

THE IMPORTANCE OF IMMUNE SYSTEM DYSREGULATION IN PEOPLE WITH DOWN SYNDROME

How does an extra copy of chromosome 21 drive the developmental and clinical features of Down syndrome? This question has been the subject of many investigations since 1958, when Jerome Lejeune reported the presence of trisomy 21 in cells of people with Down syndrome. The answer has remained elusive. Now, research from the Linda Crnic Institute for Down Syndrome points to dysregulation of the immune system as a mechanism by which the extra chromosome would cause this multi-organ, multi system condition. The implication of these results are profound, because they not only provide a new conceptual framework for future research, but also illuminate avenues for the development of novel diagnostic and therapeutic opportunities to improve health outcomes in Down syndrome.



Of the more than 20,000 genes encoded in the human genome, chromosome 21 carries fewer than 300, the lowest number of genes on any human chromosome. While consensus among scientists is that Down syndrome is a “polygenic condition,” a condition caused by increased activity of more than one gene, it is also agreed that not all genes on chromosome 21 would contribute equally to the condition. If one were to select a random group of 300 genes, it is recognized that only a few genes would be master regulators of cellular and organismal function. What then are the master regulator genes on chromosome 21 with the greatest impact on human biology? To address this question, scientists at the Crnic Institute employed an approach known as functional genomics, which involves measurements of the activity of thousands of genes across the entire genome, to identify the gene networks most impacted by trisomy 21.

OVERACTIVE IMMUNE SYSTEMS?

The first set of results from the analysis of cells of people with Down syndrome (Sullivan et al., 2016) revealed that trisomy 21 causes constitutive activation of the gene network known as the Interferon response, a key branch of the immune system responsible for fighting off viral infections. In cells from typical people, the Interferon response was dormant, but cells from people with Down syndrome seemed to be fighting off a viral infection that just wasn't there. These results immediately drove attention to four genes on chromosome 21 known as the Interferon receptors, which are required for cells and tissues to respond to a viral infection and

whose triplication could potentially trigger constant activation of this arm of the immune system.

The second set of results from the analysis of blood samples (Sullivan et al., 2017) revealed signs of chronic autoinflammation in people with Down syndrome. Measurements of approximately 4,000 different proteins in the blood identified about 300 that are differentially abundant between people with and without Down syndrome, with about half of those 300 proteins being involved in the immune system. Importantly, this study revealed signs of both constant activation and exhaustion of different aspects of the immune system, with obvious ties to the Interferon response. It is well established that the Interferon response enhances anti-viral defenses, but too much Interferon activity eventually weakens antibacterial defenses. Indeed, the results of the blood analysis were consistent with a type of immune dysregulation caused by lifelong hyperactivation of the Interferon response. Noteworthy, both studies revealed, among people with Down syndrome, strong inter-individual variation in the degree of activation of the Interferon response and autoinflammation, which could potentially be linked to the obvious clinical diversity in this population.

GREATER INSIGHTS AND POTENTIAL TREATMENTS

(continued on page 11)

A MESSAGE FROM ERIN



Spring has sprung at the Down Syndrome Association of Greater St. Louis and we couldn't be more excited! I hope you were able to join us for World Down Syndrome Day or celebrate wherever you are. I know we had a blast highlighting the many talents and achievements of people with Down syndrome. Many thanks to our Young Friends Board who hosted our celebration at Pieces: A Board Game Bar in Soulard, as well as to The Diamond Family for hosting a profit share at the Manchester store! I also can't go without thanking our many volunteers, friends, family members, and donors who joined us in the office and at our DSAGSL Rocks! concert at the Tin Roof. You all made the day and week extra-special!

Speaking of extra-special, don't forget to register for Step Up for Down Syndrome (SUDS) and the Run for 21 3.21 mile race in Forest Park, both being held on June 2nd. We've made many exciting changes to make this year's event extra-special including adding food trucks, live music, a talent showcase, vendor village, and more! There is something for everyone and you won't want to miss it!

And while I love talking about our events, this newsletter is mostly about support and education. The DSAGSL strives to be the most comprehensive resource on Down syndrome and the place our families, both veteran and brand new, turn to for information and strategies during every stage of life. I am excited to lead the DSAGSL through strategic planning this year so that we may grow our programs and services to meet the changing needs of our community. I hope to connect with many of you during this process to gather your input and ideas. In the meantime, I send a big "thank you" for all you do every day to benefit the lives of people with Down syndrome.

Sincerely,

A handwritten signature in black ink, which appears to read "Erin Suelmann".

Erin Suelmann
Executive Director

WELCOME JONATHAN

Jonathan Waldron joined the DSAGSL Board of Directors this February, continuing the strong relationship his law firm, Lathrop Gage, LLP, has had with DSAGSL for the past 13 years. As a child, Jonathan became friends with other kids with Down syndrome when he frequently accompanied his mother, a physical therapist, on home visits. Those relationships taught him the tremendous value those with Down syndrome possess and how rewarding serving them can be.

Professionally, Jonathan is a partner with Lathrop Gage, LLP, and represents corporate and individual clients in business litigation, policy-holder insurance recovery, and environmental litigation matters. Although he primarily handles large complex litigation matters, some of his most fulfilling cases have involved successful pro bono representations he has undertaken for the underserved. Before entering civil practice, Jonathan served five years in two branches of the federal government. He earned his Juris Doctor from the University of Missouri-Columbia School of Law and separate undergraduate degrees from St. Louis University in Political Science and Communications. He is a 1999 graduate of Fort Zumwalt South High School.



A native of St. Peters, Missouri, Jonathan now resides in Clayton with his wife, Catherine, and their three children: Sarah (11), David (8), and Grace (4). When not coaching his kids' youth sports teams, Jonathan enjoys outdoor activities with his family, including backpacking, canoeing, fun at the beach, sledding, and exploring state and national parks. One unusual thing most people do not know about him is that he was bitten by a shark on vacation when he was 16 years old – but still loves to spend time in the ocean!

DSAGSL.ORG GETS AN UPGRADE

The mission of the DSAGSL is to support individuals with Down syndrome and their families. The vision of the organization is to be the most comprehensive resource on Down syndrome. One of the most valuable resources the Down Syndrome Association of Greater St. Louis can offer is access to information and services on our website.

DSAGSL.org serves as a hub for everything the organization is doing to support the Down syndrome community. Visitors can find DSAGSL program details and registration forms, event information and volunteer needs, a secure donation platform and membership page, as well as a library of resources for families, self-advocates, educators, and medical professionals.

The new website design is efficiently organized and easy to navigate, and helps visitors find the information they need quickly. Research can be overwhelming and DSAGSL wanted to make sure that when people come to find answers to their questions about Down syndrome, the process is as easy as possible for them. It also features beautiful photos of our amazing families! Thank you to the photographers who donate their time each year to capture these amazing photos.

Check out the new design and let us know what you think! <https://www.dsagsl.org>



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

CONTACT US

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STUDIES SHOW INCLUSIVE CLASSROOMS CAN BENEFIT ALL STUDENTS

Today, it's well known by parents, educators, and disability-professionals that inclusive classrooms benefit students with Down syndrome and other intellectual disabilities, academically and socially. According to *A Summary of the Evidence on Inclusive Education* by Dr. Thomas Hehir, Dr. Todd Grindal, Brian Freeman, Renee Lamoreau, Yolanda Borquaye, and Samantha Burke, research shows that students with Down syndrome who spend most of their time in a classroom with non-disabled students have improved language and mathematic achievements than students with Down syndrome who do not. Additionally, students with intellectual disabilities that are included in typical classrooms are nearly twice as likely to enroll in some sort of post-secondary education, and 11% more likely to be employed and earn more per year (pg 15).

Although the academic and social benefits for students with Down syndrome who spend their time in classrooms with typical peers is widely known, there is still some concern regarding the impact inclusive classrooms may have on the academic performance of typically developing students. "They may worry that the modifications or accommodations that students with disabilities require in inclusive classrooms will impede the learning of non-disabled students" (pg 7). However, research conducted around the world shows evidence that typically developing students in inclusive classrooms can benefit from learning alongside students with disabilities.

Several studies show that there is a neutral or positive impact on the academic success of students without disabilities that are in classrooms with students who do have a disability (pg 7). Furthermore, students without disabilities that learn in inclusive classrooms are more likely to have friends with disabilities, be more likely to stand up for their peers with disabilities, be less prejudice, less patronizing, and have fewer pitying behaviors toward students with disabilities (pg 12). In addition, students without disabilities had reduced fear of human differences, accompanied by increased comfort and awareness, growth in social cognition, improvements in self-concept, and development of personal moral and ethical principals (pg 12).

So, what exactly is inclusion? The report defines inclusion as involving "a process or systematic reform embodying changes and modifications in content, teaching methods,

approaches, structures, and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences" (pg 3). In other words, when students with intellectual or developmental disabilities are in a mainstream classroom without adapted curriculum, instruction, and learning strategies, then the classroom is not fully inclusive, it is integrated (pg 3). However, integration is the first step toward inclusion.

Research suggests that full inclusion in the classroom requires collaboration and individualized plans that meet each student's needs. "Effective inclusive education requires teachers and other educational professionals to regularly engage in collaborative problem solving." The report continues, "The collaboration may involve interactions between classroom teachers, speech and language specialist, school psychologists, and the principal, who all work together to meet the needs of each individual student, dividing time and sharing resources." (pg 10). In short, it is a team effort amongst several educational professionals, along with parents, and requires an individualized approach with the student's needs directing the educational strategies.

Collaboration among professionals is key to creating a fully inclusive classroom, however, according to the article, the first step is to examine the educator's attitude toward students with disabilities and inclusive classrooms. Exposure, education, and awareness all influence the perspective an educator may already have and can also influence changing that perspective. "Research suggests a positive correlation between the amount of disability education or teacher training and positive attitudes towards inclusion." (pg 9).

In addition to examining attitudes, successful inclusion requires education, resources, strategies, and techniques for educators. "...positive effects were most common in studies where support for students with disabilities in the inclusive classrooms was well-managed through adaptive instruction and the collaborative consultation and cooperative teaching of special and general education teachers. (pg 9).



The Down Syndrome Educational Specialist Program at the Down Syndrome Association of Greater St. Louis addresses these topics with teachers, education professionals, and parents. Participants leave with knowledge of theory, as well as applicable strategies they can begin using in the classroom immediately. In addition, program participants become part

of a network of educators that receive resources, tools, and continued support as they create a more inclusive classroom.

To read the full article visit dsagsl.org/resources/education

5 TIPS FOR PARENTS TO PROMOTE INCLUSION FOR YOUR CHILD

1. Share your vision with the IEP team – for educational goals, social goals and your child’s future
2. For therapy minutes (PT, OT, SLP), discuss with IEP team on how these can happen during class time with peers
3. Share important information about your child – health, motivators, learning style. Stay in regular communication with the IEP team/case coordinator.
4. Help the classroom or school learn about Down syndrome by sharing information, presenting to the classroom or scheduling a presentation through the DSAGSL.
5. Check into the extra-curricular activities offered by the school and discuss how your child can participate.

5 TIPS FOR EDUCATING STUDENTS WITH DOWN SYNDROME IN GENERAL EDUCATION CLASSROOMS

1. Ensure that the student has access to a communication system
2. Model a classroom of belonging by allowing students to share ideas and answer questions according to their ability
3. Seat students with Down syndrome with other students and allow peers to be the first choice for supporting the student
4. Establish a “Lunch Bunch” or similar program to help with social inclusion
5. Learn about Down syndrome and consider attending the DSAGSL Down Syndrome Specialist Training offered in the summer and the school year

Adapted from

Quick Tips for Teaching Children with Down Syndrome: www.dsconnection.org, and Creating Inclusive Classrooms that Work: www.pealcenter.org

DOWN SYNDROME EDUCATION SPECIALIST 2 DAY SUMMER SESSION

July 25 & 26, 9am-4pm at the DSAGSL Office

The goal of the Down Syndrome Education Specialist Program is to provide support for educators, professionals, parents and caregivers, seeking to build meaningful education for students with Down syndrome. This is an interactive class and participants will have the opportunity to work through questions, problems, and discuss solutions with other professionals, and leave with applicable tools and resources to use right away in the classroom.

Learn more and sign up by visiting dsagsl.org/programs/education-specialist

SAVE THE DATE

SPRING

BIRDIES & BASS GOLF TOURNAMENT

Monday, May 13 starting at 9:00am
at Persimmon Woods Golf Club
dsagsl.org/events/golf

YOUNG FRIENDS BOARD 21 CLUB DAY AT THE PARK

Sunday, May 19 from 1:00pm-4:00pm
at Tilles Park in Brentwood
dsagsl.org/programs/21-club-social-events

SUMMER

RUN FOR 21

Sunday, June 2 starting at 8:00am
Race Course through Forest Park
dsagsl.org/events/run-for-21

STEP UP FOR DOWN SYNDROME

Sunday, June 2, 8:30am-12:30pm
Upper Munny Parking Lot in Forest Park
support.dsagsl.org/stepup2019

LYDIA COX MEMORIAL BIKE CAMP

Monday, June 3- Friday, June 7
South Technical High School
lydiafaithcoxfamilyfoundation.com

SMALL STEPS THERAPY CAMP

Tuesday, July 16 - Thursday, July 18
9:30am- 12:00pm at United Services for Children
dsagsl.org/programs/small-steps

DOWN SYNDROME EDUCATION SPECIALIST- SUMMER

Thursday, July 25 & Friday, July 26
9:00am-4:00pm at the DSAGSL Office
dsagsl.org/programs/education-specialist

FESTABILITY

Saturday, July 27, 11:00am-6:00pm
Missouri History Museum
festability.org

ROCK 21 CONCERT

Saturday, August 3, 12:00pm-3:00pm
Tin Roof
dsagsl.org/programs/next-steps

FALL

YOUNG FRIENDS BOARD 21 CLUB BOWLING TOURNAMENT

August 2019 - Details TBD
dsagsl.org/programs/21-club-social-events

PARENT & FAMILY WORKSHOP- TOILET TRAINING & BEHAVIOR BASICS

Saturday, September 14, 10:00am-3:00pm
St. Louis Children's Hospital Auditorium
dsagsl.org/workshops

WALK IN THE PARK

Sunday, September 29 starting at 12:00pm
Busch Stadium
dsagsl.org/events/walk-in-the-park

21 SUN SALUTES YOGA FOR DOWN SYNDROME

Sunday, October 6 starting at 9:00am
at the World's Fair Pavillion in Forest Park
dsagsl.org/events/21-suns

10TH ANNUAL DSAGSL TRIVIA NIGHT

Saturday, October 19 starting at 6:00pm
CBC High School
dsagsl.org/events/trivia

ON - GOING PROGRAMS

INFANT & TODDLER PLAYGROUPS

June 14 and September 20, 9:30am-11:00am
at the DSAGSL Office
dsagsl.org/calendar

FIT STEPS

First and third Saturday of each month
9:00am-10:00am
Anytime Fitness in Ballwin
dsagsl.org/calendar

SILVER STEPS

Last Tuesday of each month
10:30am-12:00pm or 5:30pm-7:00pm
at the DSAGSL Office
dsagsl.org/calendar

RUN FOR 21

SUNDAY, JUNE 2ND - 8:00AM - FOREST PARK

For the first time, Run for 21 and Step Up for Down Syndrome have been combined to create one incredibly fun and exciting event! The day will kick off with the Run for 21 race through beautiful Forest Park. This 3.21 mile race is a 5k *plus a little extra*, and ends at the largest celebration of Down syndrome in the area, Step Up for Down Syndrome. Race amenities include a race shirt, finisher medal, and one wristband to enjoy the Step Up Celebration. Runners are encouraged to start a Step Up Team and raise additional funds beyond their race registration to earn more wristbands to Step Up for family and friends!

Learn more at dsagsl.org/events/run-for-21



STEP UP FOR DOWN SYNDROME

SUNDAY, JUNE 2ND - 8:30AM TO 12:30PM - FOREST PARK

You won't want to miss the largest celebration of Down syndrome in the St. Louis area, Step Up for Down Syndrome! With over 2,500 people having fun and raising awareness for Down syndrome in Forest Park, this event is like no other. This festival features a one-mile awareness walk through Forest Park, games, crafts, bouncy houses, live music and performances, food trucks, and fun activities for all ages.

Attend the festival by purchasing a wristband & t-shirt combo for just \$25 per person. Or, the most popular option is to start a Step Up Team and raise funds for entrance into the festival. For every \$25 you raise, your team will get a wristband and t-shirt good for entrance into the festival! There are also several other exciting incentives and prizes for teams that fundraise, including Cardinals tickets! Make sure to ask how you can get a corporate sponsorship to add to your team total.

Learn more and sign up your team today! support.dsagsl.org/stepup2019



RESOURCE CORNER

I/DD HELP LINE

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

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

IDD HELP LINE - 1.877.256.2202

FREE DENTAL CARE

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

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

FOR AN APPOINTMENT - 314.842.5000 ext 14

RECREATION COUNCIL OF GREATER ST. LOUIS

The Recreation Council is a not-for-profit organization that assists individuals of all ages and abilities in finding engaging programs and services that best meet the interests and support needs of the individual.

The Guide to Leisure Services and Annual Summer Opportunities Guide highlight programs that are in St. Louis City, St. Louis County, and St. Charles County, and are either specifically for individuals with disabilities, or inclusive of ALL abilities.

RECREATIONCOUNCIL.ORG - 314.726.6044

PARENT & FAMILY WORKSHOP- TOILET TRAINING & BEHAVIOR BASICS

Saturday, September 14, 2019, join DSAGSL and St. Louis Children's Hospital for this important two-part seminar. The cost is \$15 for one session, \$25 for both, and just \$10 per session for each additional family member that attends. Lunch can be purchased in the hospital cafeteria. Online registration will be available in June!

Toilet Training Tips and Tricks | 10:00am - 12:00pm | Toilet Training is a definite rite of passage for children and parents. Don't let this important skill become frustrating for your family. Learn some practical tips and tricks to set everyone up for success!

Behavior Basics | 1:00pm - 3:00pm | Behavior can be frustrating and confusing, but the good news is that there is a science of learning and behavior that can help you no matter what age or stage your child is in. It is important to understand the basics of behavior because once you do, you can apply them to a variety of situations. Participants will learn these behavior basics and some effective strategies they can use to prevent and respond to their child's behavior.

About the Speaker | Stacy Taylor, MA, BCBA, Owner, Advance Behavior and Learning, has a daughter with Down syndrome. For over 18 years, Mrs. Taylor has worked as a behavior analyst providing services to people with developmental disabilities and behavioral challenges. She has worked in a variety of settings including clinics, schools and homes. In addition to providing 1:1 treatment to children, she has also provided training and consultation to parents, teachers, therapists and agencies. Mrs. Taylor has spoken at numerous conferences across the country on behavioral treatment and has served as President of the Board of Directors for the Down Syndrome Association of Central Florida. She teaches college level courses in learning, behavior and inclusion.

DSAGSL.ORG/WORKSHOPS - 314.961.2504

COMMUNITY GROUPS

DSAGSL Community Groups provide information, resources and/or emotional support for parents and friends of individuals with Down syndrome. Each group has its own personality based on location, culture, native language and the age group(s) they serve. Each community group is open to all DSAGSL members. 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

HEARTLAND COMMUNITY GROUP

(Southeast Missouri and Southern Illinois)

Meetings are second Saturday of each month 10:00-12:00 at the Cape Girardeau Public Library, Penzel Conference Room
Contact | Claire Watson | (573)334-5685 | heartland_cg@dsagsl.org
facebook.com/HeartlandDSA

CENTRAL MISSOURI DOWN SYNDROME FAMILY NETWORK

(Columbia, Jefferson City & surrounding areas)

Contact | Kate Basi (Columbia) | (573) 449-8342
Nancy Parsons (Ashland) | (573) 864-6223
Paula Backues (Jefferson City) | (573) 230-7230
Andrea Elsbury (Moberly) | (573) 489-6199
centralmodsfamilynetwork@gmail.com |
facebook.com/centralmodsfamilynetwork

KIRKWOOD/WEBSTER MOM'S NIGHT OUT

(Kirkwood/Webster and surrounding areas)

Contact | Stephanie Holmes | (314) 495-9388
Cheri Nienhaus | (618) 570-8485
kirkwood_cg@dsagsl.com |
facebook.com/groups/kirkwoodwebsterdsmoms

DADS APPRECIATING DOWN SYNDROME (DADS)

(Greater St. Louis Area)

Meetings are first Wednesday of even numbered months
Contact | Tony Sorocko | (314) 393-8548 | dadsstl@outlook.com
dadsstl.org | facebook.com/groups/270173929671043

ST. CHARLES COUNTY COMMUNITY GROUP

(St. Charles, West county and surrounding areas)

Contact | Karen Ryan | (314) 795-1419 | stc_cg@dsagsl.org
facebook.com/stcdsgroup

DOWN SYNDROME COMMUNITY GROUP OF UPSTATE MISSOURI

(Kirksville, Brookfield and surrounding areas)

Contact | Becky Pike | (660) 651-5139 | kirksville_cg@dsagsl.org
facebook.com/dscnemo

NORTH COUNTY/NORTH CITY COMMUNITY GROUP

(North St. Louis County and St. Louis City)

Contact | Sergei Marchenko | (773) 817-7054

DOWN SYNDROME GROUP OF THE LAKE OF THE OZARKS

(Camdenton, MO and surrounding areas)

This group is looking for new leadership! If you are interested in leading this group, please contact Christy
Christy@dsagsl.org | (314) 961-2504 ext 2

ILLINOIS

METRO EAST DOWN SYNDROME ALLIANCE

(Belleville, O'Fallon, Shiloh Illinois and surrounding areas)

Contact | Bob Lutz | (314) 458-6918
Amanda Lutz | (618) 789-3664
Amanda Joyce | (314) 593-0092
medsa_cg@dsagsl.org | facebook.com/MetroEastDSA

SOUTHERN ILLINOIS COMMUNITY GROUP

(Carbondale, Creal Springs, IL and surrounding areas)

Contact | Sonya Clark | (618) 303-7824 | soil_cg@dsagsl.org
facebook.com/SIDownsSyndromeSupportGroup

DOWN SYNDROME & AUTISIM (DS/ASD) COMMUNITY GROUP

Contact | Christy Klaus | (314) 961-2504 ext 2 | Christy@dsagsl.org

OTHER DOWN SYNDROME COMMUNITY GROUPS

RIVERBEND DOWN SYNDROME ASSOCIATION

(Southwest Illinois)

Contact | (618) 288-2555 | secretary@riverbendds.org
riverbendds.org

DOWN COUNTRY

(Hannibal, Quincy and surrounding areas)

Contact | (217) 617-3568 | info@upatdowncountry.com,
upatdowncountry.com | facebook.com/UpAtDownCountry

DOWN SYNDROME GROUP OF THE OZARKS

(Springfield, MO and surrounding areas)

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

LINCOLN LAND DOWN SYNDROME SOCIETY

(Springfield, IL and surrounding areas)

Contact | (217) 415-8716 | lldss@comcast.net | lldss.org
facebook.com/LincolnLandDownSyndromeSociety/

CENTRAL ILLINOIS DOWN SYNDROME ORGANIZATION

(McLean county, Bloomington/Normal and surrounding towns)

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

DOWN SYNDROME SUPPORT GROUP - BLESSING HOSPITAL

Meet every last Monday of the month at 6:30pm
11th Street Auditorium at Blessing Hospital | Quincy, IL 62305
(217) 223-8400 ext 4190

DSAGSL | IN ACTION

Playgroup

We've seen 25 littles at three playgroups over the last several months. Children and parents are invited to the DSAGSL office for a morning of playing, learning, and networking!



Rock 21 Music Program

26 rock stars took the stage on March 23rd at Tin Roof to perform songs from all musical genres after 8 weeks of practices. The event raised over \$1,000 for the program!

Young Friends Board 21 Club at Pieces: The Board Game Bar

With over 100 people in attendance of all abilities, The Young Friends Board event raised over \$700! Attendees enjoyed a taco bar, delicious cake, and over 800 board games to choose from.

Welcome New Families

We've welcomed 12 families to the DSAGSL community so far this year, and hosted 90 moms, dads, grandparents, babies, and siblings at the New Family Brunch.



Down Syndrome Education Specialist Program

25 education professionals from all over Missouri and Illinois completed all four sessions of the Down Syndrome Education Specialist Program.



World Down Syndrome Day

100 packets filled with awareness materials were mailed to local schools. In addition, several families came to the office for snacks, crafts, friendship socks, and celebration!

Disability Rights Legislative Day

4 Self-Advocates traveled to Jefferson City with parents and DSAGSL staff in March to talk to state legislators about the issues that matter to them.

Pop Up Snack Shop

There have been 3 Snack Shops so far this year at Stifel, Maritz, and Lashley & Baer, and there are currently 10 employees of the Snack Shop learning employment skills in a hands-on environment while getting paid!



These results have triggered a flurry of activity at the Crnic Institute to answer key follow-up questions: Which of the symptoms of Down syndrome could be explained by the observed immune dysregulation? To what degree is the immune dysregulation caused by triplication of the four Interferon receptors versus other genes on chromosome 21? What would be the diagnostic value of measuring immune dysregulation to predict the risk of the same person developing certain co-occurring diseases or conditions? What would be the therapeutic value of medications that inhibit the Interferon response and accompanying inflammatory process?

Several key facts are generating much enthusiasm in the pursuit of these answers. First, it is well established that a hyperactive Interferon response has negative effects on human development, as illustrated by type I Interferonopathies, a newly recognized class of genetic conditions caused by gene mutations that lead to activation of the Interferon response and share many symptoms with Down syndrome. Second, the pharmaceutical industry has developed many medications that inhibit the Interferon response, some of which are approved for the treatment of autoinflammatory conditions, such as rheumatoid arthritis, and are currently being tested for the treatment of autoimmune conditions more prevalent in Down syndrome, such as alopecia areata and vitiligo. Third, pioneer studies in mouse models of Down syndrome completed by Lenny Maroun, Ph.D., currently at the Crnic Institute, demonstrated that reducing the Interferon response improves the development of these mice (Maroun et al., 2000).

Altogether, this body of research justifies a strong investment in the study of the immune system in Down syndrome, with the obvious potential to develop diagnostic and therapeutic strategies to improve the well-being of those living with trisomy 21. To learn more about research at the Crnic Institute, visit globaldownsyndrome.org/our-story/linda-crnic-institute.

References:

Maroun, L.E., Heffernan, T.N., and Hallam, D.M. Partial IFN-alpha/ beta and IFN-gamma receptor knockout trisomy 16 mouse fetuses show improved growth and cultured neuron viability. *Journal of Interferon & Cytokine Research: the Official Journal of the International Society for Interferon and Cytokine Research*. 2000; 20, 197–203.

Sullivan, K.D., Evans, D., Pandey, A., Hraha, T.H., Smith, K.P., Markham, N., Rachubinski, A.L., Wolter-Warmerdam, K., Hickey, F., Espinosa, J.M., et al. Trisomy 21 causes changes in the circulating proteome indicative of chronic autoinflammation. *Scientific Reports*. 2017; 7, 14,818.

Sullivan, K.D., Lewis, H.C., Hill, A.A., Pandey, A., Jackson, L.P., Cabral, J.M., Smith, K.P., Liggett, L.A., Gomez, E.B., Galbraith, M.D., et al. Trisomy 21 consistently activates the interferon response. 2016; *eLife*. 5.

This article was written and published by Global Down Syndrome Foundation in Issue 2, 2018 of World Down Syndrome Magazine.

GET INVOLVED WITH DOWN SYNDROME RESEARCH

GLOBAL DOWN SYNDROME FOUNDATION : globaldownsyndrome.org | learn about research initiatives and check out the Global Webinar Series (topics on medical care and health and wellness)

LUMIND CLINICAL TRIAL FINDER: <https://www.lumindrds.org/clinical-trial-finder>

DOWN SYNDROME CLINICAL TRIALS NETWORK: <https://www.ds-ctn.org>

DS-CONNECT: <https://dsconnect.nih.gov> | families can connect with researchers & healthcare providers and participate in research studies/surveys

WASHINGTON UNIVERSITY SCHOOL OF MEDICINE RESEARCH STUDY: The purpose of this study is to learn more about brain development in infants with Down syndrome. Babies must be 0-6 months of age and have a diagnosis of Down syndrome, or be a typically developing infant to be included in the control group.
Contact Lisa Flake at 1-888-845-6786 or flakel@wustl.edu

IBIS NETWORK RESEARCH STUDY: The goal of the study is to increase an understanding of how the brain is affected in children with Down syndrome. Research participants should be between 7 -11 years old. Contact ibisnetwork@gmail.com to learn more and to sign up for the study.

GET INVOLVED WITH DSAGSL

SHARE YOUR RECOMMENDATIONS

One of the greatest resources we have as parents is the sharing of our experiences. Here at the DSAGSL office we get many calls from parents looking for medical professionals who have experience with Down syndrome. We keep a list of medical professionals that have been recommended by other parents. Please share with us the name(s) of doctors who you feel work well with your loved one with Down syndrome – especially adults. This could include internist, psychologist, psychiatrist, dentist, ENT, endocrinologist, cardiologist, therapists, and any other subspecialties. E-mail this information (or send a picture of their business card) to christy@dsagsl.org or call (314)961-2504 ext. 2.

FOLLOW US ON SOCIAL MEDIA

FACEBOOK.COM/DSAGSL

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

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

www.facebook.com/groups/DSAGSL.SharingOurStrategies

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

www.facebook.com/groups/DSAGSLReady2Work

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

www.facebook.com/groups/1646889945457015

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

VOLUNTEER OPPORTUNITIES

RUN FOR 21 & STEP UP FOR DOWN SYNDROME

Sunday, June 2nd from 7:00am-1:00pm
Forest Park, St. Louis

NEW MOTHER'S LUNCHEON

Saturday, June 15th from 10:30am-2:00pm
Spazio Westport, Chesterfield

LYDIA COX MEMORIAL BIKE CAMP

June 3 - June 7
South Technical High School

DOWN SYNDROME CENTER

One Tuesday per month, 4-5 hours
St. Louis Children's Hospital

INTERESTED IN VOLUNTEERING?

Visit our website to fill out the registration form, or contact Volunteer Manager, Abigail Beckord at abigail@dsagsl.org or 314.961.2504.

AMAZON SMILES

SMILE.AMAZON.COM

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

DSAGSL DONATION WISHLIST

HERE ARE SOME ITEMS THE ORGANIZATION COULD USE!

Colored Paper (8.5" x 11")

Cardstock Paper (8.5" x 11")

Gift cards to Target, Wal-Mart, Grocery Stores

Postage Stamps

Infant Toys

Baby bibs, washcloths, and socks



KELLY'S HOLLYWOOD

The Down Syndrome Affiliates in Action conference for Down Syndrome Association professionals from around the country was in St. Louis this year, and boy did they score big time when they booked Brian Donovan as the conference's keynote speaker. Brian directed *Kelly's Hollywood*, a documentary about his relationship with his sister, Kelly who has Down syndrome. The film takes viewers along for the ride as Brian does all he can to help make Kelly's dream come true of becoming a Hollywood superstar. The touching relationship between this brother-sister duo is charming and sweet, but their co-dependence ultimately interferes with Brian's other relationships. Grab the kleenex, this movie will warm your heart and bring you to tears.

DSAGSL members, as well as other conference attendees, had the opportunity to view the film and ask the director himself, Brian Donovan, questions afterward. The next day, Brian led an incredibly inspirational keynote session and spent the remainder of the conference making friends with every single person he came across. He performed with the Totally Awesome Girlfriends Group (TAGG), signed t-shirts and programs, took selfies, did interviews, accepted Facebook friend requests, and gave tons of hugs. Brian was genuine, thoughtful, compassionate, and down right delightful!

THE JOY OF DOWN SYNDROME

DSAGSL would like to congratulate community member, Steve Logue, on publishing his book, *The Joy of Down Syndrome*. Steve has put together a collection of stories about his son Casey, and about being a parent of a child with Down syndrome. Steve says he really just wanted to share an honest, sometimes funny, sometimes serious picture of what his life with Casey is like. His motivation to publish the stories as a book wasn't actually planned. Steve had noticed that when he told his stories about Casey to friends and even crowds, those stories brought joy to those listening. Steve wanted to share that joy with as many people as he could, and with a push from one of his close friends, he decided to write, *The Joy of Down Syndrome*.



Casey is now 19 years old, plays sports, and makes those around him laugh out loud! If you'd like to learn more, visit Steve's website joyofdownsyndrome.com

2018 ANNUAL CELEBRATION

One of our favorite events of the year, the Annual Celebration is an opportunity for DSAGSL to thank all of the amazing people, companies, and organizations that contribute to helping DSAGSL serve over 1800 individuals with Down syndrome and their families in the St. Louis area. We simply could not do it without the support of hundreds of dedicated, compassionate, generous people giving their time, their dollars, and their love to our community. The Annual Celebration in February was an evening dedicated to giving thanks to some very exceptional people that went above and beyond to support DSAGSL in 2018.



2018 SELF-ADVOCATE OF THE YEAR

Ms. Lindsey Hawkins

2018 VOLUNTEER OF THE YEAR

Ms. Margie Siegel
Ms. Sara Mackey

2018 SPONSOR OF THE YEAR

HM Employee Benefits & Risk Management

2018 POP UP SNACK SHOP PARTNER OF THE YEAR

RBO Print Logistix
Enterprise Fleet Management

2018 THIRD PARTY FUNDRAISER OF THE YEAR

DADS- Puttin' for Down Syndrome Golf Tournament

2018 PARTNER OF THE YEAR

Pujols Family Foundation



2018 IN-KIND DONOR OF THE YEAR

Cardinal Glennon Children's Hospital

2018 DONOR OF THE YEAR

Dr. and Mrs. Smith

2018 EMPLOYER OF THE YEAR

Mozingo Music

MANY THANKS TO OUR PARTNERS & SUPPORTERS



FIRST TIME STEP UP FOR DOWN SYNDROME SPONSORS

MONETA GROUP - Making Strides Sponsor

MCBRIDE HOMES - Medal Sponsor

MARCO- Big Step Sponsor

GRANTS

THE KERR FOUNDATION - Rock 21 Music Program (fka DSAGSL Rocks!)

BUILD A BEAR - New Family Celebration Baskets

DANA BROWN - Childhood Education Programming

THIRD PARTY FUNDRAISERS BENEFITING DSAGSL

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

THE DIAMOND FAMILY - World Down Syndrome Day Fundraiser

KNIGHTS OF COLUMBUS ST. PATRICKS - Fundraiser to Purchase AED Machine

GATHR FOUNDATION- Screening of "Intelligent Lives" in Edwardsville, IL

SFW PARTNERS, LLC - Genes Day Fundraiser

CHRIST THE KING CATHOLIC SCHOOL - Genes Day Fundraiser

PREMIER CHARTER SCHOOL - Genes Day Fundraiser

MS. BONNIE SHEPPARD- New Family Celebration Baskets

TIN ROOF ST. LOUIS - Rock 21 Music Program (formerly DSAGSL Rocks!)

SCHNUCKS - Bags 4 My Cause Program

BRINKMANN CONSTRUCTORS - BECAUSE Runner Up Winner

FRESH THYME FARMERS MARKET - Giving Bag Program

PIECES ST. LOUIS - World Down Syndrome Day Fundraiser



8531 Page Ave, Suite 120
St. Louis MO 63114

www.dsagsl.org



Birdies & Bass Fishing Derby & Golf Tournament

MONDAY, MAY 13, 2019

Persimmon Woods Golf Club & Lakes

Join us for the fishing derby portion of this one-of-a-kind event! Anglers are paired with a Self-Advocate teammate and compete for heaviest catch! Sign up today!

www.dsagsl.org/events/golf