DSAGSL **Donates** to LuMind Foundation

BIG NEWS! Based on feedback from our families to consider focusing on research, our Board of Directors recently voted to give a gift to the LuMind Foundation and their efforts toward cognition research. We look forward to sharing more about LuMind and research efforts happening nationwide. Thanks to all of you for the donations and support that make this possible!

**Down Syndrome **Awareness Month a Success!

Down Syndrome Awareness Month was stuffed full of activities to celebrate the many abilities of people with Down syndrome! The DSAGSL had their first billboard, static ads running at STL Cinemas and the 1st Annual Trunk or Treat held at the DSAGSL Office! Other events and activities included the 2nd Annual Talent Show, Window on St. Louis appearance, school t-shirt contests and presentations, social media campaign, state and city proclamations, super star awards and more!
Dear Friends:

As 2014 comes to an end, we want to thank anyone who is reading this for the part you’ve played in making it such a great year for DSAGSL. From our new home at 8531 Page to the number of new programs and events to the outstanding support of our fundraising events, it wouldn’t be out of line to argue this was DSAGSL’s best year to date.

That said, the season of New Year’s resolutions is upon us and we have one of our own: As good as 2014 was, we’re going to try to top it in 2015!

In this newsletter, you’ll see the new slate of DSA University programming on the way this spring. DSA-U offers direct programming for all ages of individuals with Down syndrome, and we continue to listen to your feedback in creating our course catalog. (In other words: Have an idea? Let us know!) You’re also hearing from us in the midst of planning our new Employment Initiative, which aims to prepare adults and transition-age individuals for meaningful work opportunities after their days at school have ended. We have a number of parents and volunteers involved in making this another high-quality program, and we’re excited to share it with you in 2015.

In addition to programming, it appears that advocacy efforts are making an impact as well. We were fortunate to give more community presentations during Down Syndrome Awareness Month, and as of the date I’m writing we’ve witnessed the ABLE Act’s journey of being passed in the U.S. House and moving forward to the Senate! We are preparing to see it through into law, and working with other organizations to make sure it is activated quickly in our states when it’s time.

Of course, all of this is made possible by our members. You are the ones who give so generously throughout the year, whether it’s a gift during our annual appeal taking place right now (hint, hint!) or during one of our special events. You’ll find more info in this issue about trivia, SUDS, and Run for 21 – we hope you’ll continue to work to make our growth an ongoing topic of conversation!

Thank you for the role you’ve played in such an outstanding year for DSAGSL. We are eager to keep sharing messages about our momentum and growth in 2015, our 40th year!

Sincerely,

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.
### My First Concert
by Lindsey Hawkins

“My mom and I went to a concert last Wednesday, and it was my first time to see a concert. I got the music for the band One Direction a week ago. It was great music. At the concert, it was amazing! It had bright lights and the walk was in colors as they were singing. The tickets were so close to the stage, and the music was loud. There were also fireworks going off in the concert, and they had fog before it began. I am now a fan of concerts!”

To read more of Lindsey’s blog, visit dsagsl.org/concert.

### Gus’ Playground
by Penny Long

“Gus’ Playground is located in Wilmore Park in South city. The park is located near Hampton and Gravois along River Des Peres. It is a universally accessible playground meaning there is something for people of all abilities to do, even those in wheelchairs. Our Alderman picked Gus because of his special needs and to honor the family of a police officer who gave his time to public service in the city of St. Louis. That person is Gus’ Papa Gabel who is retired from St. Louis City Police Department.

Soon there will be a sign with Gus’ picture from the grand opening and the words “Let’s Play!”

To read more of Penny’s blog, visit dsagsl.org/gus.

### Holiday Traditions
by Lindsey Hawkins, Abeo Anwisye and Grace Mehan

“1. How does your family celebrate the holidays?

**Lindsey:** I like to open gifts on Christmas Day with my family and celebrate on New Year’s Eve the best!

**Abeo:** Kwanzaa is my tradition. This year it starts December 26 and goes until January 1.

**Grace:** I love to stay home with my family. We wake up in the morning and open gifts from Santa and family. Then we eat dinner later.”

To read more of Lindsey, Abeo and Grace’s blog, visit dsagsl.org/holidaytraditions.

### Meet the New Face
by Abby Brandon

“I’d always known I wanted to do something that would allow me to make a positive difference in the world around me, but I wasn’t sure how I would do that. My senior year, I had the great opportunity to intern at the DSAGSL and from then on, I knew that I wanted to have a career in the nonprofit industry. I continued to volunteer with the DSAGSL Art Club for Adults after my semester as an intern ended, and I loved it! After I graduated, I had the great opportunity to do some temporary work as an Events Coordinator at the Donald Danforth Plant Science Center.”

To read more of Abby’s blog, visit dsagsl.org/abby.
A Focus on Aging

This fall, the DSAGSL focused on our aging population. There are many special considerations when you have a family member with Down syndrome. On November 11th, the DSAGSL partnered with the Albert Pujols Wellness Center for Adults with Down Syndrome to host “Down Syndrome and Aging” seminar featuring Dr. Cynthia Poelker and Stacey Laughlin, LCSW. Additionally, our September Coffee Talk featured Lee Bascom, MSW, LCSW, who discussed mental wellness in teens and adults. Below are highlights from these two important presentations. You can find more information at dsagsl.org/resources/health-wellness.

Physical Health
- The current life expectancy for a person with Down Syndrome is 60, a dramatic increase since even the 1980s.
- People with Down syndrome experience “accelerated aging,” meaning they face conditions and symptoms of aging at a younger age than people without Down syndrome.
- Common conditions associated with aging and Down Syndrome are vision and hearing loss, hypothyroidism, sleep apnea, osteoarthritis, osteoporosis, celiac disease, and early menopause.
- Hypothyroidism occurs in 10-40% of the Down Syndrome population. Symptoms include dry skin and brittle hair, mental and physical slowing, intolerance to cold and weight gain. Testing should occur annually.
- Hearing and vision loss can occur in up to 70% of individuals with Down syndrome. Vision and hearing should be tested every two years.
- Between 50 and 94% of people with Down syndrome will experience sleep apnea. Sleep apnea is when breathing pauses during sleep, leading to poor quality rest and can strain heart and lungs.
- Maintaining a healthy, balanced weight decreases the risk of hypothyroidism, as well as osteoarthritis. Physical activity and a balanced diet is essential!

Emotional / Mental Health
- Emotional and mental health conditions associated with aging and Down syndrome are depression, anxiety, obsessive compulsive disorder, and Alzheimer’s disease / dementia.
- The risk of depression is slightly higher in people with Down syndrome. Symptoms can include mood changes, decreased interests and ability to concentrate, sleep changes and change in appetite.
- It is important to rule out possible medical issues before diagnosing depression.
- People with Down syndrome are very empathetic and can often react to others' emotional expressions, conflicts, stresses, and tensions in their families, living environments, workplaces, and schools.
- “Loneliness is the only real disability.” Building and maintaining connections with friends and community members is essential to combat isolation and depression.
- Change in routines or people can trigger grief reactions for people with Down syndrome. Grief can be expressed differently in people with Down syndrome than those without and for longer periods of time.
- Diet, exercise, sleep, and social opportunities play a large role in mental and physical wellness. Self-care in these areas is vital to mental health.
- Self-talk can be developmentally appropriate for many adults with Down syndrome. Without hallucinations, delusions, paranoia, withdrawal from reality, or unusual affect, self-talk is not part of a mental illness.

Alzheimer’s Disease
- Alzheimer’s is the most common cause of dementia. It is the collection of illnesses that cause memory loss, decreased ability to communicate, navigate one’s environment and perform daily activities.
- It is caused by the build-up of beta-amyloid proteins outside of the brain cells and tangles of protein inside brain cells. These plaques and tangles cause brain cell death and shrinkage.
- New research shows that nearly all individuals with Down syndrome will develop the plaques and tangles, and by the age of 60+, between 60-75% will develop Alzheimer’s. The first symptoms occur at an average age of 50.
- Dementia in people with Down syndrome have more mood changes, auditory hallucinations and disturbed sleep, but a lower prevalence of aggression, visual hallucinations and delusions.
- All individuals with Down syndrome should get a baseline dementia screening at the age of 30. This will help monitor change over time.
- Some studies suggest regular exercise, recreation, and a healthy diet may have a positive impact on aging.
ABLE Act Signed into a Law!

Now that ABLE is the law of the land, DSAGSL is working to connect this benefit with our members as soon as possible. We are working with other local nonprofits to ensure legislators activate ABLE right away in our states. In early 2015, we expect to have info to share regarding how you can set up an ABLE account for your loved one with Down syndrome – and how you can inform others that can take advantage of this new law.

ABLE Act co-sponsors Sens. Bob Casey (D-PA) and Richard Burr (R-NC). Photo credit: NDSS.

March 31, 2015
Missouri State Capitol
Jefferson City, MO

The DSAGSL was once again proud to be a part of the planning committee for this event and will be participating in Disability Rights Legislative Day again this year.

We always welcome parents and self-advocates who want to represent our members and make important change affecting people with Down syndrome. Contact our office to learn more about how you can advocate for DSAGSL and our entire community!

FAQs About ABLE Accounts:

1. What is an ABLE account?
2. Why the need for ABLE Accounts?
3. Am I eligible for an ABLE account?
4. Are there limits to how much money can be put in an ABLE account?
5. Which expenses are allowed by ABLE accounts?
6. Where do I go to open an ABLE account?
7. Can I have more than one ABLE account?
8. Will states offer options to invest the savings contributed to an ABLE account?
9. How many eligible individuals and families might benefit from establishing an ABLE account?
10. How is an ABLE account different than a special needs or pooled trust?

Visit the following link to read these questions answered: http://bit.ly/1B2UeOA. Have a question that isn’t listed? Send it to emily@dsagsl.org and the DSAGSL will work to get it answered with the help of our community partners.
Mark your Calendar

Mark your calendar for these recurring DSAGSL programs, workshops and clubs. For more information or to RSVP, contact Erin at 314.961.2504 or erin@dsagsl.org

DSA-U Winter Session: Registration Closes January 20

Our fall programs were so much fun, we are running them again this winter. Classes begin January 26th. In addition to our most popular classes such as Chef for Life Cooking Class, Stories on STAGES Theater Class, Bodies and Boundaries, Art Club, and Healthy Start with Zumba, we are adding a Creative Movement class for toddlers as well as many new exciting dance, art and music programs at the St. Charles Academy of Fine Arts.

Visit http://dsagsl.org/programs/dsa-u/ or call Erin at 314.961.2504 for more information, for a complete course catalogue and to register. Registration closes January 20th.

Therapeutic Playgroups

The DSAGSL continues to host our popular and adorable monthly playgroups for children 0-3 of all abilities. Thanks to our wonderful teacher, Andi McCormick, we have expanded to offer a second play group in St. Charles. These free classes run from 9:30am - 11am on Mondays and Saturdays. Upcoming dates are:

- January 12: United Services St. Peters
- January 26: DSAGSL Office
- February 9: United Services St. Peters
- February 16: DSAGSL Office
- March 9: United Services St. Peters

Visit http://dsagsl.org/programs/dsa-u/ or call Erin at 314.961.2504 for more information.

Employment Academy Begins February 4

The DSA has heard from our members that meaningful, paid employment is a priority; therefore, we have launched our first employment initiative. This initiative will bring caregivers, job seekers, community agencies and businesses together to improve the employment landscape for our members. Part of this initiative is our new Employment Academy, a six-week course designed to improve professional etiquette, behaviors, resumes and interviewing skills.

Visit http://dsagsl.org/programs/dsa-u/ or call Erin at 314.961.2504 for more information.

Family Movie Night New Year Party

Help the DSA ring in the New Year with a fun family movie night and party on Friday, January 30th at 6:30pm. Sparkling cider will be flowing and the film will be rolling. We will be playing Muppets Most Wanted for all ages. Bring blankets, lawn chairs, snacks and friends.

RSVP to Erin@dsagsl.org or at 314.961.2504
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.

**JANUARY 16**
Education Specialist  
9 am - 3 pm  
DSAGSL Office

**JANUARY 20**
Registration Deadline for Winter DSA-U Classes

**JANUARY 30**
Family Movie Night  
6 pm - 8 pm  
DSAGSL Office

**FEBRUARY 28**
New Family Brunch  
10 am - 12 pm  
Jewish Community Center

**MARCH 14**
Trivia Night  
6 pm  
CBC High School

**MARCH 21**
World Down Syndrome Day  
Purina Farms Family Event  
11 am - 2 pm  
Purina Farms

**MARCH 22**
Relay and Run for 21  
Westport  
runfor21k.com

**MARCH 24**
Caregivers Guide to Guardianship  
5 pm - 6 pm Reception  
6 pm - 8 pm Presentation & Panel  
St. Luke’s Emerson Auditorium

Don’t miss the registration deadline for these DSA-U Classes

**At the DSAGSL Office**
- Healthy Start
- Stories on STAGES
- Mommy/Daddy & Me
- Chef 4 Life
- Employment Academy
- Teen & Adult Art Clubs at Turner Center for the Arts

**In Partnership with St. Charles Academy of Fine Arts**
- Beginning Ballroom Dance
- Show Tunes Choir and Dance
- Zumba
- Creative Moment
- West Coast Swing
- Yogapeutics
- Country/Western Line Dancing
- Poms and more!

Visit http://dsagsl.org/programs/dsa-u/ or call Erin at 314.961.2504 for more information, for a complete course catalogue and to register. Registration closes January 20th.
Congratulations to the 2014 Down Syndrome Super Stars!

Melisa and Jeremy Keltner - Your Story Photoart
Kirkwood KinderCare Staff
Alicia Klugh - Word of Life Lutheran School
Andrea McCormick
Ashley Poudrier
The Risher Family
Ruth Rosenkrans
Dr. Lisa Sutter and Team - Special School District
Brittany Vaughn - Headstart
The Village of the Blue Rose
Dr. Candace Wakefiled - Children's Dental Zone

Volunteer with the DSAGSL!

“No exercise is better for the human heart than reaching down and lifting another up.” - Jon M. Huntsman

**New Parent Support Volunteer**

Approximately 60 new babies are welcomed to the DSAGSL each year. Many of these families participate in our New Parent Support program. In this program, parent volunteers mentor new families during their baby’s first year. We are in need of additional volunteers for this program in all areas of Greater St. Louis and Illinois. Volunteers are required to attend training, which will be held at the DSAGSL office in the spring.

If you are interested in becoming a New Parent Support Volunteer, please contact Christy Klaus for a copy of the New Parent Support Volunteer Requirements. Reviewing these will help you decide if this is the volunteer opportunity for you. Christy can be reached at 314.961.2504 or at christy@dsagsl.org.

**Course Instructor**

The DSAGSL is looking for passionate educators to lead classes for our members with Down syndrome. Instructors are needed for the following classes:

- Nutrition and healthy cooking
- Resume writing and portfolio creation
- Etiquette and professional dress
- Interviewing skills
- Bike riding
- Adult art and crafts

If you are interested in leading a class, please contact Erin Suelmann at 314.961.2504 or at erin@dsagsl.org.

DSAGSL Out and About

See how DSAGSL Staff and Community Ambassadors helped spread awareness and support in our area.

- 8 Celebration baskets were presented to new families and babies with Down syndrome.
- 300+ teachers and paraprofessionals were provided education on teaching students with Down syndrome.
- 2 students from Word of Life Lutheran School won the Awareness Month t-shirt contest.
- 12 individuals and businesses were named Down Syndrome Super Stars.
- 6 families attended our first Spanish-speaking meet and greet.
Test your knowledge at the Down Syndrome Association of Greater St. Louis 6th Annual

St. Patty’s Trivia Night!

Down Syndrome Association
of Greater St. Louis

Saturday, March 14 // CBC High School // 1850 De La Salle Drive, St. Louis, MO 63141

Doors open at 6pm Trivia begins at 7pm. Reserve your table now! 314.961.2504
www.dsagsl.org

REGISTRATION IS OPEN!
www.runfor21k.com

RELAY & RUN FOR 21

HALF MARATHON
HALF MARATHON RELAY
7K RUN
FAMILY FUN RUN/WALK

REGISTRATION IS OPEN!
8.23.14 New Mother’s Luncheon

The DSAGSL and the Pujols Family Foundation hosted the annual New Mother’s Luncheon at the end of August. Approximately 35 new mothers enjoyed lunch at J. Gilbert’s Steakhouse and received a bag of gifts for themselves and their baby. This event gives new moms the opportunity to connect with one another, learn about our organizations and listen to inspiring stories from other mothers.

9.27.14 Pumpkin Palooza

The DSAGSL, in partnership with the Pujols Family Foundation, welcomed over 450 people at Rombach’s Farm for our annual Pumpkin Palooza Fall Family Picnic. Everyone enjoyed BBQ, pumpkin patches, haunted mazes and more. A great, fall, family fun time was had by all!

10.17.14 Talent Show

In October, the DSAGSL had our 2nd Annual Talent Show. Fourteen acts, including 52 participants and exhibiting artists, made us laugh, cry and feel completely inspired by the talent and creativity of individuals with Down syndrome. Everyone in attendance felt extremely “Happy!” A special thanks to Lindenwood University for their generous donation of the Cultural Center.

10.25.14 Trunk or Treat

The DSAGSL hosted the first ever Trunk or Treat on our office parking lot. Over 20 families enjoyed an unusually warm afternoon of trick or treating, a costume contest and car decorating contest. We hope to make it even bigger and better next year!

September - December Fall DSA-University Classes

Our first semester of DSA-U was a huge success! We welcomed 32 enrollees in our fall semester of classes. Classes include Healthy Start with Zumba, Chef for Life Cooking Class, Stories on Stage by STAGES St. Louis, Bodies and Boundaries and bike club. Our winter classes will be starting on January 26. Registration is open now. Register at http://dsagsl.org/programs/dsa-u by January 20.
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/S015924365464067ref=ts

Saint Charles County Community Group
CONTACT
downsyndromestc@gmail.com
(636)395-0110
Facebook: facebook.com/stcdsgroup

Northern Missouri Community Group
CONTACT
beckyjpike@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
amb2782@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@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/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! Email 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:

- Colored paper
- $0.48 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.

Order your copy of the 2015 calendar TODAY!

12 Months of beautiful, smiling faces - perfect for gifts, your home or office!

$10 per calendar, $2 per calendar to ship

Visit our website to download the order form or call the office at 314.961.2504.