



BIG news at the DSAGSL...

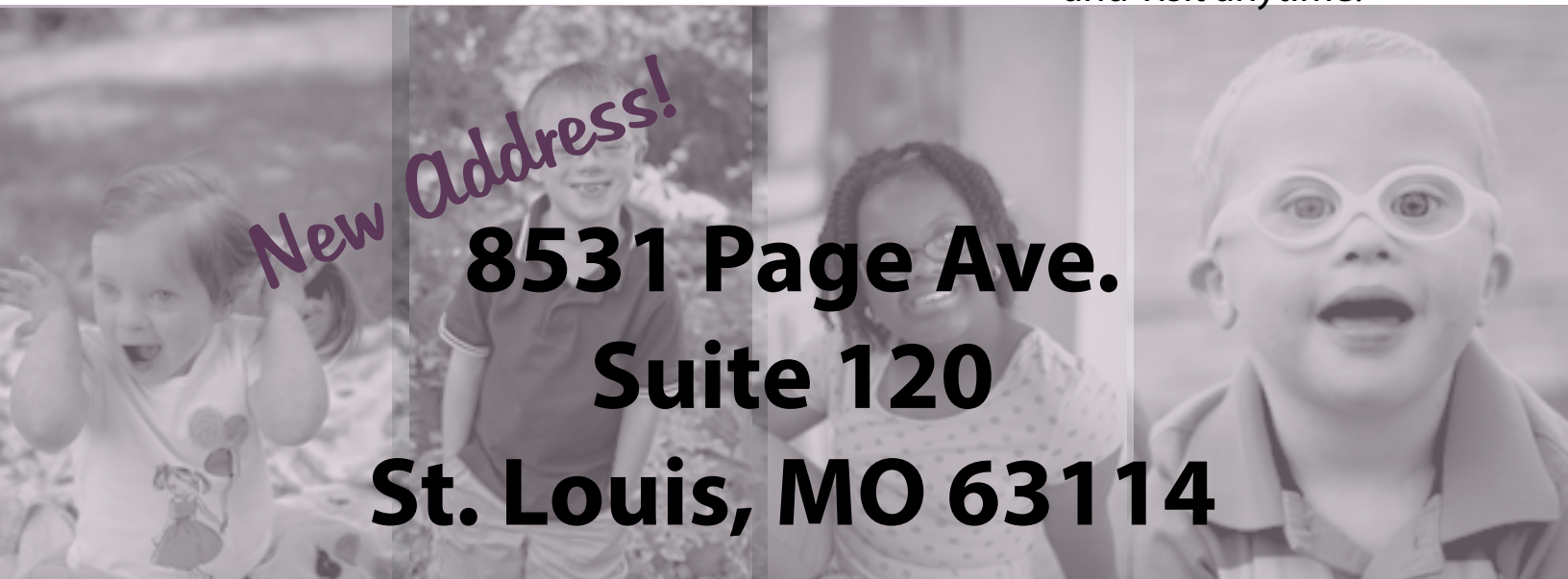
we moved!

Our new office has nearly double the space of our previous location, allowing us to offer more meetings, programs and events for our members. We expect it will become a home away from home for community groups, families and especially the 1900+ self-advocates with Down syndrome in our service area. We hosted an open house Saturday, February 22. If you missed it, stop by and visit anytime!



New Address!

**8531 Page Ave.
Suite 120
St. Louis, MO 63114**



DSAGSL
Board of Directors
2013-2014

President: Joe Harnar
Treasurer: Tom Fendya
Secretary: Dave Ruby

Board Members

Christine Alsop
Makini Anwisy
Betsy Brennan
Amy DeGuire
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Susan Pickert
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DSAGSL Staff

Executive Director
Jeremie Ballinger

Office Manager/Development Asst.
Barbara Arnold

Director of Programs & Services
Erin Suelmann

Marketing & Comm. Manager
Emily Gillardi

Family Support Coordinator
Christy Klaus

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:

I'm very fortunate and thrilled to be writing this letter from DSAGSL's brand new home at 8531 Page Avenue! We are very proud to share that this new space gives us more than twice the square footage of our old office, giving us twice as much capacity to serve all of you.



So exactly what does that mean? It means we aim to offer more direct programming for children and adults. We expect to see this office become a second home for self-advocates, and a place they can truly achieve our vision of reaching their full potential. We also plan to offer many more events, meetings and social events inside these walls for our members, and for the educational and medical communities.

This opportunity to grow is not lost on our staff or our Board of Directors. We are currently in the process of developing a three-year strategic plan for 2014-17, which will be completed before our next annual meeting in July. We welcome your input as we work to shape future years. Please don't hesitate to call or write me anytime with your thoughts about how we can deliver our mission better.

There is one more very important element worth mentioning about the new office: It's already been paid for. That is to say, any change in rent and all moving expenses are covered by the cost savings of keeping existing programs under our roof (rather than paying for facility rentals, for example), and by the great success of past events such as our Birdies & Bass golf tournament. This means that your current and future donations will not be paying for extra rent or utilities – it will pay for expanded programming and more opportunities for children and adults with Down syndrome!

We just learned that your DSA has once again met all 20 accountability standards from the Better Business Bureau. According to the BBB website, we are one of only two accredited Down syndrome charities nationwide (National DS Society being the other), and the only local DSA with BBB accreditation. We take great pride in that distinction, and will continue to do so.

It bears saying once again...it's hard to think of a more exciting time for this organization and for individuals with Down syndrome in our city. We invite you to visit our office soon if you haven't already, or to attend one of the new events and programs you'll be seeing from DSAGSL this spring and summer. Hope to see you there!

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 supports, 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

sherry.bowen@lifeskills-mo.org
(314)432-6200

Heartland Community Group

(Southeast Missouri and Southern Illinois)

Facebook: facebook.com/HeartlandDSA

CONTACT

heartlanddsa@msn.com
(573)334-5685

Central Missouri Down Syndrome Family Network

CONTACT

centralmodsfamilynetwork@gmail.com
(573)230-7230

Facebook: facebook.com/centralmods-familynetwork

Down Syndrome Group of the Lake of the Ozarks

(Camdenton, MO and surrounding areas)

CONTACT

dsgloz@hotmail.com
(573)374-8337

Jefferson County Community Group

CONTACT

Facebook: facebook.com/jeffcods
carlawerk@charter.net
(314)420-4450.

Kirkwood/Webster Community Group

CONTACT

joyce@objectnirvana.com/(314)822-2227;
dewdrop519@yahoo.com/(618)570-8485;
emily.rafliff@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

vrcorg@gmail.com
(314)222-7047

Facebook: facebook.com/pages/North-County-Down-Syndrome-Community-Group-STL/501592436546406?fref=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@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
or crisbyrd@hotmail.com, (618)684-3295
Facebook: facebook.com/pages/Southern-Illinois-Down-Syndrome-Support-Group/10150122313390495

Riverbend Down Syndrome Association

(Southwest Illinois)

CONTACT

secretary@riverbendds.org
(618)667-8771

Website: www.riverbendds.org

OTHER DOWN SYNDROME GROUPS

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.

SHARE IT!

10.29.13 DSAGSL Talent Show

Everyone had a blast at our First Annual Talent Show on October 29 at the Westport Playhouse. It was so popular, we had a standing room only audience! Our participants all showed off their tremendous talents including singing, dancing, musical performances, a magic show, Tai Chi demonstration and an art exhibit. Make sure to get your seat for the 2014 DSAGSL Talent Show on October 24!



11.24.13 Night at the Magic House

It may have been cold outside, but we had a magical evening exploring, playing and learning inside on November 24. Hands-on learning disguised as fun was the specialty of the night. Thank you to our friends at The Magic House St. Louis Children's Museum for hosting this very special evening!

1.4.14 Music Mania with Ranken Jordan

Ranken Jordan was our host for a Music Therapy event on January 4! During this morning gathering, kids ages 4-16 were able to listen to music, participate in music related games, learn how to play different instruments and of course dance! This is the second year for this event and was a success with those who attended.

Ranken Jordan offers a variety of free community events. Find more on their website at www.rankenjordan.org.



1.16.14 Education Specialist Program: Completes 7th Year!

We are proud to announce the completion of our seventh year of the Education Specialist Program in St. Louis. We have formed a successful partnership with Tri-County Special Education Cooperative to complete our first program in Carbondale, IL. Our program is designed to meet the needs of educators who support students with Down syndrome. We have served 95 individuals including educators, parents, therapists and administrators in over 30 districts across eastern Missouri and southern Illinois.

For more information or to sign up for the next session, contact Erin at erin@dsagsl.org.

2.8.14 Arch-Stravaganza

We were excited to host our second free private family event at the St. Louis Arch this year, and the night surely exceeded expectations! We had over 300 people RSVP to the event and everyone enjoyed trips to the top of the Arch, photo opps, movies, the Museum of Westward Expansion and so much more!





Registration now open - reserve your spot today!

DSAGSL will once again offer a bike camp in 2014! We are pleased to host the Lydia Cox Memorial Bike Camp from June 2-6, 2014 at South Technical High School. This camp has been made possible through the support of the Lydia Faith Cox Family Foundation, Variety St. Louis and the St. Louis Blues. The bike camp curriculum and equipment are provided by iCan Shine (formerly Lose the Training Wheels).

During our bike camp, individuals with Down syndrome will learn to ride a conventional two-wheel bicycle with the goal of becoming lifelong independent riders. Graduates of this program gain self-confidence in

their abilities, which can impact other aspects of their lives.

Registration for the Lydia Cox Memorial Bike Camp is now open at www.dsagsl.org, open to the first 35 successful applicants due to space limitations. We anticipate a full camp as always, so please plan to apply as early as possible. A camp fee of \$150 per rider will apply, and all riders must be at least 8 years old and meet additional requirements.

If you have questions about bike camp and how your child can benefit from the program, please call 314.961.2504. We look forward to sharing great success stories and photos about our camp again this coming year!

Bike Camp Volunteers Wanted!

We are looking for volunteers to work directly with our bike camp participants. This is an inspiring and rewarding opportunity to make a difference in the life of an individual with Down syndrome. You won't want to miss this event!

Volunteers can select a session time(s) from the choices below. Note that when you commit, you are committing to all five days of camp from June 2-6. You will also be required to attend a training session on Sunday, June 1.

8:15am - 9:45am 9:50am - 11:20am 11:25am - 12:55pm 1:45 pm - 3:15 pm 3:20pm - 5:00pm

Call 314.961.2504 or write erin@dsagsl.org to request a volunteer application. Volunteers will be assigned to sessions on a first-come, first-served basis. Contact us right away to guarantee your preferred session.



Registration now open!

Join us on June 8 at Forest Park and Step Up for Down Syndrome!

Sunday, June 8
Upper Muny Parking Lot
Forest Park, St. Louis

9 am: Registration
9 am - 12:30 pm: Family Festival
10:00 am: Walk Begins

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.

all about IEP resources for planning, implementing and seeing results from your child's IEP

It's that time of year again - IEP season - a time where parents and educators come together to evaluate what progress has been made and establish new goals. We have compiled a list of resources that we hope you will find helpful during this process.

IEP Resources

Making the Most of the IEP Process

<http://www.ssdmo.org/step2.html>

http://www.education.com/reference/article/Ref_Communicating_IEP/

Writing Effective IEP Goals

specialed.about.com/od/iep/a/iepGoalWriting

specialeducationadvisor.com/ten-steps-to-writing-effective-iep-goals

Laws

IDEA (Individuals with Disabilities Education Act) <http://idea.ed.gov/>

<http://www.wrightslaw.com/>

Training

Special School District Parent Workshops: http://www.ssdmo.org/cool_tools/workshops.html

MPACT is statewide parent training and information center that serves parents of children with all disabilities

<http://www.ptimpact.org/>

DSAGSL Archives: How to Have Your Best IEP - listen, watch, download information

<http://dsagsl.org/programs-resources/educational-programming/>



spreading holiday CHEER!

On December 8, the DSAGSL hosted a Holiday Party at the Maryland Heights Centre. Everyone had a great time!



dsagsHIGHLIGHTS *check out what we've been up to lately*

"We Just Got an iPad, Now What?!" - What you missed at Coffee Talk!

In January, the DSAGSL welcomed Lori and David Holbrook, parents to Hannah, owners of CHAT Bag, LLC, and expert presenters on the utilization of iPads and individuals with their daughter when she was seven and have since become passionate about improving communication through the use of technology. The presentation is archived at: <http://dsagsl.org/programs-resources/educational-programming/>.

Tips from the Presentation:

1. iPads are motivating because they offer lots of sensory input, allow independence, and provide inclusion in everyday situations.
2. When researching apps, ask yourself the following:
 - What are the reviews?
 - Is there a website associated with the app?
 - Can I contact the developer to ask questions?
 - Is there a "Lite/Free" version to try out first?
 - What is the cost involved and how does it compare to other apps?
 - What is the feedback from other parents, therapists, teachers or success/ failure?
3. Learn about apps by visiting websites, Facebook pages, Pinterest, and by reading books, blogs and news stories. Also, talk to other parents, teachers and therapists! Visit Lori's blog at <http://chatabouttablets.net/blog/resources-for-the-apple.html> for a complete list of resources.
4. When checking out app websites, ensure they are user-friendly. Great ones are user friendly and have newsletters or blogs, social media and app reviews by parents and professionals.
5. Get your child a sturdy, adjustable carrying case. Hannah carries her iPad in a CHAT Bag, made with tender loving care by her mother, Lori. For more information about the CHAT Bags, visit www.chatbag.net.



Resources from Lori and David


- iTeach Special Education – www.facebook.com/groups/iTeachSpecialEducation/
- www.pinterest.com/lasenders/
- Bridging Apps – www.bridgingapps.org
- Getting Started: iPads for Special Needs by Sami Rahman


Hannah's Top Apps on iTunes!

- Proloquo 2 Go –communication app; \$219.99
- Choiceworks –picture schedule; \$6.99
- Choiceworks Calendar – visual calendar creator; \$4.99
- iWriteWords – handwriting app; \$2.99
- Paint Sparkles – fun for letters or coloring; Free
- Twinkle's Little Stars- cause/effect; \$1.99
- Twinkle Bells – cause/effect; Free
- Photo Buttons – cause/effect; \$1.99

Contact/Connect with David and Lori:

www.chatbag.net
chatbag@hotmail.com

 / CHAT Bag

 / chatbag

AWARENESS & ADVOCACY

ABLE Act Making Progress

As you may already know, the ABLE (Achieving a Better Life Experience) Act was introduced in 2012 and reintroduced in 2013. The passage of ABLE would amend Section 529 of the IRS Code of 1986 to create tax-free savings accounts for individuals with disabilities, and assist families with costs associated with healthcare, employment, housing, transportation and education. We're pleased to share that, as of the date of this newsletter, 328 Representatives and 62 Senators have signed on to support ABLE. This number includes three of the four Missouri/Illinois senators and every member of the House from the St. Louis area. Advocates are now working to have the bill taken to a vote, which will include advocacy during February's Buddy Walk on Washington.

Our friends at the National Down Syndrome Society (www.ndss.org) have more info on ABLE and how you can use your voice on this issue via mail, email and social media. We will also post updates on our blog at dsagsl.org.

Disability Rights Legislative Day

DSAGSL is pleased to be a part of the organizing committee for Disability Rights Legislative Day in Missouri. This event will be held Wednesday, April 2 in Jefferson City and will allow advocates to spend time with their local legislators in addition to a rally and learning more about meaningful issues to people with disabilities throughout Missouri.

If you are interested in joining our delegation for this event, call 314.961.2504 or email jeremie@dsagsl.org.



upcomingEVENTS

mark your calendars -
we'll see you there!

2014 Trivia Night

March 15

It's back! Our annual Trivia Night is coming a little earlier this year and we are celebrating with a St. Patrick's Day theme. Reserve your table now and sign up your team!

RSVP now to make a night of it! Contact the DSAGSL office at 314.961.2504 or barbara@dsagsl.org.



New Family Brunch

March 28

The DSAGSL welcomes the family and friends of babies born in 2013 and 2014 to this fun, morning event! A light brunch will be served while families mingle, hear inspiring stories and ask questions of veteran DSAGSL parents. Childcare will be provided for babies and siblings!

RSVP to Christy at 314.961.2504 or christy@dsagsl.org.

Family Picnic

May 10

Join us and the Pujols Wellness Center for our FUN and FREE annual picnic. Activities will include music, bounce houses, face painting, games and crafts! There will be an area for new parents to connect with each other. Lunch will be provided. Bring lawn chairs, blankets and any outside games for an afternoon of fun!

RSVP to Erin at 314.961.2504 or erin@dsagsl.org by May 5.



DSAGSL Monthly Events

Various monthly dates

CoffeeTalk-opentoallparentsandguardians

Meetings are held in the DSAGSL office at 6:30pm

- March 18: Special Needs Financial Planning
- April 15: Down syndrome & Alzheimer's Disease
- May 20: Care of Self/Care of Others

ComicBookClub-opentoallabilities,age16-

Meetings are held at the DSAGSL Office at 6:30pm

- March 18
- April 15
- May 13

Toastmasters-opentoallabilities,age18+

Meetings are held in the DSAGSL office at 6:30pm

- March 4
- April 1
- May 6

Don't miss out!
Contact us at 314.961.2504 or
info@dsagsl.org for more info or to RSVP

For more events from our community partners, visit our
website at www.dsagsl.org

Don't miss Bodies and Boundaries - with Terri Couwenhoven, Saturday, April 12th!



Terri Couwenhoven, the nationally known author of Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality and certified sexual educator, who is also the mother of a child with Down syndrome, encourages parents to be proactive and talk directly and openly to children, teens, and adults about their bodies, personal boundaries, privacy, puberty, sexuality, relationships and abuse prevention. This six hour interactive workshop, targeting parents with children, teens and adults, will cover sexual learning in individuals with disabilities, normal sexual development across the lifespan, and issues and concerns during puberty and beyond. Terri's gentle, matter-of-fact approach combined with extensive knowledge and experience make her a popular speaker with self-advocates, parents and professionals around the country. For more information about this workshop contact Erin at 314.961.2504 or erin@dsagsl.org.

Gift a little, do a lot - the DSAGSL now has it's own new baby registries!

We work to make new parents of children with Down syndrome feel welcomed into our community by providing them with the support and resources they need during the first moments of their child's life and beyond. Recently, we started a new initiative to enhance their first days with their little one - our new baby celebration baskets! You can help fill our baskets with the essentials (and some really cute onesies) by purchasing a gift or two from one of our baby registries, now available at Target and Babies R Us. Finding our wish list is easy - simply search (first name) 'dsagsl' (last name) 'babies' in-store or online. *Have questions? Contact Christy at 314.961.2504 or christy@dsagsl.org.*



Join us for Coffee Talk!

Join us on the third Tuesday evening of each month for Coffee Talk. Topics covered will include special education applications, behavior management strategies, financial planning, dual diagnoses, mental wellness and more!

For questions or to RSVP for Coffee Talk, contact Erin at erin@dsagsl.org.

don't miss our new...

COMIC BOOK CLUB



On the third Tuesday of every month

...At the DSAGSL OFFICE from 6:30-7:30pm...

...a new club dedicated to perfecting SUPER skills like reading, writing, art and conversation....



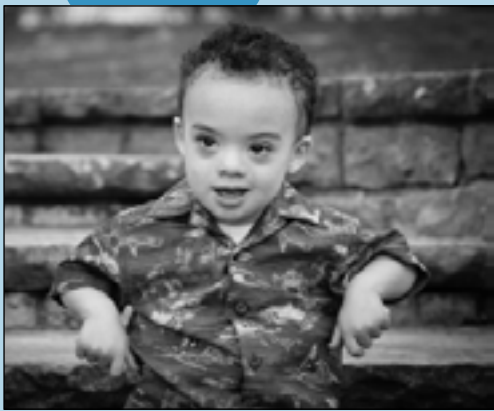
email ERIN@dsagsl.org to RSVP for our FIRST meeting of the MINDS!

World Down Syndrome Day

Celebrate value, acceptance and inclusion on 3.21!

About World Down Syndrome Day

World Down Syndrome Day was established in 2006 by Down Syndrome International, with the goal of raising awareness and mobilizing support and recognition of the dignity, rights and well-being of people with Down syndrome across the world. People with Down syndrome, their families, friends, teachers, coworkers and supporters will be celebrating across the globe. It is celebrated on the 21st day of the third month of the year, symbolic of the third copy of the 21st chromosome that characterizes Down syndrome. For more information visit www.worlddownsyndromeday.org.



World Down Syndrome Day 2014 Theme

“Health and Wellbeing - Access and Equality for All”

All people with Down syndrome have the right to access healthcare when required on an equal basis with others without discrimination and with proper assessment of the specific health needs of the individual. We will be highlighting that:

1. Having Down syndrome does not make a person unhealthy.
2. Down syndrome is a genetic condition, not an illness.
3. People with Down syndrome may have health issues throughout their lives, just like everyone else and they should have access to healthcare on an equal basis with others.
4. There are specific known health issues which may affect people with Down syndrome, for which accurate, evidence based information is available.
5. Health professionals should be aware of these specific issues when treating a person with Down syndrome.
6. Health professionals should not discriminate against people with Down syndrome by:
 - refusing to treat them;
 - blaming health issues on Down syndrome in general, or;
 - considering only specific known health issues which may affect people with Down syndrome.

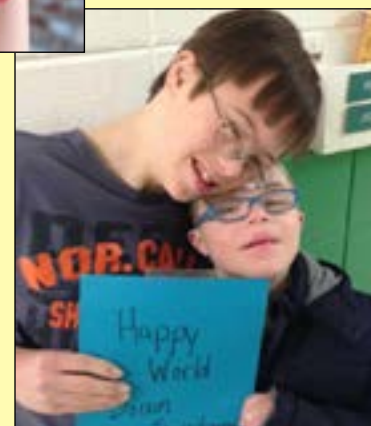
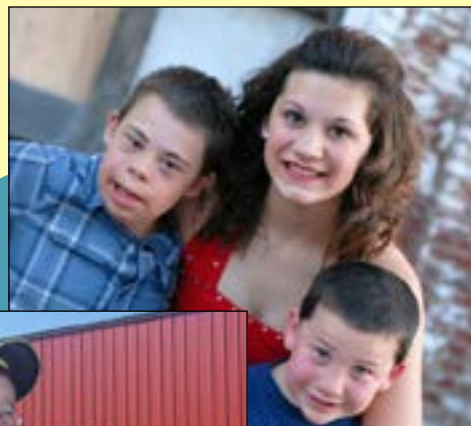


Down Syndrome Day 2014

21 Ways to Celebrate World Down Syndrome Day

- 1 Hang up a WDS Awareness Poster from our website: dsagsl.org/wdsd
- 2 Change your profile or picture or cover photo on Facebook
- 3 Attend a community group celebration
- 4 Present at your loved one's school
- 5 Follow DSAGSL on Social Media
- 6 Visit www.dsagsl.org/wdsd
- 7 Tell 3 people about people first language
- 8 Register to Run for 21 (runfor21k.com)
- 9 Share information with your health professional
- 10 Send your 3.21 photo to emily@dsagsl.org
- 11 Rent a movie or watch a TV show that features an actor with Down syndrome
- 12 Bring an age appropriate book and a blue and yellow snack to your child's class
- 13 Write a letter to the editor for your favorite newspaper or website
- 14 Show a video from youtube.com/stlouisdca
- 15 Visit a local business that employs people with disabilities
- 16 Sign up for a DSAGSL calendar photoshoot (begins Friday 3.21.14)
- 17 Register to attend the National Down Syndrome Congress Conference
- 18 Donate books on Down syndrome to your local library
- 19 Invite your child's favorite classmate over to play
- 20 Make sure your families listing is updated on the National Down Syndrome Registry
- 21 Make a donation to DSAGSL in honor of your favorite child or adult with Down Syndrome

World Down Syndrome Day Memories





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

 /dsagsl  /dsagsl  /dsagsl  /stlouisdsa

Wish List

Office Needs

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

- Auction items for Trivia Night
- Computer monitor(s)
- \$0.48 or Forever stamps
- Bubble/padded mailing envelopes
- Paper goods (plates, towels, etc.)
- iTunes gift cards (app downloads)

Check it out!

Upcoming events with the DSAGSL

- Coffee Talk: March 18, April 15, May 20
- Comic Book Club: Tuesday, March 18, April 15
- Toastmasters: Tuesday, March 4, April 1, May 6
- DSAGSL Open House: Saturday, February 22
- 2014 Trivia Night: Saturday, March 15
- World Down Syndrome Day: Friday, March 21
- New Family Brunch: Saturday, March 29
- Bodies and Boundaries: Saturday, April 12
- Family Picnic: Saturday, May 10
- Lydia Cox Memorial Bike Camp: Monday June 2 - Friday June 6
- Step Up for Down Syndrome: Sunday, June 8

Doctor Recommendations

If you know a great doctor we can share with families in the area, please send contact info to christy@dsagsl.org