Building a network for people with Down syndrome, their families and the professionals who serve them.

Pathways Therapy Services Expanding

DSG offers therapeutic services for people with Down syndrome and their families across the lifespan, through our life-changing and transformational Pathways™ program. **Families now have a variety of therapy options to better meet their needs.** Pathways™ Comprehensive provides year-long therapeutic coaching and consultative support from our team with DSG subsidizing 50% of the cost. For families who travel a greater distance, a quarterly, comprehensive program is now available called Pathways™ Light.

Pathways™ single-therapy programs will provide one-on-one, individualized support for Speech and Language Therapy, Behavior Coaching, Occupational Therapy, and Potty Training. For families with children in the range of infancy to early childhood, we will be offering Therapeutic Play Groups, for only $10 per class. This is an opportunity to receive therapeutic instruction, while becoming more acquainted with our team and other families DSG serves.

We will also continue to offer our Social Language Groups, for children and adults with Down syndrome. All services are provided by licensed Speech-Language Pathologists, Occupational Therapists, and Board Certified Behavior Analysts, with advanced knowledge in Down syndrome.

“Pathways has provided a support system to enhance my daughter and our family’s life. They have provided hope and the tools they equip us with are priceless. They are patient and celebrate our successes with us. My daughter, husband, and I walk out of our sessions a little taller. Pathways is the best investment our family has made this year.”

Contact Sarah Mai, Director of Family Services, to discuss your options today. sarah@kcdsg.org #913-213-5484

LEARN MORE: PATHWAYS321.ORG
A Perfect Little Redhead With Down Syndrome

My wife was 13 weeks pregnant when we learned there was a 99% chance our son could have DS. My wife received the call the day after we had our 3D scan showing us the gender of our baby. It was the day after we named him. My wife was the one who explained the possibility of him having Down Syndrome to me. At birth, however, while my wife was recovering from c-section the doctor told me “You, know what’s wrong with him right?” Of course, I said no, because, with all the difficulties experienced during delivery, DS was the furthest thing from my mind.

My initial reaction to the news was denial. I truly believed that while he may have DS he would not have any physical and/or learning disabilities as a result of it. Instead, I believed he would overcome all obstacles without issues. My biggest initial fears were that he wouldn’t live long. I couldn’t bare the thought of losing my son. Before my son was born I didn’t know anyone with Down Syndrome. When it came to telling others, the last thing my wife and I wanted was sympathy. We were very careful in releasing the information so that it was made public to as many of our friends and family as possible all at one time. We tried to eliminate the chatter of “did you hear.” Once the diagnosis was confirmed, our Pastor made the perfect announcement to our church congregation as my wife and I listened online. We both posted the information on our social media pages immediately following. We have experienced nothing but positive feedback and support.

Obstacles to accepting the diagnosis. It was hard to see beyond my son’s perfection. He is pure love. It is still hard at times to accept the diagnosis because when I see Zane, I see my son and he is perfect to me. As far as health issues, Zane was born with 5 small holes in his heart, a hernia, difficulty breathing, and low blood sugar. Aside from having legal guardianship of our 16yo nephew, Zane is our only child. My wife has been very accepting of the diagnosis. But she was a little upset in the beginning due to being afraid of the unknown. We have never looked at Zane’s diagnosis as being something negative in our life. If anything, his diagnosis has made our relationship stronger. It has also made my faith in God stronger. All the struggles that Zane has overcome have been amazing to me. He is our little miracle. My superhero.

I have never seen DS while looking at my child. I see Zane, my son. The perfect little red head with a mohawk and webbed toes on both feet. The fighter who pushes himself hard to meet his milestones. And the angel who is full of more love than a human being could possibly have. My faith in God is what has really enabled me to embrace the diagnosis. I know that He picked my wife and I to care for Zane like only we can do. We have a church family as well as our personal families who stand behind us and support us in every way. All of our friends and family have responded with love. The changes in our life now are mainly, just lack of sleep. But seriously, my goals have changed. Things I thought were once important don’t seem to matter anymore. I am more family oriented now. Each day I look forward to hearing about or seeing what new obstacles Zane has overcome. It is amazing to watch him progress.

Reprinted with permission from Zane’s dad. Read the original post at cedarsstory.com/syndrome-diagnosis-dads
New Book Helps Breastfeeding Mothers

Breastfeeding and Down Syndrome: A Comprehensive Guide for Mothers and Medical Professionals, the new book by Julia’s Way, a 501C3 non-profit organization, includes information on everything from preparing to breastfeed, breastfeeding after heart surgery, getting to the breast after tube feedings, and much more.

If you are a new or expectant parent, you will find everything you need to know to successfully breastfeed your baby with Down syndrome, including dozens of mothers’ stories to help reassure you that babies with Down syndrome CAN breastfeed.

If you are a medical professional, you will appreciate the Pro Tips designed specifically to guide you in helping your patients overcome any challenges they may face. Each chapter is written by an expert in the field using the latest evidence-based research.

“I wish this book had been around when I was trying to figure out how to breastfeed my son. Breastfeeding & Down Syndrome will give you the best strategies to establish a breastfeeding relationship with your baby.” — Stephanie Meredith, Mom of Andy, co-author of Welcoming a Newborn with Down Syndrome: A New Parent’s Guide to the First Month

“A much-needed resource for moms, and even healthcare providers, this book gives guidance, practical tips, and encouragement” — Melanie Cromwell, RN, IBCLC, San Diego Breastfeeding Center

Because Julia’s Way has a deep commitment to helping babies with DS breastfeed successfully, this book is available to download free of charge. Print copies are available as well and all proceeds from the sale of this book go directly to Julia’s Way to help continue to fund its work supporting mothers who want to breastfeed their babies with Down syndrome.
**EASTLAND FRIENDS**

Tema sera sobre la caminata, se acerca la fecha y hay que prepararnos. Porfavor de confirmar a Yadira Murguia 913-563-8951 o a Brenda Quintana 816-278-0219

**DOTTE FRIENDS**

Hope to see you at the DSG holiday party on December 8th at Overland Park Convention Center. See details and RSVP by visiting kcdsg.org

**ST. JOSEPH FRIENDS**

Nov/Dec meetings not decided at time of publication printing. Email jocofriends@gmail.com for more information.

**NORTHLAND BUDDIES**

Nov/Dec meetings not decided at time of publication printing. Follow Northland Buddies Facebook page for more details on upcoming events.

**LAWRENCE/ TOPEKA FRIENDS**

Birth – three playgroups for babies with DS on the first Tues. of each month from 9:30-10:30am at TARC in our Children’s Playroom. Families can come in through the main doors or through the playground doors. For information about LTF Friends please contact Wendy at 785-506-8616 or at toplaw-friends@tarcinc.org

If you have a teenager with DS be sure to check in with julie@kcdsg.org as DSG is now hosting teen events once a month in Topeka or Lawrence and we’d love to have your teen join us!

**FLINT HILLS**

Nov/Dec meetings not decided at time of publication printing. Contact Brianna Nelson-Goff to RSVP or to learn more information about the group at bnelson@ksu.edu
NIH Funds $77 Million in Down Syndrome Research

With millions of new dollars for research on Down syndrome, federal officials have effectively doubled their investment in understanding the chromosomal disorder in the last year alone. The National Institutes of Health said it has committed to some $35 million in additional grants for the 2019 fiscal year, bringing the agency’s total spend on Down syndrome research to $77 million. As of this time last year, NIH funding for Down syndrome stood at $36.8 million.

The latest grants are part of the agency’s investigation of Co-occurring conditions across the Lifespan to Understand Down syndrome, or INCLUDE, project. The initiative, which began in 2018, brings together several NIH institutes and centers to address health and quality-of-life issues among those with the chromosomal disorder while also examining co-occurring conditions like Alzheimer’s disease, autism, cataracts, celiac disease, congenital heart disease and diabetes.

“Individuals with Down syndrome are both affected by and protected against many of the conditions that afflict the general population,” said Francis S. Collins, director of the NIH. “By improving our understanding of the basic biological mechanisms of Down syndrome and making clinical trials more accessible and specifically tailored to individuals with Down syndrome, we expect that research from the INCLUDE project will benefit everyone.”

The NIH funding is going toward projects examining the genetics of Down syndrome, congenital heart defects common in those with the condition and trials to address sleep apnea in children with the chromosomal disorder, among other efforts.

Research will focus on:
- Conducting targeted, high-risk, high-reward basic science studies on chromosome 21.
- Assemble a large study population of individuals with Down syndrome
- Include individuals with Down syndrome in existing clinical trials.

Learn more about the INCLUDE Project: [https://www.nih.gov/include-project](https://www.nih.gov/include-project) Register your loved one in the DS-Connect registry for updates on trials for people with Down syndrome. Originally published [www.nih.gov/news-events/news-releases](http://www.nih.gov/news-events/news-releases)
Federal Funds Support Post-Secondary Education for Disabled Students

The U.S. Department of Education is weighing in after confusion forced some students with disabilities to withdraw from or forgo applying to post-secondary programs. The federal agency issued a question-and-answer guide recently specifying that both vocational rehabilitation and Individuals with Disabilities Education Act funds can be used to cover the cost of dual enrollment, comprehensive transition programs and other postsecondary offerings for people with disabilities.

The move comes a year after several dozen advocacy groups and other stakeholders wrote to Secretary of Education Betsy DeVos asking for guidance on the issue. Many families request that school districts pay for students with disabilities to enroll in postsecondary programs during their final years of eligibility under IDEA. Or, once out of high school, families ask vocational rehabilitation to foot the bill for such programs.

But, disability advocates said that confusion stemming from the Department of Education and its Rehabilitation Services Administration had led some schools and vocational rehabilitation agencies to refuse to pay for postsecondary programs while others did. As a result, some students with intellectual disabilities missed out on postsecondary programs because their school or vocational rehabilitation funding was discontinued while other students were dissuaded from applying, advocates said.

The 16-page document issued jointly by the Education Department’s Office of Special Education and Rehabilitative Services and the agency’s Office of Postsecondary Education aims to level the playing field. The document addresses the ability of students with disabilities to be dual enrolled in high school and at a post-secondary institution and it spells out who may pay for services.

“All students deserve the freedom to pursue an education that is challenging and allows them to reach their full potential,” DeVos said. “I hope this information will make clear what the law says and serve as a resource to families, individualized education program (IEP) teams and state VR agencies as they continue to collaborate and find ways to increase postsecondary opportunities — and success — for students and youth with disabilities.”

Stephanie Smith Lee, senior policy adviser at the National Down Syndrome Congress, said the Education Department’s guide looks “very promising” on an initial read, but would require further analysis. The document seems to clarify that vocational rehabilitation funds can be used for postsecondary programs, she said, but the statements surrounding IDEA appear more nuanced. Nonetheless, Lee welcomed the Education Department’s input on the issue and said it would surely make a difference for students with disabilities. “This is going to open doors,” she said.

Originally published on Disability Scoop by Michelle Diament

Variety KC Grants Help Children Be More Active and Independent

Since 1934, Variety KC has helped thousands of children with disabilities in by providing mobility and communication devices as well as opportunities for inclusion within our community. We believe all kids should Be Active, Be Social, and Belong!

**Variety KC Kids on the Go Mobility Grant**
If your child needs enabling equipment such as a wheelchair, van lift, house ramp, adaptive car seat or stroller, a specially-equipped bicycle, tricycle, or stairlift,

**Variety KC Assisted Technology Grant**
Assistive Technology provides communication devices for children with physical and cognitive disabilities. If you need help communicating with your developmentally-disabled child, please apply for assistance.

**Variety KC Go Baby Go! Grant**
The Variety KC GoBabyGo! Program provides modified toy ride-on cars to provide mobility & sociability for children with special needs.

Apply for a grant online by visiting:
varietykc.org/get-help/
Holiday Tips to Avoid Stress!

The holidays are packed with fun, food, festivities and for some of us, stress. For families with special needs, the unfamiliar sounds, smells and visitors can sometimes be disruptive. Minimize your stress this holiday season with these strategies to help keep your loved one with Down syndrome engaged and calm.

Find calm where you can. Schedule quiet times during the day—short periods when you can give your full attention and tune in to their needs. Establish a “code word” to say when he/she feels overwhelmed. Giving control during activities can also help reduce anxiety.

Set a schedule. Most people with DS thrive on routine. Provide a visual schedule of events for holiday activities. Discuss the schedule and provide information for each activity and share who will be a part of those events.

Watch for sensory overload. The holidays are full of stimulation and can be overwhelming. Bring ear plugs to loud events. Possibly limit holiday decorations in your home. Remind your family member to use the “code word” if feeling overwhelmed. Make your environment as calm, and if necessary as routine, as possible.

Prepare your family and friends. Talk to family members and friends ahead of holiday events. Discuss your family member’s specific needs and what helps make him or her feel comfortable and safe. When visiting friends or relatives, bring some of his or her favorite items for comfort, if that will help him/her be stay calm during visits.

Originally published at: tinyurl.com/stresstips Slovak

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**Holiday Party**

**DECEMBER 8TH**

9 - 11 AM

OVERLAND PARK CONVENTION CENTER
6000 COLLEGE BLVD  OVERLAND PARK, KS

Join us for breakfast with Santa, family pictures, and visit stations where kids can engage in winter wonderland sensory activities with our therapy team. Be sure to visit our college fair tables to learn more about exciting post-secondary programs for people with Down syndrome.

Kids 12 and under are invited to visit our Holiday Shop to select and wrap gifts for family members. All items will be $3 or under and volunteers will help our shoppers.

REGISTER BY DECEMBER 1ST AT KCDSG.ORG

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**Shopping with the STARS!**

Everyone is welcome at the Holiday Shoppe!

**When?** During the DSG Holiday Party on Sunday, December 8th 9-11 AM

**Who?** People with Down syndrome and their siblings who are 3-12 years of age

**What?** The holiday Shoppe will be run by our STARS teens! Parents will drop kids off for a few minutes to shop with a volunteer elf who will assist them to pick out and wrap gifts and pay for their purchases. Parents will have the chance to visit with our therapy team during that time to learn more about great gift ideas to help their children be more independent!

**How much does it cost?** All items in the shop will be $3 or less. Shoppers should come with a shopping list and **CASH ONLY** as this will help our teens with checkout.

Register your shopper when you sign up for the DSG Holiday Party
Parents, educators, therapists, administrators and service providers are invited to join us for a great day of learning on Saturday, November 16th at the Stoney Creek Conference Center. Our presenters will cover topics such as behavior, reducing prompt dependency, improving fine motor skills, enhancing speech, communication and social skills, fostering independence and the transition to adulthood.

Our keynote speaker will be self advocate Elijah Mayfield, who will share information about his childhood, graduating from high school, working and learning to drive a car. Elijah received the Self-Advocate of the Year award from the National Down Syndrome Society (NDSS) in Washington D.C. for his ongoing efforts to improve the daily lives of individuals with Down syndrome.

Download the brochure and register online by visiting: kcdsg.org/dsg-central-missouri

Fees are $55 for one attendee and $100 for two attendees. Lunch is included with your registration fee.

Celebrate Inclusive Schools Week

Inclusive Schools Week is an annual event sponsored by the Inclusive Schools Network (ISN) which is held each year during the first full week in December. Since its inception in 2001, Inclusive Schools Week has celebrated the progress that schools have made in providing a supportive and quality education to an increasingly diverse student population, including students who are marginalized due to disability, gender, socio-economic status, cultural heritage, language preference, and other factors.

The Week also provides an important opportunity for educators, students and parents to discuss what else needs to be done in order to ensure that their schools continue to improve their ability to successfully educate all children.

Download a celebration toolkit and share with your school to encourage them to participate and promote greater inclusion and acceptance!
For people with Down syndrome, financial planning has long been restrictive and complicated. Those who receive benefits through the government are severely limited in their personal finances. In order to continue receiving those benefits, they will typically have a $2,000 resource limit, which means they can never have more than that amount in their personal accounts, rendering them virtually impoverished.

Imagine what it must be like for a young person with Down syndrome, growing into adulthood and never being able to truly save and make long-term financial plans.

That’s why my family and I were very proud to witness some important enhancements to the ABLE Act for Kansans in May 2018. ABLE stands for “Achieving a Better Life Experience,” and it’s a program that provides accounts in which people disabled before age 26 can save up to $100,000. It’s a nationwide bill that was passed in 2014, and then administered by each state accordingly. Now in Kansas, a contributor to an ABLE account will be able to deduct up to $3,000 per year from their state income, $6,000 for a married couple. In addition, they have waived the “Medicaid Clawback” upon death, which would have caused the family to pay back any Medicaid support that the individual received during their life, assuming there was a balance left in the account. (The State of Missouri also allows tax deductible contributions, but they’re still determining how to deal with any clawback provisions.)

This is life-changing legislation for people like Lily, my daughter with Down syndrome. Now we can make contributions to Lily’s ABLE account, as little as a $25 per month or as high as $15,000 per year. Today or in the future, we can use these funds for expenses that her disability benefits wouldn’t be able to cover.

This is so important, because young people with Down syndrome have more opportunity than they’ve ever had growing up in today’s environment. They’re far more likely to go into higher education and/or work than in previous generations. Without this new program though, that might not be an option.

Think of it this way. The ABLE account is like a retirement plan for your child that starts now. Parents of children with special needs used to have to use their primary funds to make sure they could care for their child into adulthood, but ABLE allows families to start planning far in advance, greatly benefiting their entire family.

One of my favorite things about ABLE is that anyone can contribute to someone’s account. When our neighbor, Rachel, who also has Down syndrome, graduated from high school this past year, she passed out a link to her ABLE account and asked friends and family to make contributions. She’s already using it wisely to provide for a better future at Missouri State University. Rachel and her family were instrumental in getting the ABLE act passed on the federal level, and invited my family to advocate in Kansas. I can’t express how much of an honor it was to be present for the signing of the updated bill at the DSG with Lt. Governor Jeffery Colyer, and to see Lily smile as she represented her community of people with Down syndrome.

While Lily doesn’t completely understand how much this means for her future, she does understand that someday she’ll be able to work in an office, like her dad, and make her own paycheck. She’s made that part very clear to me!

If you know someone with a disability, help ensure that they know about this new opportunity. And if you’re a parent or grandparent, start contributing to your relative’s ABLE account now. Here are some helpful websites with additional resources:

- ABLE National Resource Center – [www.ablenrc.org](http://www.ablenrc.org)
- Kansas ABLE Savings Plan - [savewithable.com/ks/home.html](http://www.savewithable.com/ks/home.html)
- Missouri ABLE Savings Program - [www.moable.com](http://www.moable.com)

My wife Tammy and I were blessed to have our daughter Lily born with Down syndrome back in 2007. The Down Syndrome Guild of Greater Kansas City has been instrumental in providing us with support, creating connections to other families and referring us to specialists in the community ever since. As a living testament to this support, Lily is now an independent and active 6th grader in her Olathe Middle School and living life to the fullest.

Her arrival not only prompted our family to learn as much as possible about navigating life with special needs, but I have made it one of my specialties as a Certified Financial Planner Practitioner to make sure that all families know how to plan financially for a person with special needs. We can’t thank the DSG enough for their help over the years and the services that continue to deepen each year.

Submitted by Matt Syverson, CFP
[ soundsstewardship.com](http://soundsstewardship.com)
DSG Teens and Adults With DS Invited to Usher at Nutcracker

DSG partnered with the Kansas City Ballet and Kauffman Center for the Performing Arts last year during their performance of the Nutcracker. We brought teens and adults with Down syndrome to the performance to help welcome guests, provide programs and usher them to their seats. We are thrilled to be invited back again this year to usher on December 18th for the 6 PM performance.

Anyone 12+ years of age with Down syndrome is invited to apply to usher with us. Interested applicants must be comfortable in large settings, able to follow directions, walk moderate distances and be friendly and outgoing.

Ushers who are selected will be required to dress according to Kauffman requirements and be at the show by 4:30 PM for training. A chaperone is required to attend with them.

Kauffman would like 30 ushers with DS at the performance. Learn more by visiting kcdsg.org/starsevents Questions or want to apply? Please contact julie@kcdsg.org for more information.

Host a Dress Down for Down Syndrome Day to Benefit DSG

Do you and your co-workers/friends like wearing jeans to work? Here is an easy way to be comfortable all day AND to also help those with Down syndrome. Help spread awareness and display the many gifts and talents of individuals with Down syndrome by hosting a Dress Down Day!

If requested, DSG can provide you marketing fliers, participant stickers and collection envelopes. Contact info@kcdsg.org or 913-384-4848 to request more information on how to host a dress down for down syndrome day.
Legacy Gifts Make an Impact at DSG

DSG recently received memorials in honor of loved ones who have passed away. Each of these donations comes from the heart and shows reverence for people who are no longer with us. We are honored when families think of DSG during a difficult time and we extend our deepest sympathies to the family and friends of the following:

Kerry Lundergan  Judy McGill
Marty Cole  Shirley Kusmaul
Rick Stuart  Phillip McElhaney
Kim Foley  Jesus Lopez
Timothy Beatti  Keith Rodden

Contact info@kcdsg.org if you would like to discuss donations designated to DSG in honor of your loved one.

KBP Foods and KFC Stores Raise $47,000 for People With Down Syndrome

Over 40 KFC restaurants in the KC metro area and surrounding areas participated in a coupon book sale drive for five weeks this fall. Stores had the opportunity to win promotional prizes and to do additional fundraising outside of coupon books to support DSG’s vital programs and services.

We are proud to share that through this great partnership, over $47,000 was raised to help people with Down syndrome achieve their full potential! Thank you KBP Foods and KFC for your amazing support!

Northland Elks Support DSG

DSG has a long standing partnership with the Northland Elks Lodge. They host an annual breakfast and donate all proceeds to support DSG programs and have also written several grants to fund items for DSG’s new parent welcome baskets.

This year’s breakfast raised over $3,300! We appreciate the past and continued support and all that the Elks have done to enhance our mission and work.
New Parents
Join us for Breakfast

Saturday, Nov 2, 2019
9:00 AM-11:00 AM

DSG Office  5960 Dearborn Street, Mission, KS

Parents of children with Down syndrome ages 0-2 are invited to our new parent breakfast.

Bring your extended family members too, for a wonderful opportunity to connect with others.

"We LOVE these group meetings! It was nice to hear everyone’s story and the facilitators did a GREAT job."

RSVP by Oct 28th at kcdsg.org

**Child care and breakfast provided**