WE ARE DSG

The Down Syndrome Guild of Greater Kansas City (DSG) is a guiding light for families in need of support — and an anchor, dedicated to helping people with Down syndrome live to their fullest potential. We are the lifespan service provider for people with Down syndrome and their caregivers in the United States.

Our mission — and our heart — is to deliver support for people with Down syndrome, their families and the professionals who serve them. We strive to be the expert resource on Down syndrome in the country. And we’re focused on community mobilization, creating solutions for people with Down syndrome.

We broaden awareness, foster positive attitudes and change the life course of people with Down syndrome. We push the upper limits of what’s possible for those we serve. Because when people with Down syndrome have the opportunities they need to thrive, everyone wins.

Thank you for your support . . . yesterday, today and tomorrow. Together, we are DSG.
This past year has been a year of vision for DSG. We’ve built on our heritage and legacy of service to people with Down syndrome, their families and our entire community.

Monumentally, this past year, we embarked on our first-ever capital campaign. We’ve laid strategic plans that answer this question: what if?

What if . . . we lean into our expertise to be the lifespan service provider for people with Down syndrome and their caregivers in the United States?

What if . . . we create a space that reflects the potential we see in every person with Down syndrome?

What if . . . we build the center of the Down syndrome ecosystem with a campus that mirrors the top-tier services people with Down syndrome deserve?

The answer to these strategic questions is our Lifelong Learning Campus, a project that will enable DSG to change the lives of the people we serve now—and for generations to come.

Developing innovative and first-to-market services and support, DSG is the only organization in the region committed to serving the lifespan for people with Down syndrome. From birth to late adulthood, DSG meets each individual where they are and focuses on building skills needed to live life to its utmost potential.

This is DSG: a community that empowers people with Down syndrome to live the fullest life possible. Everything we’ve achieved this past year points back to our focus as an innovative, dynamic organization that continues to reimagine the possibilities for people with Down syndrome.

This past year was one of milestones and monumental growth. From the purchase of our building next door and our vision for a Lifelong Learning Campus coming to fruition to the launch of our innovative, therapeutic services program called Pathways, DSG is expanding at a pace we have never experienced before.

While we’re grateful to have taken strategic steps to serve our community with excellence, we’re even more grateful for our generous supporters. To those who give their time, talent and treasure, thank you. Thank you for generously partnering with us as we grow into our best chapter yet as an organization.
Growing to Provide Lifespan Services

Developing innovative and first-to-market services and support, DSG is the only organization in the region committed to growing to better meet the needs of people with Down syndrome, from birth to late adulthood. We are reimagining the life course of people with Down syndrome by focusing on education, employment and independent living—because they are critical to leading meaningful lives.

Being a change-agent requires a shift to a proactive posture and perspective: creating the strategies that will change what life looks like for those with Down syndrome around the country. DSG leaned into our mission and crafted a vision for our future service strategy.

We established six pillars guiding our mission as our organization expands to serve the ever-growing needs of our members, across the lifespan, leading them to experience their best lives. Our six pillars include: Daily Living; Communication and Social Skills; Community Engagement; Health, Wellness and Safety; Self-advocacy; and Vocational Development.

“Pathways has literally put us back into being able to function in the community, not just in our home. It’s lonely, and it’s a hard journey, and they help when things are really hard. They are 100% on your side, on your team, cheering you on.”

— Mother of Tate, a 5-year old with Down syndrome and Cortical Visual Impairment
DSG Grows Services, Launches Therapeutic Services

In January 2019, DSG doubled down on our goal of changing the life trajectory of people with Down syndrome by launching Pathways™ — our comprehensive therapeutic services program. DSG is the only organization in the country to serve individuals with Down syndrome and their families through a comprehensive therapeutic and individualized model.

Designed for people with Down syndrome ages 4 - 20, services are facilitated by our highly skilled therapy team that includes two full-time Occupational Therapists, a Speech-Language Pathologist, and a Board Certified Behavior Analyst. Pathways™ equips the individual, and his/her parents, caregivers, and extended family members with skill-building strategies and individualized supports that are targeted to daily life in the home and community.

The primary goal is to maximize potential for a meaningful and productive adulthood that includes employment, daily life independence, community integration, and social inclusion. In 2020, we will roll out expanded, a-la-carte options for families to select which option is right for them.

In the first year, Pathways™ served 53 families. Of the families enrolled in 2019, a total of 90% have renewed their commitment for 2020.
Current Services and Support

DSG continues to strengthen our current services while also developing new, innovative service lines in anticipation of the future needs of individuals with Down syndrome. Services and support for which we increased access include:

- **Parent Support Gatherings:** for parents and extended family of children, ages birth through two years old, this quarterly event offers an opportunity to connect with other families to share fears, ask questions, listen to success stories, and learn about various resources.

- **PALS:** designed specifically for kids ages 7-11 with Down syndrome, Peers Actively Learning Skills (PALS) offers children opportunities to learn valuable social skills, create lasting friendships and develop independence.

- **STARS:** created for ages 12 to 18, Special Teens Achieving Real Success (STARS) provides a safe learning environment for teens to learn social, prevocational, and life skills to help them reach their greatest potential.

### Teen Mission Moment

Katie, a member of STARS, our teen programming that helps explore employment skills, had a goal to work at KFC when she turned 16.

Last fall at our Golf Tournament, DSG Board member Mike Kulp, President and CEO of KBP Foods (which operates nearly 800 KFC and YUM! Brands restaurants across the country) heard about Katie’s goal. He found Katie, who was volunteering at our event, and put her in touch with the right people to help her achieve her goal!

We caught up with Katie earlier this year and she loves her job and she is thrilled that she reached her employment goal with KFC!

“I am so grateful DSG offers seminars and that I was able to attend. I would be totally lost right now without the opportunity to learn from experts who know how to help me ensure my daughter becomes less stubborn and more independent.”

— Mother of Ellie, a 5-year old with Down syndrome
Teen/Adult Mission Moment

Planning for a Bright Future: DSG Hosts Job Fairs and Mock Interviews for Teens and Adults

With a focus on living independently and employment opportunities, DSG brought together the community with a vision for the future with our quarterly Job Fairs and Mock Interviews. Most recently, our Job Fair was attended by 25 teens and adults (self-advocates) with Down syndrome and 18 different local businesses.

Marie Leathers, OTR/L, RBT, DSG’s Occupational Therapist, organized the event to ensure it was meaningful and productive for not only attendees, but also employers. “As an occupational therapist, my main goal was for every self-advocate to participate and have a meaningful experience,” said Marie. “I graded the activities, which means increasing or decreasing the difficulty, to meet each person where they are—for just the ‘right’ challenge.”

Parents found that DSG had the suc-

Community Outreach

Being the only organization in Kansas City solely dedicated to serving individuals with Down syndrome, DSG is becoming a congregator of community assets to ensure access to opportunities that past generations have not experienced. Serving a large geographic area covering approximately 50 counties in Kansas and Missouri, we have relationships with many other organizations.

Currently, DSG is engaged with 22 hospital systems in the Kansas City metropolitan area that communicate with us when there is a birth of a baby with Down syndrome. DSG has also developed Down syndrome specialists in all 45 school districts and two Catholic Archdiocese. They are engaged with our seminars that provide education regarding advocacy for students with Down syndrome.

DSG also created partnerships with Rockhurst University and the University of Kansas, offering DSG as a clinical site for master’s level occupational therapists to complete their Level II practicums. In 2023, DSG will become a site for doctoral students at Rockhurst University to complete their capstone assignment for their Doctor of Occupational Therapy.
WE VALUE OUR PARTNERSHIPS WITH FAMILIES AND SCHOOLS AND SEEK TO PROVIDE RESOURCES AND TOOLS TO HELP ALL STUDENTS WITH DOWN SYNDROME ACHIEVE THEIR FULL POTENTIAL.

cess of each individual in mind. “I didn’t think Caleb would benefit from a job fair because his speech is very delayed, even among kids with Down syndrome,” explained Petrice, Caleb’s mom. “However, his SLP at school convinced me to let him try. That is when I reached out to the DSG Pathways team and they were all so excited to help Caleb be as successful as possible. He was provided so many supports; video modeling, visual schedule, visual prompts, and the Touch Chat app.”

With nearly 20 staff and volunteers on site, each attendee was provided support tailored to his/her abilities to ensure optimal participation and growth from the experience. “Using visual supports, augmentative and alternative communication (AAC), environmental modifications (splitting the businesses into three rooms to help prevent over-stimulation), our self-advocates received that perfect amount of a challenge,” said Marie. “Our staff and volunteers provided support tailored to the individual, ranging from either 1:1 support, 2:1 support, or no support at all.”

Caleb’s experience was a positive one, according to Petrice: “I think Caleb understood that this was preparing him for a job—and to be an adult. It was a huge confident booster—he was very proud of himself.”

As Petrice and Caleb prepare for his future, they believe this event was helpful. “Caleb felt like he was given the opportunity to be as independent as possible—just having the experience is always a plus,” explains Petrice. “This will help him be better prepared for an actual interview in the future.”
Fundraising

**DSG Experiences Another Banner Year for Revenue, Due to Generous Support**

After a number of successful fundraisers throughout the year and a historic number of donations and grants, DSG’s audited financials shows 2019 closing with total revenue and other support of $1.96-million.

**Stats for revenue:**
- **Revenue:** DSG experienced our second-best revenue year in DSG’s history, with $1.96-million.
- **Grants:** applied for an all-time record high of 50 grants in 2019, with 16 being awarded to benefit our programs and services.
- **Fundraising Events:**
  - **Step Up Walks**
    - Our KC Step Up Walk raised over $481,000 in corporate sponsorships, donations and in-kind contributions
    - The Central MO Step Up Walk: 660 participants, gross revenue was $65,000

Both the Kansas City and Central Missouri walks were a day of family fun for all our families and a celebration of their loved one or friend with Down syndrome. We had 6,557 guests attend this special day.

**The Tee Up for Down Syndrome Golf Tournament:** We raised over $252,000 this year, with 40 corporations coming together to support our mission.

**2019 Private Cellar Wine Tasting & Auction:** The event grossed $140,318 with 300+ guests in attendance.
Financial Breakdown

DSG had strong operating income results. In 2019, management funded significant acquisition and pre-construction costs out of the operating budget so the profit margin ratio was impacted. If those costs would have been moved to debt obligations, the profit margin ratio would have been approximately 8%. In addition, DSG total revenues and other support have grown significantly post merger and will continue to rise as new service lines are developed and philanthropic support increases.

Net Asset Growth

Through astute financial management, DSG continues to grow stakeholder equity allowing for new program development and service expansion.
Where We’ve Been

DSG was founded in 1984 by two families who shared a vision to support families experiencing the birth of a child with Down syndrome. Like all loving parents, they wanted their kids to thrive, and they wanted support and community. They wanted their children to grow up happy, healthy, encouraged and empowered. They wanted their children to live lives full of possibility and potential. From these families, DSG was born.

DSG was incorporated in 1986 and received its 501(c)(3) not-for-profit exempt status in 1987. We’ve invested the past 35 years developing a proven approach to comprehensive support services and programs, an approach other Down syndrome organizations across the country replicate.

In 2017, DSG began taking strategic, future-focused steps when it merged with First Downs for Down Syndrome. Soon after, the merged organization hired its first Chief Executive Officer to unite the cultures and lead a team to new heights.

WHERE WE STAND

“Isaac loves the process of being ‘dropped off’ at PALS, which gives him a sense of independence that he enjoys. He benefits from interacting with his peers, which is one of our goals for him. We hope that he will make friendships here that will last a lifetime as they grow up into STARS (DSG’s teen program) together and beyond.”

— Parents of Isaac, an 8-year old participant of PALS
Where We Are Today

**DSG is committed to service:**
We're deeply dedicated to growing to deliver services and support across the lifespan of our members. Our industry-leading talent and servant mentality provides a sophisticated presence in the national Down syndrome landscape.

**We're well-positioned with unmatched expertise:**
Our team brings 150+ years of experience in serving people with intellectual and developmental disabilities, nonprofit leadership, fundraising, communications, programming and more.

**DSG has a strong fiscal foundation:**
Due to our disciplined financial approach, and the generosity of donors and grantors, we've integrated a strong cash position with escalating philanthropic and programmatic revenue. At the core of this is our ability to invest early in programs and offer high-impact opportunities to those we serve.

**Innovation is in our DNA:**
Our innovation and first-to-market services drive our goal of positively impacting multiple generations. We’re reengineering the life course of people with Down syndrome by focusing on education, employment and independent living — all crucial to living the fullest life possible.

**DSG’s reach is limitless:**
Today, we’ve broadened our footprint like never before through digital connection. We’re beginning to serve families in and outside our region digitally, each day. This capacity eliminates barriers, allowing us to engage with babies through mature adults, people in urban and rural communities and far beyond the Kansas City metro. This has always been our goal, and today, boundless connection is our reality.

“Pathways has made grandparenting even more wonderful! Each meeting helps us better appreciate, understand, and support our beloved six-year-old granddaughter. Along with our daughter and son-in-law, we learn ways to encourage our charming, feisty, amazing granddaughter to be more appropriately social, follow directions, use her words and communicate, and so much more.

— Grandparents of Annabelle, 1st grader with Down syndrome & Pathways participant
With Your Generosity, Where We’re Going Tomorrow

The need has never been greater, and DSG is poised to answer the call. We’re setting the stage to establish our Lifelong Learning Campus in 2020.

As the nucleus for program development and system innovation, the Campus will transform the lives of people with Down syndrome in our Kansas City region and our nation. We will create a space that reflects the potential we see in every person with Down syndrome; a space that is equipped to foster community; and develop and deploy innovative services.

With the support of donors and grantors, we look forward to building a headquarters equipped to evolve at the same pace as DSG. We’re excited to build a campus that mirrors our top-tier services — powered by gifts to DSG. We’re positioned to expand far beyond our local impact, making a difference on a national scale.

At this critical point in our history, and our future, we’re thankful. Thank you for understanding the value of investing in the lives of people with Down syndrome. Together, we are making a multi-generational impact. And the best is yet to come.

Infrastructure Improvements Include:

- Social enterprise opportunities
- State-of-the-art technology
- Enhanced building security
- Outdoor adaptive playground
- Outdoor seating
- Outdoor community garden
- Natural lighting
- Expanded parking access
- Landscape/hardscape
THE DOWN SYNDROME GUILD TEAM

With more than 150 years of experience in nonprofit, leadership and philanthropy, our team is poised to lead DSG to new heights.

DSG Executive Team | What do you look forward to most on this journey with DSG?

Dr. Jason Drummond  .................................................. Seeing individuals reach their full potential
Chief Executive Officer
B.S. - Business Administration, MidAmerica Nazarene University
B.S. - Public Relations, MidAmerica Nazarene University
M.S. - Education, University of Kansas
Ed.D. - Higher Education Administration, University of Kansas
24 years of experience

Amy Allison  ................................................................. Working with families, educators, medical professionals, legislators, employers and community members as we collectively help empower people with Down syndrome to live their best lives and achieve their dreams
Vice President of Education and Advocacy
B.S. - Psychology, Brigham Young University
B.S. - Sociology, Brigham Young University
25 years of experience

Vanessa Figg  ............................................................... Being a part of a mission that seeks to change a generation of lives—and sharing that story far and wide!
Vice President of Marketing
B.A. - Communication, Villanova University
M.A. - Mass Communication, University of Central Missouri
17 years of experience

Sarah Mai, OTR/L ..................................................... I look forward to the future when we can truly see longitudinal progress. It will be a joy to know that our services and supports contributed to better outcomes in the lives of people with Down syndrome, whether it’s greater independence, employability, community inclusion, or more meaningful social connection
Vice President of Lifespan Services
B.S. - Occupational Studies, University of Kansas
M.A. - Occupational Therapy, University of Kansas
23 years of experience

Amy Stoll ................................................................. To sharing our vision and dreams with our donors and supporters. Their generosity and trust in DSG, have provided the families and individuals we serve, with the best possible outcomes. I am eager to watch the people we serve, lead fulfilling lives within their community
Vice President of Philanthropy
B.S. - Education, University of Kansas
M.A. - Education, University of Kansas
23 years of experience
Lifespan Services Team | What do you look forward to most on this journey with DSG?

**Megan DeBoom, BCBA, LBA**  
Director of Behavioral Services  
B.S. - Psychology, University of Texas  
M.A. - Special Education, University of Kansas  
11 years of experience  
I am looking forward to collaborating with the team of service providers at DSG. Each one of us brings years of experience and expertise to DSG’s journey. I am fortunate to be a part of a team that is committed to serving our self-advocates, our self-advocates’ families, and our community.

**Jessica Fahey**  
Program Coordinator  
B.A. - Communication, University of San Diego  
7 years of experience  
I look forward to learning, growing and challenging myself and the individuals we support to be the best version of ourselves. I love that DSG is always pushing for progress!

**Marie Leathers, MOT, OTR/L, RBT**  
Occupational Therapist  
B.S. - Applied Behavior Science, University of Kansas  
M.A. - Occupational Therapy, University of Kansas  
6 years of experience  
I am grateful to work for an organization where I am surrounded by passionate colleagues and able to serve such wonderful families. I am most excited to design and revise services to best meet our family’s needs, continue to grow and expand our organization, and become leaders in our field.

**Betsy Sylvester, CCC-SLP**  
Director of Speech and Language Services  
B.F.A. - Speech Pathology, Baylor University  
M.A. - Communication Disorders, University of Central Missouri  
16 years of experience  
I love working with the self-advocates and their families. I look forward to walking beside them as they learn new skills and break down barriers to live their best life possible.

**Tyler Goevert**  
School Age Program Manager  
B.S. - Psychology, Kansas State University  
M.A. - Special Education, University of Kansas  
Graduate Certificate: Applied Behavior Analysis  
8 years of experience  
I can’t wait to begin providing fun, meaningful events for our self-advocates that provide a judgment-free space for both growth and socializing!

**Lauren Bingham, BS, BCaBA, LaBA**  
Adult Continuing Education (ACE) Program Manager  
Board Certified Assistant Behavior Analyst  
B.S. - Applied Behavioral Sciences, University of Kansas  
Concentration in Psychology  
10 years of experience  
Changing the lives of adults with Down syndrome. I truly believe that ACE will transform the standard for adult services and I am excited to implement a program that will grow skills, build a community and be the launching pad for hopes and dreams.
External Relations | What do you look forward to most on this journey with DSG?

**Johnna Ingham**
Executive Assistant
- B.S. - Agriculture/Animal Science, University of Central Missouri
- M.S. - CSPA, University of Central Missouri
- 22 years of experience

**Judith Raub**
Director of Database Management and Technology
- B.S. - Paralegal, Eastern Michigan University
- B.S.B.A. - Accounting, University of Central Missouri
- 36 years of experience

Administrative Assistants | What I like best about working at DSG. . .

**Zach Neff**
Employed with DSG for 2 years

**Elli Walker**
Employed with DSG for 3 years

**Sara Niederhauser**
Employed with DSG for 2 years

I really like to work at DSG and to help people. I like to help the Pathways team with projects on the computer and I also like to help by giving tours to visitors. DSG helps people by having activities that help people grow. I love to work at the DSG because I help make people happy and make them smile.

I love the DSG because I feel like I’m helping out. When kids come in with their parents I get to say ‘Welcome to the DSG, how can I help you?’ and I feel glad that they are there. I feel excited that they come to the DSG to learn about responsibilities and how to live a good life.

It’s fun! I like to work with all of my coworkers and I like to help people—and to work with people. I am a hard worker! DSG makes people with Down syndrome feel good.

Seeing the endless possibilities for our members and their families.

I love working with data and look forward to contributing to the data to make a meaningful contribution in assisting the team in achieving our mission.

I really like to work at DSG and to help people. I like to help the Pathways team with projects on the computer and I also like to help by giving tours to visitors. DSG helps people by having activities that help people grow. I love to work at the DSG because I help make people happy and make them smile.
<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mike Frazier</td>
<td>President &amp; CEO, ReeceNichols</td>
</tr>
<tr>
<td>John Melvin</td>
<td>Chair, Development Committee</td>
</tr>
<tr>
<td>Bob Fagan</td>
<td>Vice President, CBRE</td>
</tr>
<tr>
<td>Chris Sorensen</td>
<td>Member, Vice President, JE Dunn Construction</td>
</tr>
<tr>
<td>Joe Roos</td>
<td>Treasurer, Partner, BKD</td>
</tr>
<tr>
<td>Jo Ann Butaud</td>
<td>Member, Attorney, Evans &amp; Mullinix</td>
</tr>
<tr>
<td>Amy Fauss</td>
<td>Secretary, Chief Operating Officer, CrossFirst Bank</td>
</tr>
<tr>
<td>Deborah Kass</td>
<td>Member, Retired, Human Resources Executive</td>
</tr>
<tr>
<td>Mike Kulp</td>
<td>Chair, Governance Committee, President/CEO, KBP Foods</td>
</tr>
<tr>
<td>Russell Rein</td>
<td>Member, Vice President for Ambulatory Services and Practice Management, University of Kansas Health System</td>
</tr>
</tbody>
</table>

OUR INVESTMENT IN OUR TEAM IS A DIRECT INVESTMENT IN PEOPLE WITH DOWN SYNDROME AND THEIR FAMILIES: A STRONG STAFF AND STRONG WORKPLACE RESULT IN STRONG OUTCOMES.
Expanding to Meet the Needs of the Down Syndrome Community

DSG to Build Lifelong Learning Campus to Provide Lifespan Services

DSG is embarking on our first-ever capital project with a vision to change the lives of people with Down syndrome in the Kansas City region and around the nation. As an organization, we have outgrown our current facility and must expand to better serve the Down syndrome community—from birth through late adulthood.

Through our market research, we identified a real community need for continuity of services and support, from birth through late adulthood. In response, we imagined people with Down syndrome of every age, receiving efficient, effective services and support—all within our new Lifelong Learning Campus.

Designed to evolve at the same expansive pace as our organization, this 11,000 square-foot, multi-functional Campus will mirror the top-tier services we're creating and delivering. Leveraging all the resources the Campus will provide, our members will have the opportunity to:

• receive therapeutic services
• enjoy meaningful employment opportunities
• gain independent living skills
• explore creative outlets
• utilize technology
• socialize and enjoy a sense of community

With our services and support available in one location, the Campus will increase access, capacity, and continuity of services, which will increase the likelihood of positive outcomes for the families we serve.
Addressing a Critical Lack of Services for Adults with Down Syndrome

A major challenge that will be addressed by our Campus is the severe lack of services for adults with Down syndrome. For individuals with Down syndrome, services including education, nurturing care and socialization are plentiful until they reach age 21. After that, services are not nearly as robust. As a result, many adults with Down syndrome live disengaged, lonely lives. They may spend their days sitting at home alone or with a series of caregivers in a day program. DSG believes that age 21 should not mark the end of their story.

DSG to Launch Adult Day Program in 2020

Based on a significant need expressed by the families we serve, DSG will launch our new Adult Continuing Education (ACE) Program in late 2020! Our goal is to equip adults with Down syndrome with the skills that will help them to live a meaningful life by maximizing their independence and productive participation within their community. ACE is a fee-for-service, learning program for adults with Down syndrome that will take place, Monday-Friday, 9 am to 3:30 pm.

Expanding to Serve Another Critical Developmental Phase

Developed for the unique space within the Lifelong Learning Campus, our Therapeutic Play Groups will launch later this year. These play groups for ages 3 – 6 years old will be facilitated by our therapy staff to increase socialization skills, while growing friendships. Until now, DSG has provided limited services for this critical developmental phase in the lives of children with Down syndrome.
WE BROADEN AWARENESS, FOSTER POSITIVE ATTITUDES AND CHANGE THE LIFE COURSE OF PEOPLE WITH DOWN SYNDROME.