DSAGSL Receives Seven National Awards

DSAGSL returned from the National Down Syndrome Affiliates in Action Conference in Las Vegas, Nevada with seven national awards: Affiliate of the Year, Best Website, Best Social Media, Best Promotional Items, Best Broadcast Media, Best Printed Items and 2nd Place Best Outdoor Advertising. Thank you to all our members who assist to keep the DSAGSL great.

Employment Initiative Making Strides

Please join us in congratulating Megan Layton, for her position with State Farm Insurance, Abeo Anwisye for her position with J.W. Terrill and Scott Williams for his position at the DSAGSL Office. The DSAGSL has heard from parents and community agencies about the trials and tribulations people with Down syndrome face when looking for and retaining employment. The DSAGSL has developed an initiative that involves agency support, employer relations, community engagement, and parent and self-advocate education with the goal of finding our members paid, meaningful employment. This is an important undertaking and we need your help! Contact Erin to get involved with our committee, employment academy, employer relations or if your company would like to discuss hiring one of our talented members! You can reach Erin at erin@dsagsl.org or at 314.961.2504 ext. 105.
Hello Friends,

Happy Spring! We send this newsletter to you just after a very busy season at the DSAGSL. There is much to share about what we’ve accomplished in the past few months. For example, with your help we have achieved the following:

- First, we are extremely proud to share that YOUR Down Syndrome Association of Greater St. Louis has been selected as Affiliate of the Year by our national trade organization, Down Syndrome Affiliates in Action. In total, seven national awards came home to St. Louis from the AIA conference in March. Thank you to each of you who gave us the feedback and support to make this possible.
- As you know, the ABLE Act is now the law of the land! We’ve heard many people ask what is next to make sure they can take advantage. We are currently working with lawmakers in Missouri and Illinois to enable these laws in our states. At last check, both states have passed ABLE through one part of their legislature, and we’re eager to see it become state law in 2015.
- Thanks to all of you, we have just completed another record-breaking DSAGSL Trivia Night. We’ve also just celebrated World Down Syndrome Day, complete with awareness on three local television stations and our first-ever WDSD party at Purina Farms that hosted over 300 people!
- Finally, momentum is building quickly for our Employment Initiative. We’ve placed our first three self-advocates in employment situations to better their skills, and there is more success on the horizon. Employers in St. Louis are starting to realize the value of people with Down syndrome. While this in itself is a win in our book, we look forward to more progress on this front.

There has been so much that our families have made possible through their efforts, as you can see. But this is the time of year where we also look forward to what we can accomplish in the summer months – to that end, you’ll see summer program & event information in this newsletter. But it’s also a time to look ahead to how we can make DSAGSL even stronger for the next year.

How do we do that? By Stepping Up for Down Syndrome!

The largest Down syndrome event in St. Louis returns to Forest Park on Sunday, June 7. In this issue, you’ll see information about how you and your family can register and celebrate Down syndrome with us at our SUDS Walk. This event is so very important in helping us provide vital programming for children and adults with Down syndrome. Also, it’s so much fun! There’s nothing better than seeing families enjoy a day where we are all more alike than different, and where individuals with Down syndrome are celebrated. As they should be.

Whether it’s in June at Forest Park, or at another time this summer, we are excited to be a part of the life of your favorite individual with Down syndrome. Thank you for your continued involvement and support!

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.
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.

The Little Emily that Could
by Beth Diveley

“Emily’s personality is my favorite thing about her as a whole person. There are so many wonderful aspects of her personality that it’s hard to name just one.

We should never assume that anyone with Down syndrome can’t do what other people can do. We all have our strengths and weaknesses, but that doesn’t make us any more or less of a person than anyone else. For all the new parents reading this, slow down! Love your baby because they are after all a baby first, and never put limitations on them.”

To read more of Beth’s blog, visit dsagsl.org/emily.

World Down Syndrome Day
by Lindsey Hawkins and Paige Brune

1. How do you celebrate World Down Syndrome Day?
   Lindsey: I plan to hangout with my friends at a bowling event.
   Paige: I donated my art work to St. Louis Children’s Hospital as a random act of kindness, and I plan to hang out with friends.

2. What does the day mean to you?
   Lindsey: It means helping others like I do at the Down Syndrome Association office to celebrate the day.
   Paige: I feel it is a day to create awareness for people with Down syndrome.”

To read more of Lindsey and Paige’s blog, visit dsagsl.org/wdsdcelebrations.

Grand Marshal
by Isabel Trower

“"I was the Grand Marshal. I was throwing candy and bracelets to the people. The people were smiling and waving at me. I was singing Frozen. I was with my family, and I could see my friends. I am so happy people went to the parade and then I get to go to a restaurant.”

To read more of Isabel’s blog, visit dsagsl.org/isabel.

DSAGSL Interns
by Alyssa Renaud and Heather Hodge

Alyssa: “I’ve always had a passion for working with individuals with developmental disabilities because I find it very rewarding to help others realize their full potential.”

To read more of Alyssa’s blog, visit dsagsl.org/alyssa.

Heather: “I was drawn to the opportunity to intern at DSAGSL because of my Aunt Carolyn who had Down syndrome. It is the perfect place to learn and spread awareness at the same time.”

To read more of Heather’s blog, visit dsagsl.org/heather.
A Focus on Guardianship

60 parents, professionals and caregivers attended the March 24 presentation on Guardianship: Options and Alternatives. This presentation was graciously provided by Bhavik R. Patel, JD. Mr. Patel, who is an attorney at Sandberg Phoenix & von Gontard and is the firm’s chair of the Wealth Planning Group and Special Needs Planning Group. In addition to many other professional credentials, Mr. Patel is also Founder and Chairman of the Board for Families at Ease, a local not-for-profit entity focused on delivering information about programs, services and resources available for special needs children and their families. We were also joined by a wonderful panel of parents who each had unique perspectives to bring to the discussion. In case you missed the event, below are important tips to remember when considering options for your loved one’s future. For more information on guardianship, please visit the DSAGSL Website at dsagsl.org/resources or the Alternatives to Guardianship project at moguardianship.com.

Types of Guardianship Defined

- **Guardianship:** This is the most restrictive limitation on personal decision-making that a court can place on a person. This is the result of a court hearing that establishes the need to appoint a guardian to assume substitute decision-making powers for another person deemed incapable of exercising his or her own rights. The ward loses the right to vote, choose where to live, obtain a license, approve medical procedures, enter into contracts, etc.

- **Limited Guardianship:** Very similar to guardianship, but the “ward” maintains certain legal rights and freedoms dependent on the individual’s skills and needs.

- **Conservatorship:** This is similar to guardianship but deals only with financial matters of an individual deemed unable to manage his/her own finances. The conservator must report to and seek approval from the court for expenditures but has no authority over other decision making in the individuals personal affairs.

- **Representative of Payee:** This is considered less restrictive than guardianship or conservatorship. Individuals receiving SSI or SSDI may receive benefit checks directly or the checks can be sent to a representative payee who will assist the beneficiary with financial management and payment obligations. Court action is not needed to establish an RP but regular reports must be submitted to the Social Security Administration.

- **Power of Attorney:** This is perhaps the least restrictive of options. If a person is a competent adult, he or she may authorize in a private written agreement, another individual to assume power of attorney. This agreement authorizes a person to enter into legal agreements and manage financial affairs in the name of the other person.

Parents are the natural guardians of their children until the age of 18. In the state of Missouri, all persons become emancipated (become their own legal guardian) when they turn 18 years old, regardless of their ability. It is important to start planning early.
AWARENESS & ADVOCACY

Check Out How We Celebrated World Down Syndrome Day!

WDSD T-Shirts Still Available in Youth Sizes
Get yours while they last! These beautiful t-shirts were designed by a student at Word of Life Lutheran Academy during our Down Syndrome Awareness Month. Call the office at 314.961.2504 to order yours.

Random Acts of Kindness
Twenty volunteers with and without Down syndrome made some lucky individuals’ days by surprising them with flowers and candy. Each individual received a note encouraging them to pass the kindness forward.

Purina Farms Family Event
Our first event at Purina Farms was a blast! Over 200 children and children at heart joined the DSAGSL for a fun day of lunch, dog shows, animal petting, educational lessons and play! Thank you to Purina Farms for welcoming us to your space.

Relay and Run for 21
The 4th Annual Relay and Run for 21 took place on Sunday, March 22 and welcomed 581 runners and walkers on the 21K, 7K and 2.1K routes. This spectacular event gathered our highest number of participants in the event’s history and raised funds to support the DSAGSL, DADS St. Louis and the Pujols Family Foundation. Thank you to the DADS and all of our wonderful runners, vendors and volunteers!

DSAGSL Attended Disability Rights Legislative Day
The DSAGSL traveled to Jefferson City for Disability Rights Legislative Day. Megan Layton, self-advocate and member of the DSAGSL Board of Directors spoke on the ABLE Act, really charging the crowd. After her speech, Megan met with state legislators to ask for their continued support for the ABLE Act on the state level.
Mark your Calendar

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

Ensuring Success: Behavior Solutions for Pre-Teen Years
Saturday, April 25, 10am - 1pm
DSAGSL Office

The DSAGSL is proud to bring you this three hour workshop. You will hear from Brandon May, MSW, BCBA, LBA and a panel of parents on decoding frustrating behaviors and strategies to ensure your pre-teen is successful in school and social life. Breakfast will be served. This event is free of charge. RSVP to erin@dsagsl.org or by calling 314.961.2504 ext. 105.

Exciting Summer Programming
Times and Dates Vary by Program
DSAGSL Office and St. Charles Academy for the Arts

DSA-U offers programming for all ages. This summer we are continuing our popular Toastmasters Club, Therapeutic Play Group, SAGE Group and Art Club. We are happy to bring back such favorites as Healthy Start, Social Dance, Mommy/Daddy and me, Bike Club and more! For a complete list of all summer programs both at the DSAGSL and at the St. Charles Academy for the Arts, visit dsagsl.org/programs/dsa-u. RSVP to erin@dsagsl.org or by calling 314.961.2504 ext. 105.

Cow Folk Cookout
Saturday, May 9, 4pm - 7pm
Florissant Knights of Columbus

Join the DSAGSL for an evening of cowboy and cowgirl fun. Dancing, dinner, music, bounce castles, games and more. Dressing up is encouraged! RSVP to abby@dsagsl.org or by calling 314.961.2504 ext. 101 by May 4.

Behavior Strategies and Solutions
Tuesday, May 12, 5pm - 8pm
St. Luke’s Emerson Auditorium

In partnership with the Wellness Center for Adults with Down Syndrome, we bring you another quarterly workshop for parents of teens and adults. This workshop will discuss solutions for problem and worrisome behaviors in older teens and adults with Down Syndrome. RSVP to erin@dsagsl.org or by calling 314.961.2504 ext. 105.
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. For a complete list of events visit: dsagsl.org/calendar-of-events.

**DSAGSL Pedal Party**
Saturday, May 16, 11am - 1pm
DSAGSL Office

Ride a two-wheeler? Still on a trike? Come party with us! To kick off summer, the DSAGSL will be offering helmet fittings, fun bike goody giveaways, pedal-less Strider bike trials, food, drinks and a large space for everyone to pedal their bike of choice. RSVP to abby@dsagsl.org or by calling 314.961.2504 ext. 101.

**Lydia Cox Memorial Bike Camp**
MO: June 1-5, IL: June 8-12, All Day
MO: South Tech High School, IL: Liberty Middle School

Register your loved one for this amazing camp! In partnership with the Lydia Faith Cox Family Foundation, iCan Shine, Variety St. Louis, Maplewood Bicycle, South Technical High School and Edwardsville School District, we are proud to bring two weeks of the camp that teaches individuals ages 8+ to ride a two wheel bike. RSVP to erin@dsagsl.org or by calling 314.961.2504 ext. 105.

**Football Camp for the Stars**
June 12-13, 5pm - 8pm
Vianney High School

The DSAGSL is once again partnering with Football Camp for the Stars, a national organization that brought you last year’s excellent two-day camp. Gentlemen 13+ are welcome to join us! Visit dsagsl.org/programs/DSA-U or contact Jeremie at jeremie@dsagsl.org or by calling 314.961.2504 ext. 106 for more info.

**DSAGSL Hockey Camp**
August 7: 5pm - 7pm, August 8: 11am - 1pm
Hardee’s Iceplex

DSAGSL is partnering with Total Hockey, Hardee’s Iceplex, NHL hockey players, St. Louis Blues Alumni and AAA athletes to bring an authentic floor hockey camp to our members! Camp is open to any athlete with a disability 13 and up. The camp features instruction from the St. Louis AAA Blues Coach. For more information or to register, contact emily@dsagsl.org or 314.961.2504 ext. 103.
**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.

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

50+ individuals with Down syndrome participated in our Down Syndrome University.

9 students graduated from our first Employment Academy, our newest program to support our members obtaining paid, meaningful employment.

14 members attended DSA-U classes in conjunction with St. Charles Academy of the Arts.

62 educators, parents, and therapists completed our Education Specialist program.

10 members attended the Bodies and Boundaries Workshop series.

10 new classes began in partnership with the St. Charles Academy of Arts.

54 individuals attended our Therapeutic Playgroups for ages 0-3 years old.

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**volunteer CORNER**

Upcoming Volunteer Opportunities

**Cow Folk Cookout:** Sunday, May 9, 4p - 7p, Florissant Knights of Columbus

**DSAGSL Pedal Party:** Saturday, May 16, 11a - 1p, DSAGSL Office

**Bike Camp:** MO June 1-5 at South Tech High School, IL June 8-12 at Liberty Middle School

**Step Up for Down Syndrome:** Sunday, June 7, 9a - 1p, Upper Muny Parking Lot

**Football Camp for the Stars:** June 12-13, 5p - 8p, Vianney High School

Thank you to all our members and friends who generously donated their time by volunteering at the New Family Brunch, Trivia Night, Purina Farms, Relay and Run for 21 and DSA-U Winter Session. We could not have done it without you!

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Volunteers do not necessarily have the time; they have the heart.
-Elizabeth Andrews
What is Step Up for Down Syndrome?

The DSAGSL hosts Step Up for Down Syndrome (SUDS) each year as its annual awareness and fundraising walk. The walk takes place in June in St. Louis and is the largest fundraising event for our organization. Families, friends and co-workers join forces in teams for their favorite people with Down syndrome for a day of fun, support and a little exercise.

How can I register?

Register online now at www.dsagsl.kintera.org/stepup and get your team together to spread the word and make a difference with SUDS! Every participant (walker) can create their own fundraising page to share with friends and family members! Fundraising pages are a great way to invite the people you know to celebrate individuals with Down syndrome, while sharing your personal story.

Golf in support of the DSAGSL this summer!

Driving for the Upside of Downs

Timberlakes Golf Course
Saturday, June 6

Help support those with special needs and register today! This event also features a golf clinic for individuals with disabilities wanting to learn! For more information contact Travis at 217.710.1883 or info@drivingfortheupsideofdowns.org or visit the website at www.drivingfortheupsideofdowns.org.

Working Wonders for Downs

Annbriar Golf Course
Friday, June 12

Form a team today and help us support families who have a child with Down syndrome. For more information contact Jay at 314.856.3131 or w4downs.WJK1@yahoo.com or visit the website at www.WorkingWonders4Downs.com.

Birdies & Bass

Persimmon Woods Golf Course
Monday, August 31

Teams compete in a full day of golf preceded by a fishing derby with self-advocates, teams can shave strokes off their golf score by reeling in a big fish from one of the lakes on course. Our event also features an auction! For more information contact Jeremie at 314.961.2504 or jeremie@dsagsl.org.
12.7.14 **Annual Holiday Party**

The DSAGSL hosted the Annual Holiday Party at the Maryland Heights Centre. The afternoon featured hot cocoa, snacks, karaoke, photos with Santa, a photo booth, face painting, arts and crafts, dancing and more! It was the perfect way to spread holiday cheer with our members and fun was had by all who attended. We cannot wait to do it again next year, and we hope to see you there!

1.30.15 **Family Movie Night**

DSAGSL members and staff snuggled down to watch Muppets Most Wanted at the DSAGSL Office with popcorn, snacks, and drinks. Everyone came in their pajamas and brought their pillows and stuffed animals to enjoy the movie, too! Watch the DSAGSL Calendar and Facebook for the next movie night.

2.22.15 **Night at the Magic House**

We had another wonderful evening at the Magic House on February 22. Nearly 200 of our members joined us for an evening of science, exploration, history and magic! Thank you to the Magic House for making such a great family event possible. Stay in touch with the DSAGSL, so we can see you at more upcoming family events!

2.28.15 **New Family Brunch**

In February, the DSAGSL hosted our 2nd Annual New Family Brunch. Fifteen new families, including parents, grandparents, aunts, uncles, siblings and new babies enjoyed connecting with each other and hearing from local families and community groups. Thank you to all who were able to attend, our guest speakers and volunteers!

3.14.15 **Trivia Night**

The Annual St. Patty’s themed trivia night was a great success! Together, we raised over $31,000 to support individuals with Down syndrome and their families. The night was complete with delicious food, 50/50 raffles, a silent and live auction and of course, lots of trivia.
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.ratlff@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?ref=ts

### Saint Charles County Community Group  
CONTACT  
downs syndromestc@gmail.com  
Facebook: facebook.com/stcdsgroup

### Northern Missouri Community Group  
CONTACT  
beckypike@gmail.com, (660)627-7453; kmccurry@shighway.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: met roeastdsa.org  
  Facebook: facebook.com/groups/245883765486/

- **Southern Illinois Community Group**  
  (Carbondale, Creal Springs, IL and surrounding areas)  
  CONTACT  
  jaa kander1@yahoo.com, (618)922-5846  
  Facebook: facebook.com/pages/Southern-Illinois-Down-Syndrome-Supp ort-Group/10150122313390495

### OTHER DOWN SYNDROME GROUPS

- **Riverbend Down Syndrome Association**  
  (Southwest Illinois)  
  CONTACT  
  secretary@riverbenddds.org  
  (618)667-8771  
  Website: www.riverbenddds.org

- **Down Country**  
  (Hannibal, Quincy and surrounding areas)  
  CONTACT  
  info@upatdowncountry.com  
  217-617-3568  
  Website: www.upatdowncountry.com  
  Facebook: facebook.com/U patDownCountry

- **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  
  llds@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.
### 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 or two from one of our baby registries at Target or Babies R Us. Find our wish list by searching 'dsagsl' (first name) 'babies' (last name) in-store or online. Contact Christy at 314.961.2504 or christy@dsagsl.org with questions.

### Stay Connected

#### E-News Blasts

Are you receiving our e-mails? We send out an e-news blast several times a month filled with information, reminders and upcoming events. We also contact our members via e-mail when we have last minute special opportunities that you won’t want to miss. Please call our office at 314.961.2504 to make sure we have your current e-mail address so you don’t miss out!

#### 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!