

EDUCATE • EMPOWER • ENGAGE



Annual Report 2021



DOWN SYNDROME ASSOCIATION
OF GREATER RICHMOND

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Leadership Message



As the pandemic continued into 2021, the losses, needs, and impact on individuals with Down syndrome increased. Individuals with Down syndrome experienced loss in many areas of their lives including school, employment, and social connections. The needs for families increased as well, and families shared with us things like, "Mark was not the same...he struggled to understand why he didn't do anything anymore and how to occupy his time." As the pandemic continued, so did DSAGR. We persisted in educating, empowering, and engaging individuals and families. Services were provided virtually and, when it was safe to do so, in person. We hosted the Summer Employment Academy in person again. We worked to restore employment opportunities for individuals with Down syndrome in the community by demonstrating how businesses can work with job coaches to support employment. In a time when more people had "we're hiring!" signs out than ever before, we were advocates about the skills individuals with Down syndrome have to offer.

As the year continued, new stories emerged, stories of hope, restoration, and wholeness. Families who experienced the loss of employment now called and shared, "Kelly got a job again," and "eighteen months later Mark has finally returned to the workforce...He is so excited he often gets ready to go to work hours in advance." Parents shared that the individuals who were once "a shell of themselves" were now "thriving" and "so happy to be working" again. 2021 was a year of amazing impact with many individuals with Down syndrome and their families! Yet, there are still more families to reach and more work to do to reach our vision for a community in which all individuals with Down syndrome are fully included and valued members. Thanks to the generosity and giving of our many donors, businesses, board members, and volunteers, onward we go into 2022!

Jennifer Case, LCSW, Executive Director

Mark Boone, President

A Special Note from Terri Lancaster, former Executive Director:

In 2021 I concluded my 8th year as Executive Director and I'm very thankful to have served our Down syndrome community, alongside the amazing staff and Board of Directors. During my tenure we experienced enormous growth and have changed the way individuals with Down syndrome are educated, employed and included in our community. DSAGR is well positioned to move into its next phase of growth with the development of a robust multi-year strategic plan, committed community partners, and donors who value how we always have our mission at the forefront of everything we do. I have every confidence that the leadership team and staff will continue to grow, diversify and provide the most effective programs and services that meet the unique needs of our families. It's been an honor and joy for my family and I to be part of such a great organization for over 25 years. We look forward to continuing to support the DSAGR as volunteers and wish you all the best.

Terri Lancaster

Mission Statement

To benefit the lives of individuals with Down syndrome and their families through individual and family support, education, community awareness and advocacy.

Vision

We envision a community in which individuals with Down syndrome are fully included and valued members.

Impacting our Community

651 Active Families

Welcomed **75** New Families:
26 Babies &
49 Additional New Families



Provided Support & Program Services to
Richmond, Williamsburg, Charlottesville,
The Central Shenandoah Valley
and Southern Virginia

\$244,584 Provided **\$244,584** in education and social programs, conferences, classes, and seminars for individuals with Down syndrome, their families, and professionals across Virginia.

263 Provided Continuing Education to 263 Educators, Families & Community Leaders

1,400 Engaged 1,400 Volunteers who gave 6,327 Hours of Service

11 Provided New Parent Resource Packets to 11 local hospitals and medical professionals

WHAT IS DOWN SYNDROME?

DOWN SYNDROME IS THE MOST COMMON GENETIC CONDITION, YET ITS CAUSE IS STILL UNKNOWN. INDIVIDUALS WITH DOWN SYNDROME HAVE THREE COPIES OF THE 21ST CHROMOSOME. WHILE THERE ARE SOME COMMON CHARACTERISTICS AND PHYSICAL TRAITS ASSOCIATED WITH DOWN SYNDROME, EACH INDIVIDUAL WITH DOWN SYNDROME IS UNIQUE. THE ADDITIONAL GENETIC MATERIAL IMPACTS AN INDIVIDUAL'S COURSE OF DEVELOPMENT.

- People with Down syndrome have an increased risk for certain medical conditions, including congenital heart defects, respiratory problems, hearing impairments and Alzheimer's disease.
- Down syndrome is the leading cause of intellectual and developmental delays, which are typically mild to moderate. More importantly, each individual also has many strengths and talents to be celebrated.
- Life expectancy for people with Down syndrome has increased dramatically in recent decades, from 25 in 1983 to 60 today.

Down syndrome in the U.S.



14 per 10,000 live births annually.
6,000 babies with Down
syndrome are born annually.

Down syndrome in Virginia



In Virginia, approximately 123
babies are born with
Down syndrome annually.

Educating our Community

PROGRAMS

9th Annual Disability Education and Transition Virtual Conference
The Learning Program Levels I, II & Plus
Summer Employment Academy
Learn to Grow in Baby's 1st Year (new)
Moving On! Road to Independence: Building Social and Communication Skills
Education Webinars (VCU ACE IT in college and Special Needs Trust with Arc of Northern Virginia)
Nothing Down About It: Educator Webinar (new)
Parent Chat: Back to School and Inclusion

DATA

8 students and 8 businesses completed the Summer Employment Academy
7 educators completed the "Nothing Down About It" Webinar
16 IEP consultations
18 participants in "Moving On" 6 week series
2 series held in 2021
26 families participated in the Learning Program Series (September 2020-May 2021)

IEP Consultation Services

Jessica's story



Jessica, a DSAGR member and mother to Everett, who has Down syndrome and is hearing impaired, accessed DSAGR's IEP support in 2021. Jessica shared with DSAGR staff that a month before school began (and without an IEP meeting), she was informed that Everett would not be allowed to attend his neighborhood school alongside his peers. Jessica said, "After many tears, I got to work committed to changing the outcome for both our sons. **One of the most important things I did was pick up the phone and get connected with Kim Owens, Education Director at DSAGR.** Her knowledge coupled with her passion for inclusion gave me the courage and connections to advocate for what I knew to be best for Everett and our family. I will forever be grateful that the DSAGR, and their connections, stood beside us; because of the actions of many, Everett is fully included and thriving in his neighborhood school. We hear consistently that he is a 'beloved member of his classroom community,' and is meeting benchmarks in both language arts and math!" - Jessica, mother to Everett

Summer Employment Academy

Hope's story

Hope has done the Summer Employment Academy over the course of several summers and we now prioritize it for her summer plans. It is invaluable to experience different locations for work, and to discuss her feelings about it afterwards, as we consider her first real job. Kim Owens, Education Director, and Cassie DiFrango, Teacher, do an amazing job organizing the sites with community partners who truly understand what a valuable workforce we have in our community. The best part, though, is the pride in Hope's eyes as she shares her workday with us. - Jill, mother to Hope



Empowering our Community

PROGRAMS

- Dads Night Out
- Moms Night Out
- Splash Day
- Williamsburg BBQ
- Miniature Golf
- Picnics
- Tazikis Dinner Out
- Potlucks
- Park and Play
- Trunk or Treat
- Trail Walk & Scavenger Hunt
- Ornament Decorating
- Annual Holiday Party
- Williamsburg Holiday Party
- Charlottesville Holiday Party
- Step Up Singers
- Winter Games (virtual)
- Hands Up Meet and Greet (virtual)
- Lunch Club 8 sessions (virtual)
- Valentine's Memory (virtual)
- Spring Games Jeopardy, Word Scramble, Cinco de Mayo Bingo, I Spy (virtual)
- Preschool Art & Play (virtual)

DATA

- 12 Moms' Gatherings (Virtual & In-person)
- 3 Dads' Gatherings (Virtual & In-person)
- 14 Kids' social group events (Virtual & In-person)
- 15 Adult social group events (Virtual & In-person)
- 11 Family Programs



Empowerment through Connection

"Two weeks after David was born, we received his Down syndrome diagnosis. Having a lot of questions and even more anxiety, I contacted the DADS group at DSAGR. That very same day, another Dad contacted me, and in the process shared his own positive experience of parenting a child with Down syndrome. He encouraged me to attend the next DADS meet-up, and I've been involved ever since. The DADS group is friendly, inclusive, and incredibly knowledgeable, with years of experience and advice that's always willingly shared." *Billy, father to David*

Empowerment through Skill Development

During The Fun4Life Lunch Club students joined in a Zoom call to make a variety of foods. One parent, Emily, says "This was **one of the only zoom classes that my son attended enthusiastically every week.** He learned about virtual participation and following directions on a zoom call. The social aspects were wonderful....Mary Margaret [*Family Care Coordinator for DSAGR*] worked magic at getting the participants to tune into each other and have conversations, as well as following instructions for cooking some healthy and delicious dishes. **It was a real self-esteem and social boost.**" *Emily, mother to Max*



Empowerment through Employment

During the pandemic Kelly lost both of her jobs. Lucy shared, "**we took advantage of the unexpected free time by developing Kelly's skills in the kitchen and around the house, indoors and out.** Kelly continued her childcare training online so she would be ready when called back to work. The DSAGR network and its place in the broader Richmond area – along with Kelly's experience and desire to work with children – were integral to Kelly's re-employment. **Kelly started two jobs working with children in January 2022.** She is thrilled to be working again and to be working with children." *Lucy, mother to Kelly*

Engaging our Community

Programs & Services

- First Call for New or Expectant Parents
- Parenting Class for Parents of Babies with DS
- Community Engagement & Education Scholarships
- Dual Diagnosis Support Group (DS Plus)
- Hispanic Outreach
- Grandparent to Grandparent Support Group
- Virtual Education Programs
- Advocacy & Awareness
- Individual & Family Support
- Individual Education Plan (IEP) Consultations
- Employment Outreach
- Health Outreach
- Volunteer Engagement

Data

- **26** New and expectant parents provided individual support through First Call
- **54** Family Care needs provided individual support
- **8** Learn to Grow Parenting Classes
- **37** Community engagement scholarships provided



Welcoming Livie

Thoughts from mom, Jessie, about our New Parent Series for parents during the first year of life



Jessie, a new mom, shares about the impact of the Learn to Grow program. She said, **“I loved this class! I found it helpful in multiple ways. Each week was a different topic. PT, OT, eye and ear exams, feeding, speech, what to expect after you age out of EI, etc.** I took notes and still refer to them each time we visit the doctor. For example, I had no idea there was a certain type of dilated eye drops that cannot be given to a person with DS. And I make sure each time we visit the eye doctor that they know this information... Livie was a 2020 baby, and more than the 1st year of her life was spent in hospitals and then in quarantine. It was lonely. This class gave me a chance to virtually connect with other parents of kiddos the same age having similar experiences. I am forever thankful for the knowledge I gained through this series.”

Welcoming All

Reflections from Mi Familia volunteers

Maria and Ynma, mothers of children with Down syndrome, volunteer by providing Spanish interpretation services. Maria shared that she feels “if you have a good network of parents, you can get answers immediately...**I wanted to help other parents.** You’ll be surprised how many new parents are going through the same situation.” Ynma Tejada says, “for me, being a very joyful family ambassador, I know that I may have the opportunity to share and help many parents with my experiences in one way or another since I have a girl with Down syndrome...Our children need much of us and we must be the ones who teach and direct them in their lives to become independent and strong. More than that, just seeing that smile that fills the soul and makes us continue.” Volunteers like Maria and Ynma make what we do at DSAGR possible.



2021 Highlights

- Provided \$15,698 in Scholarships to 37 individuals with Down syndrome
- Served 651 individuals with Down syndrome and their families
- Provided 116 Social & Educational Opportunities with 1308 attendees participating
- 3 Holiday Celebrations and Santa Visits for 436 families across VA (398 in RVA)
- Launched the 1st Learn to Grow 8-Week Class covering a variety of early childhood development topics
- Held the 1st Virtual Education Conference- 136 attendees from 30 school districts across Virginia and 14 states joining together for 3 sessions of learning, networking, and inspiration
- New partnership with Longwood University, Beyond Boundaries, Mike King Radio, and Henrico County

FINANCIAL DATA & COMMUNITY COLLABORATORS

Community Partners

ARC of Northern Virginia
 ARC of Virginia
 Beyond Boundaries
 Department of Aging and Rehabilitative Service
 Dominion Energy
 Henrico County
 Home Care Delivered
 Knights of Columbus
 Longwood University
 Mike King Radio Show
 Partnership for People with Disabilities
 Parent Educational Advocacy Training Center
 Penn Station East Coast Subs
 T/TAC at VCU
 VA Department of Education
 VCU Department of Occupational Therapy
 VCU Rehabilitation Research and Training Center
 VCU School of Dentistry
 VCU School of Medicine
 VCU School of Physical Therapy


National Partnerships

Down Syndrome Affiliates in Action
 Global Down Syndrome Foundation
 National Down Syndrome Congress
 National Down Syndrome Society

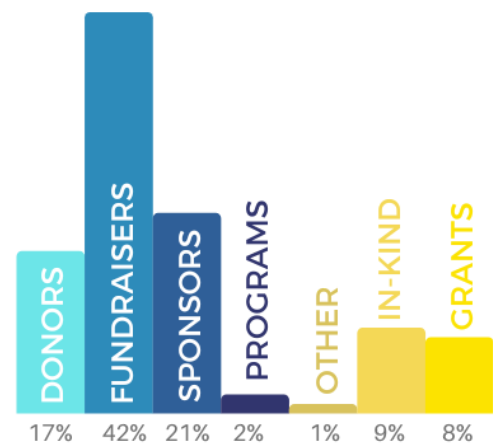
Strategic Priorities in 2022 & Beyond

- Grow community partnerships and collaborations
- Deepen programs and services
- Focus on diversity, equity, and inclusion
- Rename to reflect expanded service area
- Expand First Call Program
- Expand Adult Programming

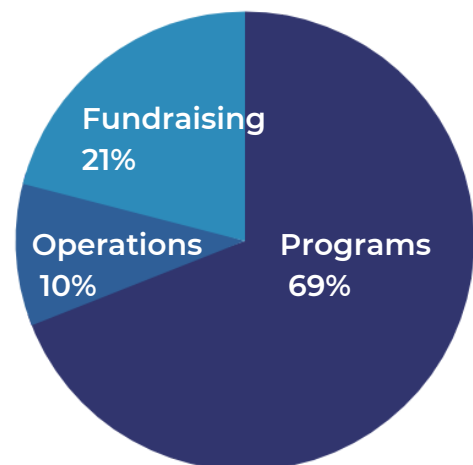
SUMMARY

 **2021 Total Revenue is \$491,836, which includes \$41,825 of in-kind donations. DSAGR has \$439,685 in cash funds and investments.**

2021 REVENUES



2021 EXPENSES



SPONSORS & SUPPORTERS

Presenting (\$10,000+)

ATLANTIC UNION BANK
COUNTY OF HENRICO

ESTES EXPRESS LINES

JR MAINTENANCE SERVICES
WEST CHARITABLE TRUST

Partner (\$5,000 - \$9,999)

DOMINION ENERGY
DPR CONSTRUCTION & FACEBOOK
HENRICO COUNTY RECREATION
& PARKS

JOHN LEDDER MEMORIAL GOLF
TOURNAMENT
MIX 98.1
PEATC

THE FEATHERSTON FOUNDATION
TRUIST
VCU - RRTC

Step UP (\$2,500 - \$4,999)

BEST VERSION MEDIA
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OF RICHMOND AT VCU
CUSTOM CREATION LIGHTSHOW, INC.

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FOUNDATION
FOX RICHMOND
HOME CARE DELIVERED

REACH MAGAZINE
RICHMOND FAMILY MAGAZINE
ROSIE'S EMPORIUM
TOPGOLF

Team (\$1,000 - \$2,499)

A.B.A. WELL AND SEPTIC SERVICES
ABLENOW
ALL AMERICAN MOBILITY
ANTHEM HEALTHKEEPERS
BLAKEMORE CONSTRUCTION
CORPORATION
BRINDLEE MOUNTAIN
FIRE APPARATUS, LLC
CENTER FOR FAMILY INVOLVEMENT
AT VCU

COTIVITI CARES
DAVID TILLER & ASSOCIATES
ENTWISTLE COMPANY
GREATER RICHMOND CIVITAN CLUB
KEITER CPA
MAIN STREET HOMES
MANCHESTER MOOSE LODGE #699
MILLER & ASSOCIATES
NATIONAL DOWN SYNDROME SOCIETY

PAGE AUTO GROUP
PENN STATION EAST COAST SUBS
RICHMOND CHRISTMAS MOTHER
TEK RVA, LLC
TRAVELERS
VIRGINIA BOARD FOR
PEOPLE WITH DISABILITIES
VIRGINIA CAPITAL TRAIL
VIRGINIA WOMEN'S CENTER

FUNDRAISERS [INDIVIDUALS]

Distinguished (\$7,500)

ANGIE EVANS

CLARENCE & CAROL WILLIAMS

Champion (\$5,000 - \$7,499)

BOBBY & DEBBIE ABERNATHY
TOM & KRIS HASKINS

BOB & TERRI LANCASTER

KEN & CYNTHIA LANTZ
GREG & MARA WEEDA

Superstar (\$2,500 - \$4,999)

JONATHAN & AMANDA ARNO
MICHAEL & LAURA BARKER
MARK & VICKI BOONE
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KEVIN & AMY HUGHES
MIKE & BOBBI JONES
JOHN & PRISCILLA NEMETZ
DAVID & JAMIE NICHOLLS
AUNDREA SMITH
AARON STEELMAN & TRACY ROBINSON

Premier (\$1,000 - \$2,499)

PARIS BALL & MARIA GULLICKSON
CHRIS & MEGAN BLAKE
JOSEPH BOLICK & SARAH LANG
TYLER & JOCELYN BRADSHAW
AME BRANAM
FRED & AMY BRAVO
BEN BROMLEY & CHRISTI STAFFORD
SCOTT & KENDALL BRUINGTON
CALEB COFFEY & HALEY KING
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