DSDN

DOWN SYNDROME DIAGNOSIS NETWORK

inform • connect • support

Annual Report
FY2020

Dear Members and Friends,

While 2020 was the year that no one expected due to COVID-19, it was also the year that we saw from our staff and volunteers a tremendous amount of adaptability, unwavering support, and a drive to excellence in challenging circumstances.

The pandemic has completely changed the way we work, learn, connect with others, and care for our loved ones and ourselves. During this time of social distancing, face-to-face support options for expectant and new parents to a child with Down syndrome have been limited. Our team stepped up in big—virtual—ways to continue to provide as much support to new parents as possible. Though our sixth year of operations looked different than planned, this year gave us many opportunities to drive our mission forward not only through our core capabilities, but also in new and innovative ways.

We continue to be anchored to our mission: to connect, support, and provide accurate information to parents—and the medical professionals who serve them—from the time of diagnosis through age three, while fostering the opportunity for lifelong connections. This year, we were well positioned to offer consistent support to parents in our dozens of birth clubs and 50+ topical online support groups. In our groups we captured 17 percent of new parents to children with Down syndrome, and we reached 14,000 members connected online. We also shifted our annual Rockin' Mom™ and Rockin Dad in-person retreats to a virtual Rockin' Retreat in which more than 1,000 parents participated.

The ongoing contributions from our volunteers and donors are unmatched, and we strive to lead with integrity and intentionality to honor their work. Thank you for continuing to support our purpose and mission. As we look ahead to FY2021, we are excited to introduce our next three-year strategic plan focused on extending our reach and programming, ensuring organizational sustainability, and intentionally cultivating partnerships. And while we are uncertain what the next year will bring, we are confident in the capabilities of our staff and volunteers. Alongside all of them, DSDN will continue to thrive as the largest organized network of parents with a new or recent Down syndrome diagnosis, and the only national organization specifically focused on the diagnosis experience and parenting in the first three years. We've got this!

Respectfully submitted,

Melissa Shutwell

Melissa Shutwell, Board President

Jen Jacob

Jen Jacob, Executive Director

DSDN

about us

Our Mission

To connect, support, and provide accurate information to parents—and the medical professionals who serve them—from the time of diagnosis through age three, while fostering the opportunity for lifelong connections.

Our Vision

That every Down syndrome diagnosis will be delivered in an unbiased, factual, and supportive way every time, and that families can quickly find meaningful connections.

Guiding Values

- Families have the right to accurate and unbiased information about Down syndrome at the time of diagnosis, and we value the role that medical professionals have in providing that information.

- Access to support at local, national, and online levels is incredibly important to families with a new diagnosis, and we value the resources that exist for families outside of DSDN and seek to collaborate and share those resources with our members.

- The contributions of our volunteers are unmatched, and we strive to honor their work by leading with integrity, intentionality, and care.

- We strive to innovate and create programming that is directly relevant to the needs of the families we serve through our mission.

Commitment to Diversity & Inclusion

We value the diversity that exists within the Down syndrome community and strive to reflect that in our team, the community we serve, our programs, and our services.

FY2020 at a glance

DSDN BY THE NUMBERS...

14,000 = Families served in our online, private, moderated birth club groups

17% of new families with a Down syndrome diagnosis reached

1,000+ Parents attended the virtual Rockin' Retreat

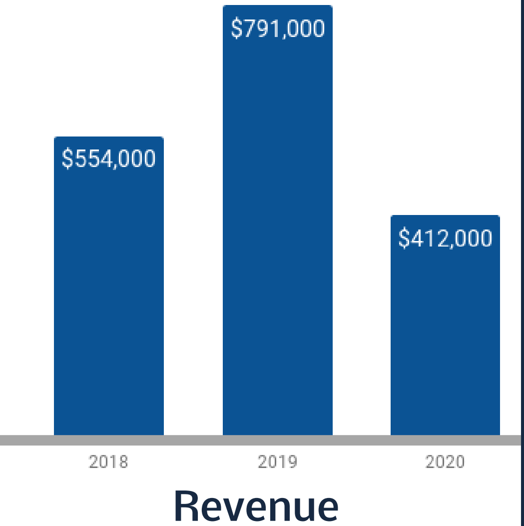
DSDN brochures and resources sent free of charge to local organizations and medical providers → **6,200**

More than **150** DSDN volunteers

$320,000+

Raised by over **1,500** donors

1,200+ ⏩ Families touched through our Rockin' Family Fund (welcome gifts, care cards, memorial wind chimes, and



Revenue
November 1-October 31

Over **150K** people learned about our DSDN mission through our fundraisers

Membership
November 1-October 31

support & connect

DSDN serves more than 14,000 families in our Rockin' Mom™ and Dad online communities, which support parents beginning in pregnancy and throughout their child's life. In FY2020, we continued to grow our reach and added 17 percent of families with a new diagnosis in our online groups.

Engaging and supporting a diverse community is important to DSDN. In 2020, we continued to increase membership in the Rockin' Dads group to more than 1,300 dads. Our Rockin' Moms en Español group and the Black Families Down Syndrome Network (BFDSN) both continue to grow and thrive to provide support to families in those communities. Our BFDSN group now serves more than 700 parents!

Online Group Highlights

- Added almost 2,000 parents to our private, small and large birth-club Rockin' groups; more than 1,000 of these were moms with a baby under age one.
- Added 350 new dads.
- Captured 17 percent of families with a new diagnosis.
- Expanded to more than 50 subgroups to allow families with common interests and backgrounds to connect.
- Continued training and support for a group of 100 online administrators and moderators.

support

Our Rockin' Family Fund (RFF) supported more families than ever before this year! We provided more than 1,200 families with pregnancy and newborn welcome gifts, scholarships, care cards, and memorial gifts.

Although in-person events did not go on as planned this year, we delayed scholarships for the winners to 2021. NDSC moved their event to a virtual conference, and through the RFF we provided registrations for 10 families to attend.

Our pregnancy gifts are in their second year, and we nearly doubled the number sent in 2019! We are so grateful to be able to support, congratulate, and honor families through our Rockin' Family Fund.

Rockin' Family Fund Highlights

- Sent almost 300 pregnancy gifts to families expecting a new baby with Down syndrome.
- Sent 80 care gift cards to families in the hospital.
- Sent 56 families memorial wind chimes in memory of their child.

you've got this and we've got you

in memory

connect

VIRTUAL Rockin' Retreat Highlights

2020

We've Got This

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK

What a year indeed! The most anticipated weekend of the year for many, our annual Rockin' Mom™ and Dad retreats were cancelled due to the pandemic. But our team rallied, and we were able to host a virtual event to provide a little encouragement and entertainment for our members. More than 1,000 parents joined us for a weeklong celebration online where we played BINGO, had a virtual exhibit hall, gave away prizes, shared parent stories, heard from some celebrities, and took a few moments for ourselves. Although nothing could compare to our onsite meetups, it was great to provide some fun for our rockin' moms and dads!

Black Families Down Syndrome Network Highlights

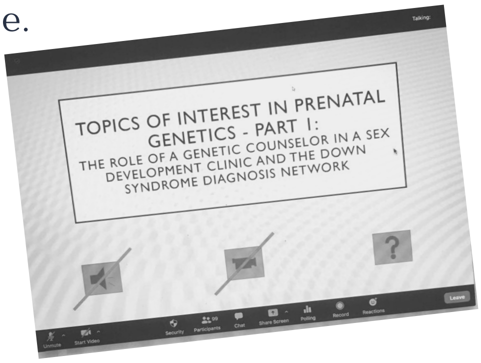
The Black Families Down Syndrome Network (BFDSN) has continued to grow in numbers and support for families of color—membership almost doubled this year! With all that happened across the country this year, it highlighted the great need for our strategic plan work in addressing specific needs for black parents as they raise their child with Down syndrome, including physician bias in diagnosis conversations and disparity in medical care for both mother and child. Our BFDSN leadership team attended the annual African American Conference on Disabilities, and we have big plans for 2021!

inform

Due to the pandemic, most of the onsite events transitioned to virtual conferences this year, challenging us to reach providers in different ways. Our team spent time creating new paths to reach our mission and vision goals.

Our medical outreach directors continued to build relationships with industry leaders to ensure patients with a new diagnosis are provided with accurate, current information and resources. Starting in 2020, DSDN was listed as a resource for patients receiving a positive screen for Down syndrome through two of the leading prenatal testing companies.

DSDN began more targeted conversations with industry and professional organizations/societies around disparity in care for black families at the time of a new diagnosis and how we can work together to make change.



TOPICS OF INTEREST IN PRENATAL GENETICS - PART 1:
THE ROLE OF A GENETIC COUNSELOR IN A SEX DEVELOPMENT CLINIC AND THE DOWN SYNDROME DIAGNOSIS NETWORK

Medical Outreach Highlights

- Partnered with organizations such as Lettercase, Massachusetts Down Syndrome Congress, and National Down Syndrome Adoption Network to provide key materials to local organizations, new parents, and medical providers.
- Exhibited for the first time at the Society for Maternal-Fetal Medicine annual conference.
- Presented via webinar to more than 200 medical providers on how to deliver a Down syndrome diagnosis.

From a medical provider after a DSDN webinar presentation:

"For years, I led with 'I'm sorry' as I prepared to give a diagnosis of Down syndrome. Then I realized how negative that could be. I really appreciate the guidance to use 'I have some unexpected news.' Thank you."

inform

DSDN continues to develop relationships with local organizations across the country to ensure all families find the connections and support they need locally and online.

Our team attended the annual Down Syndrome Affiliates in Action (DSAIA) conference and talked about our DSDN mission, programming, and services with Down syndrome—focused organizations across the country.

We celebrated Down Syndrome Awareness month in October with our third annual Local Support Rocks campaign highlighting all of the important work local organizations do for families. More than 100 organizations were nominated. The winners this year included:

- Down Syndrome Association of Central Oklahoma
- Down Syndrome Network of Oregon
- Families Exploring Down Syndrome

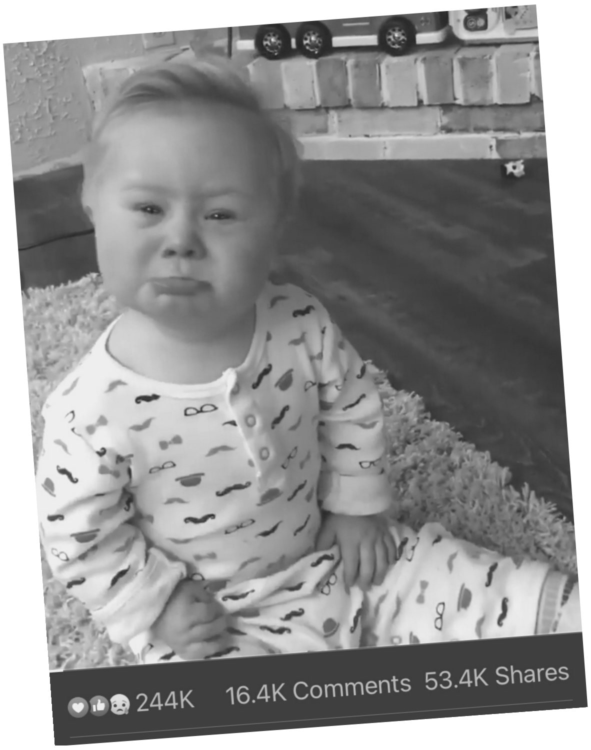
Local Partnership Highlights

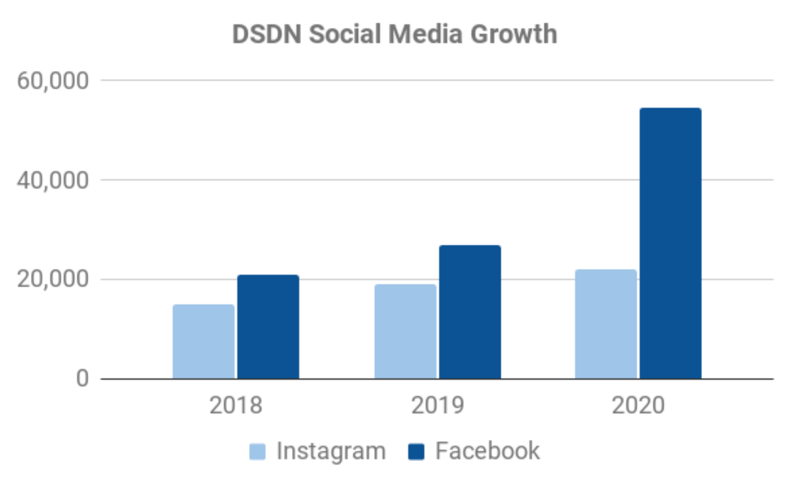
- Shared through social media about virtual/local events across the country.
- Sent 6,000+ free brochures to local organizations and medical providers.
- Exhibited at the Down Syndrome Affiliates in Action (DSAIA) annual conference in Orlando.
- Gave away three $2,100 grants during our Local Support Rocks campaign in October.

inform

Our dedicated DSDN social media team continued to grow our network and reach as we worked to share experiences and stories from families around the world. Our goal is to share balanced information that is inclusive of the many different paths families take on this parenting journey.

2020 was a huge year of growth for our Facebook page especially, and we had our first "viral" post featuring Walter (below) that was viewed by 1.9 million people around the world!





Social Media Highlights

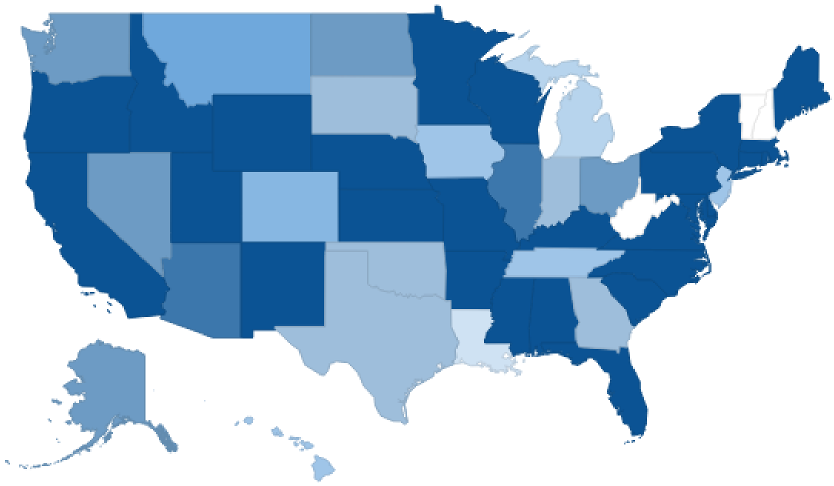
- Gained more than 30,000 new followers on social media.
- Posts regularly reached hundreds of thousands of people worldwide.
- Shared about many virtual events and resources to support families at home.

financials

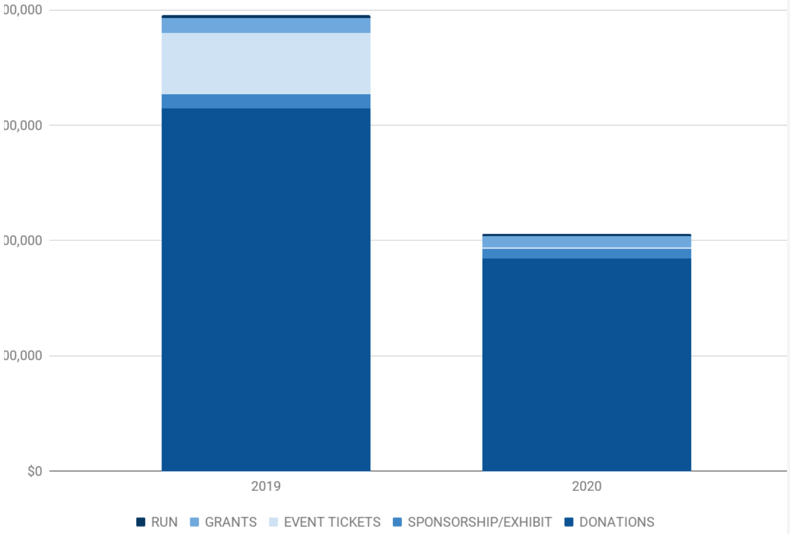
Even amidst a global pandemic, the support for our DSDN mission and vision remains strong. Although we did not set any records this year with our fundraising, we were able to sustain our programming and services for families and offer refunds for the cancelled retreat events. We offered a FREE virtual retreat for parents in our community and offered a VIP registration option with some added perks for a fee. We also hosted a virtual walk/run as part of our virtual retreat event. With the bulk of our medical outreach onsite events cancelled, our spending decreased. And through the pandemic, parents still welcomed babies with Down syndrome into the world. Our Rockin' Family Fund spending focused on welcome gifts for new and expectant parents, care cards, prizes for our fundraisers, and memorial gifts to honor the loss of a child.

In FY2020, we had more than 1,200 individual donors from across almost every state. Hundreds more supported friends and families through online social media—based donations.

We truly appreciate the grantmakers, sponsors, and thousands of donors who contributed financially to DSDN in 2020 to change the diagnosis experience for new families and ensure they receive the support they desire.



Revenue Comparison



	2019	2020
EVENT TICKETS	**$106,387**	**$2904**
SPONSORSHIP/EXHIBITS	**$23,699**	**$16,175**
DONATIONS	**$629,592**	**$369,168**
GRANTS	**$26,000**	**$19,000**
AUCTION/RUN	**$5769**	**$4950**
TOTAL REVENUE	**$791,447**	**$412,197**

financials

The mission of the Down Syndrome Diagnosis Network is to connect, support, and provide accurate information to parents—and the medical professionals who serve them—from the time of diagnosis through age three, while fostering the opportunity for lifelong connections. Our vision is that every Down syndrome diagnosis will be delivered in an unbiased, factual, and supportive way every time, and that families can quickly find meaningful connections.

Mission Areas of Focus

INFORM

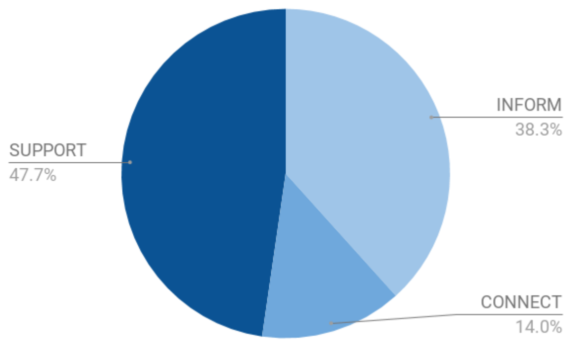
- Distribution of DSDN brochures, cards, and information
- Medical outreach exhibits and materials

CONNECT

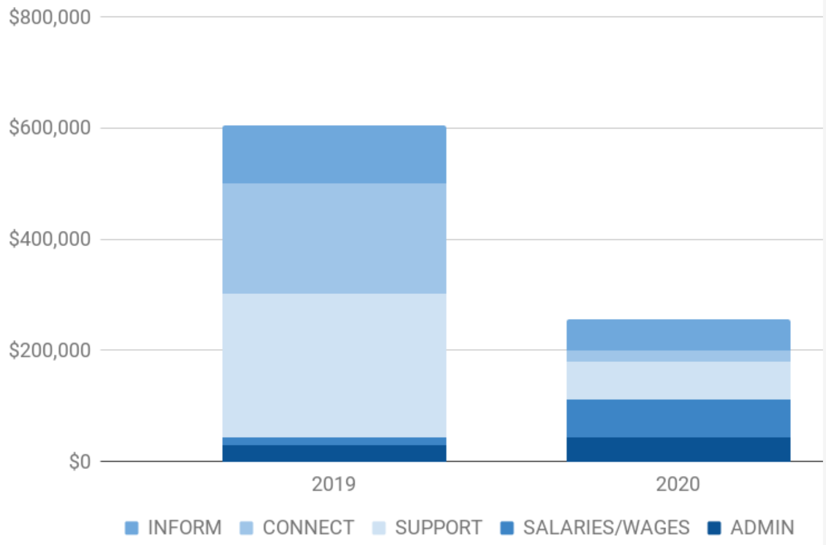
- Attending, exhibiting, and sponsoring national Down syndrome conferences
- DSDN Virtual Retreat costs

SUPPORT

- Fundraiser Prizes
- Rockin' Family Fund
  - Welcome gifts
  - Pregnancy gifts
  - Memorials
  - Care cards
  - Scholarships
  - Retreat registration support



Expense Comparison



	2019	2020
INFORM	$104,623	$55,672
CONNECT	$198,586	$20,331
SUPPORT	$258,538	$69,333
ADMINISTRATIVE	$30,026	$42,918
SALARIES/WAGES	$13,364	$67,663
TOTAL EXPENSES	$605,138	$255,917

financials

A community with a purpose. Our network of rockin' moms and dads believe in the power of community and supporting one another at each stage of the journey. This year more than 240 individual fundraisers helped bring in almost $300,000 in donations to support DSDN's mission and vision. While raising money for DSDN is wonderful, the best part of their efforts is the incredible amount of advocacy and awareness our rockin' families bring to the Down syndrome community. Through their work, the 2020 fundraisers reached more than 150,000 people!

We know how difficult it can be for parents to find time and money to focus on themselves, so we are in our fifth year of offering prizes for those who fundraise for DSDN. In addition to those prizes we offer parents to offset costs to attend the DSDN Rockin' Mom™ or Dad retreat, this year we offered opportunities for our top fundraisers to honor organizations that were also important to them.

This year, our fundraisers celebrated the following organizations with donations in their honor:

- **Down Syndrome Association of Central New Jersey**
- **Down Syndrome Association of Connecticut**
- **Down Syndrome of Louisville**
- **DSDN - Medical Outreach**
- **DSDN - General Fund**

Top 5 Fundraisers of 2020

- **Jenny Di Benedetto**
- **Alley Clemens**
- **Heather Imbriale**
- **Nav Ramzan**
- **Mary Beth Norton**

Why I Fundraise...

"DSDN is a responsive organization, built by the community it serves, with a laser-focused mission to serve at the earliest stages of the Down syndrome journey. I am honored to be able to donate time, money, and resources to support their important work. Fundraising not only delivers dollars to help fund programs that directly help families and medical providers, it also confirms the fact that there are limitless numbers of people in this world who choose to show up for our families every time we ask. The Down syndrome journey may not always be easy, but to find the path paved with love and support makes a big difference."

Luca's rockin' mom, Jenny Di Benedetto

MANY THANKS TO OUR 2020
OFFICIAL DSDN ROCKIN' FUNDRAISERS

Aimee Radford
Alexa Hinz
Alley Clemens
Allie Peters
Allison Marie
Allison Simpson
Ally Trujillo
Amanda Bedtke
Amanda Caffrey
Amanda Wheaton
Amber Clark
Amber Gale
Amber Slager
Amy Hardeman
Amy Luke
Amy Schauer Dalke
Amy Wilke
Amy Barrett Bartlett
Angela Castillo-Sterry
Angie Dugas
Angie Currie
Ashlee Wallace
Ashley Dirks
Ashley Ziemann
Ashley Cencer
Ashley Broshous
Ashley Martin
Ashly Williams
Becky Sievers
Becky Damico
Becky Merrill
Beth Swanson
Beverly Romero
Brandi Dennis
Brian Barlean
Brianne Minga
Britney Stewart
Brooke Miller
Bryn Shaffer
Caitie Hurley
Candice Bouronich
Cari Weiffenbach
Carla Johnson
Cassie Krzoska
Cassy Chesser
Chelsey Schueller
Chermaine Shaw
Christy Cooper
Cindy Wimsatt
Clarissa Bradford
Corinne Dauksavage
Courtney Morse
Courtney Carns
Crystal Worley
Dana Altone
Daniel Blonsky
Danielle Wood
Danielle Orr
Danielle Elisabeth
DeAnna Robertson
Elaine Alvarez
Elizabeth Vance
Emily McCranie
Emily Livingston
Eric Kronebusch
Erica Walsh
Erin Klones
Erin Ribar
Erin Horton
Erin Norman
Faith Hayes
Farah Lyner
Francine Scaccia
Frankie Johns
Genevieve Davis
Gina Buffone
Gina Klahn
Grace Mischenko
Grant Restuccio
Hannah Pascucci
Heather Imbriale
Heather OSullivan
Heather Lynne
Heather Bradley
Heidi Gage
Holly Hille
Hope Gibson
Jackie Ferrier
Jackie Ward
Jackie Weldon
Janelle Carino
Jeff Manning
Jena Wehmhoefer
Jenna Salcedo
Jenness Stock
Jennifer Tough
Jennifer Crary
Jennifer Sheran
Jennifer King
Jenny Di Benedetto
Jenny Ehlers
Jess Casper
Jessica Winter
Jessica Parker
Jessica Davis
Jessica Stull
Jetter Freeman
Jewels DeCorsey
Jill Lisy Urich
Jill Kyser
Jillian Benfield
Jillian Neville
Joanne Taylor
Jody Langford
John Tutor
Jordan Perez
Joy Barlean
Julia Kozel
Kara Vanskike
Kara Ecker
Kara Clason
Karen Olsen
Karen Larson
Kassy Velasco
Kate Powe
Katherine Meyers
Kathleen Seitz
Katie Anderson
Katie Grant
Katie McHargue
Katie Smith
Kayla Brown
Kayla Tutor
Kaylea Perkins
Kayte Simpson
Kelci Mattfeld
Kellie Renfro
Kelsey Bergsieker
Kim Weber
Kimberly Walton
Kristi Denner
Kristin Dickerson
Kristin Mayo
Kristin Crumb
Kylee Jackson
Laura Jacobs
Lauren McWhorter
Lauren Moreland
Lauren Kaplan
Lauren Mansour
Lauren Young
Lauren Payne
leticia acosta
Lisa Schleicher
Lisa Sturm
Lisa Rancourt
Liz Reid Loehrer
Lydia Kelley
Maggie Leydig
Mallory shuck
Mallory Diercks
Mandi Dalton
Maranda Everson
Maria Doran
Marie Eclavea
Mary Beth Norton
Maura Brady-Er
Meagan Schriewer
Megan Cataline
Melanie Farmer
Melanie Harrington
Melissa Shutwell
Melissa Harvey
Melissa Griffiths
Mercedes Alvis
Michael Pace
Michael Conway
Michele Hilgart
Mickey Eastin
Mikayla Doeden
Mike Bradley
Mike Simpson
Morgan Oestreich
Nadine Currier
Nav Ramzan
Nikelle Pledger
Nikki Drago
Nina Reiss
Paige Cisney
Patrick Nichols
Peyton-Leigh Holmes
Preslee Sanders
Renee Wolfe
Robin Osteen
Robin Lattierre
Sally Waldron
Sandy Estep
Sara Krambeer
Sara Peterson
Sara Sporar
Sarah Petrone
Sarah Milbratz
Sarah Clark
Sarah Young
Sarah Griffin
Sarah Sisneros
Sarah Lacey Smith
Sarah Blonsky
Sarah Fenster-Goldfarb
Shakyra Cora
Shalyn Green-Gaden
Shamara DeHerrera
Shannon Prausa
Sharon Louise Perry
Sharon Sabol
Shelby Gasior
Shelly Petersen
Sheryl Pasamonte
Sierra Tran
Stacey Russell
Stacy Tils
Stephanie Helmuth
Stephanie Panebianco
Stephanie Bonovitch
Stephanie Phillips-Roeder
Stephanie Lowe
Taylor Norris
Terri Joyce
Tiffany Stafford
Tiffany McGinnis
Tina Marino
Torri Attebury
Traci Vaugh
Tracy Marie
Trisha Romero
Troy Remick
Vanessa Kale
Veronica Shaw
Victoria Edwards
Ximena Bessert

a look to the future

Each year, our Board of Directors meets to focus on long-term strategic planning. This year, the team laid out the strategic plan for the next three years. The plan builds on our previous strategic plan with a keen eye toward organizational sustainability and growth. The planning process included an assessment of current performance, member feedback, a two-day planning session, and multiple reviews and approval.

2021-2024 Strategic Objectives

Reach

We will continue to improve and grow our technology platforms and partnerships to reach as many families as possible with a new Down syndrome diagnosis—each with their own unique needs.

Programming

We will expand the resources and activities available to families from diagnosis to age three, with a specific focus around dissemination of resources and information, crisis intervention, and care.

Organizational Sustainability

We will expand and scale our organization to proactively serve our mission long term.

Partner Outreach

We will continue to cultivate partnerships that help further our mission, particularly around medical organizations, local DSAs, and relevant national service organizations.

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Melissa Shutwell
Wisconsin

Vice President
Jenny Di Benedetto
Illinois

Secretary
Cathleen Small
California

Treasurer
Jill Urich
Ohio

Becky Bausman
California

Heather Bradley*
Minnesota

Kelli Caughman
Indiana

Yadira Regla-Cuevas
California

Joe Scott
Pennsylvania

Bethany Van Delft
Massachusetts

Operations Directors

Executive Director
Jen Jacob*

Black Families Down Syndrome Network
Kelli Caughman
Sharon Kendrick

Development Director
Stacey Graves

Fundraising
Jessica Pace

Rockin' Family Fund
Natalie Palin
Trisha Romero

Local Partnerships
Kristin Moss
Lauren Young

Medical Outreach
Jenny Di Benedetto
Hannah Pascucci

Retreat - Mom
Mandy Ramzan
Michelle Steffen
Katie Williams

Retreat - Dad
Andrew Hilgart
Grant Restuccio

Support
Christy Cooper

Social Media
Crystal Tillman
Trish Robinson

Additional Support

Fundraising
Amira Lawrence
Mary Beth Norton
Danielle Wood

Rockin' Family Fund
Bob and Nancy Landess
Hap and Marcia Steed

Shipping
Nicole Kunkel

Social Media

Graphics
Kristin Overland

Facebook
Shannon Prausa

Instagram
Stefani Settlemire

Pinterest
Crystal Staley

Twitter
Diane Hill

* Co-Founder

Medical Outreach Team

Amanda Dickinson
Amber Whitton
Ayesha Stachula
Brett Schneider
Erin Ribar
Heather Imbriale
Jackie Weldon
Jaclyn Skalnik
Jenness Stock
Jennifer Tough
Jennifer Wright
Jessica Schuster
Jessica Wooten
Jillian Benfield
Kelly Kulzer-Reyes
Kelly Konechne
Kimberly Wyse
Kristi Denner
Kristin Moss
Mahri Ozguc
Marisa Dunn
Sarah D Twomey-Mercurio
Scotti Brackett
Shelly Peterson
Sue Krekelberg
Torri Attebury
Vanessa Kale

Medical Advisory Team

Terri Couwenhoven, MS
Lauren Coyle, MD
Maureen Tart, MD

Online Birth Club and Subgroup Support Team

Amanda Brunning
Amy Barrett Barlett
Amy Hardeman
Amy Luke
Amy Stroud Jansen
Angela Elaine Massa King
Angela McCarty
Ashley Dirks
Ashley Durden
Ashley Engele
Ayesha Stachula
Becky Carey
Beth Crain
Beth Swanson
Britney Stewart
Camdyn Arey Russell
Carolyn Chase
Cassie Krzoska
Chermaine Shaw
Christine Hanes
Chrysii Skrypec
Corey Wingate
Crystal Kent
Dan Szostek
Dawn Koh
Elaine Lee
Elizabeth John Vance
Elizabeth Martinu
Erica Hillyer
Erica Shaeffer Manning
Erin Statz
Fernanda Martinez-Sanchez
Hadiza Abdullahi
Harmon Davis
Heather Bessman
Heather Walker Castillo
Heidi Ann Carvella-Van Kirk
Jeffrey Dice
Jennifer King
Jennifer Newell
Jennifer Tough
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Jordan Heberlein
Joy Allison Parman
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Karen Lee
Kate Manduca
Keisha Gray
Kelli Caughman
Lauren Hacht
Lauren Zwick
Leah Morgan Silverman
Leslie Meadows
Lindsey Smith-Mingus
Livia Mackley Allen
Mallory Shuck
Mara Thompson
Marisa Dunn
Marissa Mahon
Mary Beth Moore
Mary Cardle
Mary Heng
Mayfe Zurita-Almeida
Megan Dodd
Melissa Davidson
Melissa Call
Melissa Stoltz
Meredith Hawley Pysnik
Mike Demers
Miranda Galvin
Nicole Scott
Oluwaseyi Imaobong
Akintunde Johnson
Randy Pippin
Rebecca Roberts
Rhys Gay
Ryan McDonald
Samantha Paradis
Sara England
Sarah Holt
Sarah Milbratz
Sarah Petrone
Sarah Smith
Shannon Prausa
Sharon Kendrick
Shawna Cooper
Shelby Gasior
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Stephie Trimble
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Tera Moore
Trish Sullivan Robinson
Twyla Tatum