnosed with Catatonia. Each patient improved when treated with a combination of benzodiazepine, a drug commonly used to treat anxiety, and electroconvulsive therapy.

"The wonderful thing is that Catatonia is a treatable cause of regression," said Miles, a pediatrician who led the Down syndrome clinic at MU for many years. "When we treat these patients who otherwise would be condemned to stupor-like existences, they can return to their baseline level of functioning. So, not only do we have a diagnosis, but we also have a treatment that is backed by years of successful use by psychiatrists. We're also beginning to know how it works to correct imbalances in neurotransmitters in patients."

Miles said she wants families, physicians, teachers and therapists to know that Catatonia causes regression in Down syndrome so individuals with the disorder can receive accurate diagnosis and treatment. But, more research is needed to better understand Catatonia, identify its prevalence among patients with Down syndrome and improve treatment, Miles said.

"I consider it a public health issue to determine how often Catatonia occurs in patients with Down syndrome," Miles said. "We don't know what predisposes kids with Down syndrome to develop Catatonia. However, one of the things we do know is that individuals with Down syndrome tend to acquire autoimmune disorders, so we're looking into autoimmune function and its possible connection to Catatonia."

Miles collaborated with Neera Ghaziuddin of the University of Michigan and Armin Nassiri of Community Psychiatry in San Jose, California. Their study, "Catatonia in Down syndrome; a treatable cause of regression," is published in the journal *Neuropsychiatric Disease and Treatment*.

Walk with us!



Come out to the Down Syndrome Association of Greater St. Louis' annual Walk in the Park at Busch Stadium on Saturday, September 26. Peprally starts at 3pm, followed by a walk around the warning track to raise awareness for Down syndrome before the Cardinal stake on the Brewers at 6pm!

Find out how you can order a ticket package today!
www.dsagsl.org/WITP 314.961.2504



Talent Show

Friday, October 9

6:30 pm - 8:30 pm

Lindenwood University Cultural Center

The DSAGSL is excited to announce we will be holding our 3rd Annual Talent Show! Our Talent Show highlights the amazing abilities of our members with Down syndrome of all ages. Get your application from Erin at erin@dsagsl.org or by calling the office at 314.961.2504.

dsagsl **IN ACTION**

Our members and fans at work in the community

DSAGSL *Out and About*

The DSAGSL has been busy welcoming new babies, offering programs, hosting fun events and promoting awareness in the community. Check out what we've been up to.



17 Celebration Baskets were presented to new families and babies with Down syndrome.



24 Toastmasters attended our monthly meetings to gain public speaking skills and confidence.



18 new babies were born between April and August.



10 adults and caregivers participated in our SAGE Advocacy Lunch and Learns this summer.



6 students graduated from our Employment Academy Summer Program.



42 mothers attend the New Mother's Luncheon in August.

volunteer **CORNER** *volunteer needs and updates on programs*

Interested in getting more involved with the DSAGSL? Below is a list of areas with volunteer opportunities. For more information or to apply, please contact Abby at 314.961.2504 ext. 101 or abby@dsagsl.org.

Committee Volunteer Needs

Programs and Services Committee helps design, plan and enact DSAGSL programming. This includes DSA-Up programming, Education Specialist workshops and community awareness education. Meets monthly or bi-monthly, depending on programming needs.

Employment Committee assists with DSAGSL's Employment Initiative. They will reach out to potential employers, prepare people for the workplace and will help plan curriculum for the Employment Academy program. Meets monthly or bi-monthly.

Internships

Education Specialist Intern: duties include reaching out to partners, assisting with workshop organization, managing the workshops, working with Programs and Services Committee.

Bike Camp Intern (Spring): duties include registering participants, recruiting volunteers, working with Camp vendors and partners, attending both Bike Camps in Edwardsville and St. Louis.

Health and Wellness Intern: duties include planning and running our Healthy Start Day program, assisting with other health and wellness related programming, working with the Programs and Services Committee.

Job Mentors: duties include preparing individuals with Down syndrome for the workplace, educating employers and potential employers, assisting with job training, regular meetings with employers and caregivers, and working with the Employment Committee.

Event Volunteer Needs

3rd Annual Talent Show: 10.9, Lindenwood University Cultural Center, 6:30pm - 8:30pm

Holiday Party: 12.6, Maryland Heights Centre, 2pm - 5pm

Friend2Friend: Ongoing flexible schedule, various locations

AWARENESS & ADVOCACY

October is Down Syndrome Awareness Month!

Here are FOUR ways to help us celebrate...

1 Talent Show

The DSAGSL will be holding our 3rd Annual Talent Show on Friday, October 9 from 6:30 pm – 8:30 pm at Lindenwood University Cultural Center. The show highlights the amazing abilities of our members with Down syndrome of all ages. Get your application from Erin at erin@dsagsl.org or by calling the office.



2 Student T-Shirt Contest

Get students involved in the celebration. We are planning our second K-12 t-shirt contest for DSAM. Students of all abilities are encouraged to create a unique design celebrating our friends and family with Ds. Winning design(s) will be used on our World Down Syndrome Day t-shirt on March 21st. Contact Erin at erin@dsagsl.org or by phone to get contest sign up forms for your child's school.



3 Down Syndrome Super Star

Do you know someone who has gone above and beyond for an individual with Down syndrome and/or the Down syndrome community? We want to know about your Down Syndrome Super Star! Send their name and contact information as well as a brief description of why this person shines to erin@dsagsl.org. We want to celebrate them during DSAM!



4 Social Media Photo Campaign

Send us a photo of your loved one with Down syndrome with a 2-3 sentence description of your loved one, why Down syndrome awareness is important, or a message you would like to share with the community. Submit to Emily at emily@dsagsl.org.



Celebrate with us!

The year 2016 marks the DSAGSL's 40th Anniversary. Want to join the committee planning all the fun? Have some old pictures, documents, etc you would like to share as a part of our history? We would love your help.

Contact the office at 314.961.2504 or info@dsagsl.org.



Mark your Calendar

Mark your calendar for these recurring DSAGSL programs, workshops and clubs.

Football Camp for the Stars

October 3: 9am - 12pm, October 4: 1pm - 4pm

Vianney High School

The DSAGSL is once again partnering with Football Camp for the Stars, an national organization that brought you last year's excellent two-day camp. Anyone 13+ are welcome to join us. Visit dsagsl.org/programs/dsa-uo or contact jeremie@dsagsl.org or by calling 314.961.2504 ext.106 for more info.



Special Needs Financial Planning Thursday, October 8

8:30am-9:30am (w/light breakfast) or 7pm-8pm (w/dinner)

DSAGSL Office

There are more options than ever to ensure your son or daughter is taken care of financially. Ask questions and learn from a MetLife financial planning specialist during this one-hour workshop. There are two opportunities to attend with food provided.

3rd Annual DSAGSL Talent Show

Friday, October 9, 6:30pm - 8:30pm

Lindenwood University Cultural Center

We hope you can join us for our favorite night of the year as the DSAGSL presents our 3rd Annual Talent Show! Last year we saw visual and performing arts from over 60 talented individuals with Down syndrome. RSVP or get your registration form by emailing gerin@dsagsl.org.



Housing and Long Term Care for Adults

Tuesday, November 10, 5pm-6pm: Reception, 6pm-8pm: Presentation

St. Luke's Emerson Auditorium

The DSAGSL and Wellness Center for Adults with Down syndrome bring you a panel of experts in long-term care and housing. You will learn about the options in the St. Louis area and important considerations for planning your loved one's future. RSVP to abby@dsagsl.org.

Save the Date

Save the date for these upcoming DSAGSL fundraisers, family events and programs. For more information or to RSVP, contact the office at 314.961.2504 or by emailing info@dsagsl.org. For a complete list of events visit: dsagsl.org/calendar-of-events.

Annual Holiday Party Sunday, December 6, 2pm - 5pm Maryland Heights Centre

It's the most wonderful time of the year with the DSAGSL. Join our family in celebrating the many holidays of this season. There will be crafts, a photo booth, pictures with Santa, refreshments, karaoke, dancing and more.



Night at the Magic House with KEEN December 14, 6pm - 8pm The Magic House

Our friends at Kids Enjoy Exercise Now (KEEN) have invited our members for a night of fun and learning at the Magic House in Kirkwood. Provided by a grant from the Saigh Foundation, our families can enjoy this awesome St. Louis attraction for free!

DSAGSL Trivia Night TENTATIVE DATE: Saturday, February 27, 7pm CBC High School

DSAGSL's Trivia Night is one of our longest running fundraisers. Team stake part in an evening of challenging and fun trivia rounds and our silent auction is always loaded with outstanding prizes to take home. We also make sure nobody goes home hungry for most teams, a new trivia round means a new round of food from a local restaurant. Stay tuned for registration information.



World Down Syndrome Day Celebrations Saturday, March 12 - Monday, March 21 Various Locations in St. Louis area

World Down Syndrome Day is an international day of celebration for individuals with Down syndrome. We will have a week of activities including a family funday, Run for 215K and half marathon, movies and more, all leading up to 3.21. To help plan an activity in your community, contact Erin at erin@dsagsl.org. Stay tuned!



Down Syndrome Association of Greater St. Louis

8531 Page Ave., Suite 120
St. Louis, MO 63114
Phone: 314.961.2504 Fax: 314.989.1579
Website: www.dsagsl.org



Wish List

Office Needs

Drop by our office if you would like to donate any of the following items:

- AED
- \$0.49 or Forever stamps
- Bubble/padded mailing envelopes
- General office supplies
- Paper goods (plates, towels, etc.)
- iTunes gift cards (app downloads)
- Gift cards to local grocery stores

New Baby Registry

Purchase a gift for two from one of our baby registries at Target or Babies R Us. Find our wish list by searching dsagsl(firstname)/babies(lastname) in-store or online. Contact Christy at 314.961.2504 or christy@dsagsl.org with questions.

Stay Connected

2016 Calendar Pre-Sale

Don't miss out on a calendar full of smiling faces! The Friends for All Seasons DSAGSL Calendar will be available for pre-order October 1. Call the office at 314.961.2504 or email info@dsagsl.org to pre-order your copy today! Join us at Walk in the Park on September 26 for the reveal of this year's cover.

Blogs

Have you read the personal stories on our blog? Have you thought to yourself that you would love to share you and your loved one's story? E-mail emily@dsagsl.org. We can provide prompt questions and all the help you need!