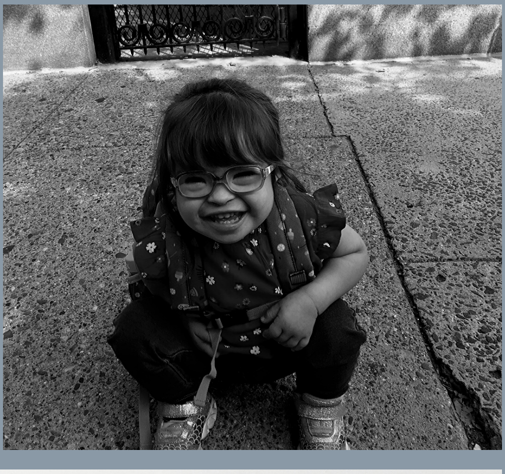
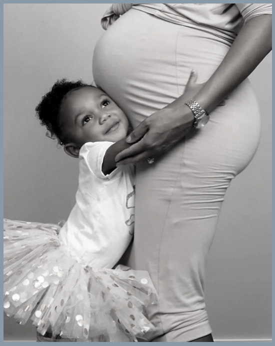
DSDN

DOWN SYNDROME DIAGNOSIS NETWORK

inform • connect • support





**The mission of DSDN is to connect, support, and provide accurate information to families with a Down syndrome diagnosis.
DSDN envisions a world in which families have unbiased, family-centered, and factually accurate diagnosis experiences every time and quickly know they are not alone.**

# Annual Report
# FY2019

# Dear Members and Friends,

It is hard to believe that we are already wrapping up our fifth year at DSDN! This year held our most incredible growth yet and a few changes as we continue to grow and to serve families and our mission.

One change you will notice this year is a change in leadership. Co-founder Heather Bradley stepped down as board president this spring. Former DSDN Director of Support Melissa Shutwell was selected as the new board president. We are grateful for Heather's vision to begin DSDN and her years of service as she continues to serve on the board.

This year also brought an adjustment to our fiscal year reporting dates. Rather than continuing to use the calendar year, our new fiscal year (FY2019) will be from November 1 through October 31. This change was made to better align our reporting with our annual events and fundraising campaigns.

As you will see in this report, FY2019 was another remarkable year for DSDN, with record-setting growth in online group membership and offerings, retreat attendance, medical outreach impact, and fundraising.

All of this is possible because of the generous support we receive from our staff, volunteers, donors, and members! Our team focuses diligently to ensure our mission remains at the heart of our work, which has enabled our organization to continue to grow and reach more families and medical providers. Because of everyone's hard work, DSDN is the largest national organization supporting parents with a new Down syndrome diagnosis. Thank you for being a part of our mission, and here's to an even bigger 2020!

Respectfully submitted,

Melissa Shutwell

Melissa Shutwell, Board President

Jen Jacob

Jen Jacob, Executive Director

DSDN

# FY2019 at a glance

DSDN

**11,405** = Families served in our online, private, moderated birth club groups

**14** Medical conferences exhibited at to talk with providers about the diagnosis experience

**760** Parents attended the Annual Rockin' Mom™ and Dad Retreats

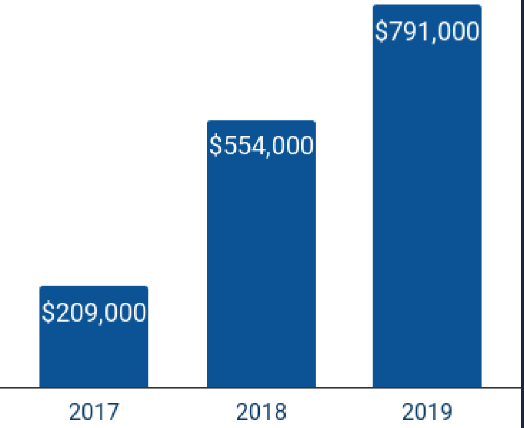
DSDN brochures and resources sent, free of charge, to local organizations and medical providers ➡ **8,900**

**More than 150** DSDN volunteers

**$629,092**

Raised by over **3,000** donors

**1,000+** ⏩ Families touched through our Rockin' Family Fund (welcome gifts, care cards, memorial wind chimes, and scholarships)

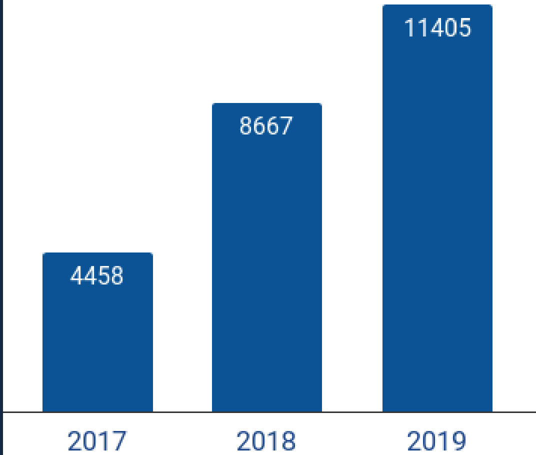


Revenue Increase

November 1-October 31

**Over 200K**

people learned about our DSDN mission through our fundraisers



Membership Increase

November 1-October 31

# support & connect

DSDN serves more than 11,000 families in our Rockin' Mom™ and Dad online communities, which support parents beginning in pregnancy and throughout their child's life. Part of our three-year strategic goal is to capture in our network 30 percent of families receiving a new diagnosis. In FY2019, we reached 15 percent of those with a new diagnosis.

Engaging and supporting diverse members is important to DSDN. In 2019, we continued to increase membership in the Rockin' Dads group to more than 1,000 dads. Our Rockin' Moms en Español group and the Black Families Down Syndrome Network both continue to grow and thrive to provide support to families in those co

## Online Group Highlights

- Added almost 1,300 moms into our private, birth-club Rockin' Mom groups; more than 700 of these were moms with a baby under age one.
- Added 500 new dads.
- Captured 15 percent of families with a new diagnosis.
- Expanded our subgroups from 45 to 50 to allow families with common interests and backgrounds to connect.
- Continued training and support for a group of almost 100 online administrators and moderators.

# support

Our Rockin' Family Fund (RFF) supported more families than ever before this year! We provided more than 800 families with pregnancy and newborn welcome gifts, scholarships, care cards, and memorial gifts. To help provide additional support to parents and reduce costs to attend our annual retreats, the RFF offset the amount not covered through the parent registration fee. This year we also increased the number and amount of scholarships we offered to families. Parents applied for the scholarships and winners were randomly chosen and announced on World Down Syndrome Day, March 21.

In FY2019 we also launched our pregnancy gifts for those that join our expectant mom group!

you've got this and we've got you

## Rockin' Family Fund Highlights

- Began our pregnancy welcome gifts and sent more than 200 to families in the first year.
- Sent 60 care gift cards to families in the hospital.
- Sent 31 families memorial wind chimes in memory of their child.
- Increased scholarships to include:
  - Two for the Rockin' Dad Retreat
  - Five for the Rockin' Mom Retreat
  - Five for the NDSC Annual Convention

# connect

FY2019 was a record year for our fifth annual Rockin' Mom™ Retreat! After filling registration to 500 within a few days, the DSDN team regrouped and prepared to welcome 700 moms to Nashville. Weekend speakers included Chairman of Special Olympics Timothy Shriver, author and speaker Mardra Sikora, veteran Rockin' Mom Joyce Tucker, and self-care specialist Liza Kindred.

We continued our retreat goals to connect moms and help them recharge, while also giving them opportunities to give back to new and expectant parents.

Our 2020 Rockin' Mom Retreat will take place at the Gaylord Rockies in Denver in September. We will continue to offer fundraising opportunities for parents to attend and help offset travel costs.

## Rockin' Mom Retreat Highlights

- 700 moms attended our fifth annual retreat.
- DSDN partnered with Down Syndrome Association of Middle Tennessee for Mom's Night Out at City Winery.
- Moms composed 1,000 cards for new Rockin' parents.
- More than 30 exhibitors participated—double the previous year.
- In our post survey, moms reported feeling:
  - 80% connected
  - 88% inspired
  - 80% recharged

connect. inspire. recharge

# connect

## Second Annual Rockin' Dad Retreat Highlights

In 2019, DSDN also hosted our second annual Rockin' Dad Retreat! We welcomed 60 dads from across the country to Denver to connect and recharge. In addition to sightseeing and taking in a Colorado Rockies game, the men spent time with Global Down Syndrome Foundation learning about the latest medical research focused around Down syndrome and writing cards to send to new dads joining the group. The 2020 event will host up to 100 dads in Kansas City, Missouri!

## Black Families Down Syndrome Network Highlights

The Black Families Down Syndrome Network (BFDSN) has also grown in big ways this year as DSDN continues to increase support for families of color and further reach the goals in our three-year strategic plan. Within its first year, the BFDSN online group has reached more than 400 parents! The team also hosted a luncheon at this year's retreat. Complete with speakers Joyce Tucker and Roxanne Hoke Chandler, the group focused discussions on growing support for new families and finding ways to better reach and connect.

# inform

FY2019 was a remarkable year for DSDN's medical outreach team! Our team attended 14 medical conferences across the country to talk with clinicians and providers about the diagnosis experience.

Our medical outreach directors continued to build relationships with industry leaders and medical organizations, including the American College of Obstetricians and Gynecologists (ACOG) and the Council on Resident Education in Obstetrics and Gynecology (CREOG), to ensure patients with a new diagnosis are provided with accurate, current information and resources. Starting in 2020, DSDN will be listed as a resource for patients receiving a positive screen for Down syndrome through two of the leading prenatal testing companies.

Our team was also able to lead sessions on delivering a diagnosis for medical residents attending CREOG's Educational Retreat. These sessions provided much insight for both the residents and DSDN as we build our patient advocacy platform. After our workshop, 74 percent of attendees reported feeling more confident in giving unexpected news to a patient.

## Medical Outreach Highlights

- Participated in the ACOG Advisory Panel on Prenatal Genetics to inform on diagnosis care pathways.
- Led training on how to deliver a diagnosis for medical residents at the annual retreat for CREOG.
- Exhibited at 14 medical conferences across the United States, including all 7 regional ACOG meetings.
- 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.

# inform

Throughout 2019, DSDN continued to develop relationships with local organizations across the country that are supporting new families.

We also celebrated Down Syndrome Awareness month in October with our second annual Local Support Rocks campaign highlighting all of the important work local organizations do for families. More than 70 organizations were nominated. The winners this year included:

- Down Syndrome Association of Tulsa
- Down Syndrome Association of Connecticut
- Down Syndrome Association of Greater Winston-Salem

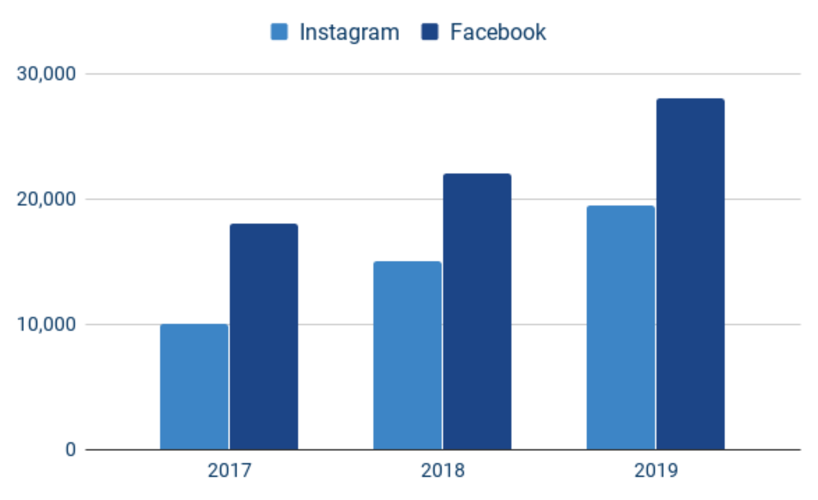
## Local Partnership Highlights

- Shared through social media about local events across the country.
- Sent 8,900 free brochures to local organizations and medical providers.
- Exhibited at the Down Syndrome Affiliates in Action (DSAIA) annual conference in St. Louis.
- Gave away three $2,100 grants during our Local Support Rocks campaign in October.
- At the Rockin' Mom retreat, assembled 400 welcome gifts to provide to local groups to help congratulate new Tennessee families.

# inform

In 2019, our 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. We hope new parents, especially, can find comfort in seeing relatable content and resources.

Facebook is still our primary social media space, and our Facebook page likes increased by more than 5,000 this year. We have also focused on growing our Instagram page, and more than 4,000 new followers joined us this year on Instagram.



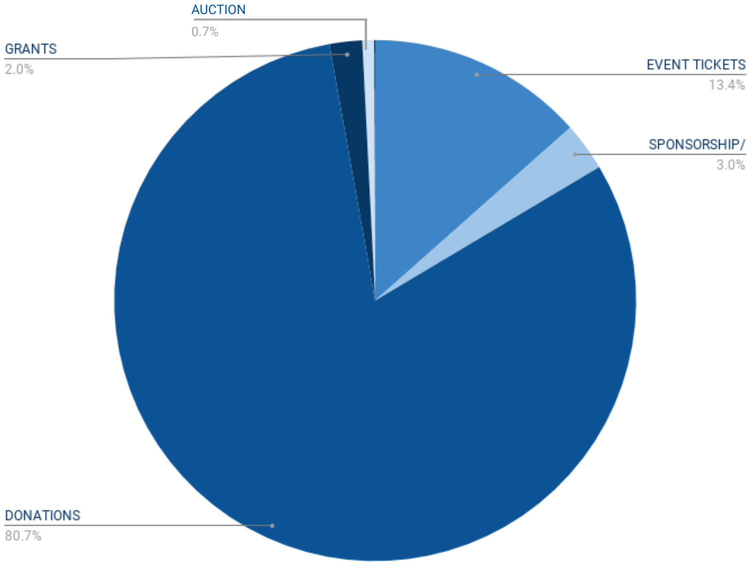
## Social Media Highlights

- Gained more than 9,000 new followers on social media.
- Posts regularly reached thousands of people worldwide.
- Shared about our team and stories from families to help our audience better understand our mission and focus.

# financials

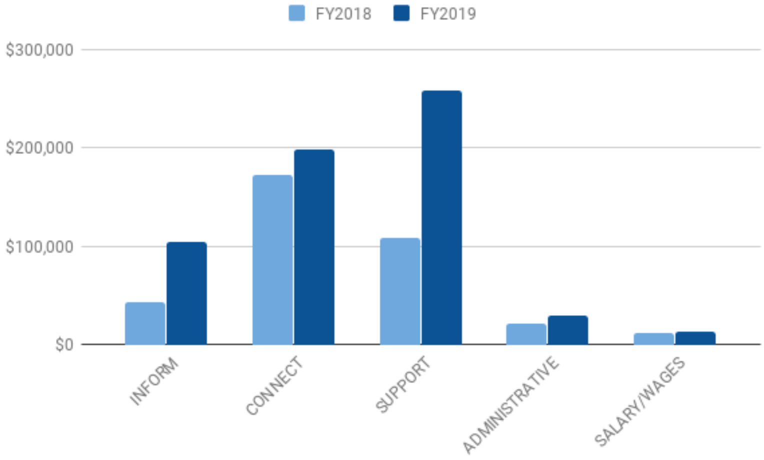
FY2019 continued to be a year of tremendous growth as we build a fiscally sound organization to fuel our mission and vision for the future. Our DSDN team worked to spend responsibly and effectively to best support meeting our short- and long-term organization goals. The data here represent our new fiscal year (November 1—October 31) in comparison to the same time period the previous year. More than 200 individual fundraisers helped to bring in donations this year and shared about our mission to more than 200,000 people! We are so grateful to the grantmakers, sponsors, and thousands of donors who contributed financially to DSDN in 2019 to change the diagnosis experience for new families and ensure they receive the support they desire.

## Revenue Comparison



| | FY2019 | FY2018 |
|---|---|---|
| **EVENT TICKETS** | **$106,387** | **$49,750** |
| **SPONSORSHIP/EXHIBITS** | **$23,699** | **$28,210** |
| **DONATIONS** | **$629,592** | **$463,641** |
| **GRANTS** | **$26,000** | **$0** |
| **AUCTION** | **$5769** | **$9165** |
| **TOTAL REVENUE** | **$791,447** | **$554,766** |

## Expense Comparison



| | FY2019 | FY2018 |
|---|---|---|
| **INFORM**<br>• Medical Outreach<br>• DSDN Material Distribution | **$104,623** | **$43,537** |
| **CONNECT**<br>• Annual DSDN Retreats<br>• National Conferences | **$198,586** | **$172,239** |
| **SUPPORT**<br>• Rockin' Family Fund<br>• Fundraiser Prizes | **$258,538** | **$108,899** |
| **ADMINISTRATIVE**<br>• Insurance, filing fees, postage, etc. | **$30,026** | **$21,435** |
| **SALARIES/WAGES** | **$13,364** | **$12,716** |
| **TOTAL EXPENSES** | **$605,138** | **$358,826** |

## Board of Directors

**President**
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
Virginia

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

**Down Syndrome and Cancer Coalition**
Becky Carey
Megan Dodd

**Fundraising**
Jessica Pace

**Rockin' Family Fund**
Paula Ferrari
Natalie Palin
Trisha Romero
Sharon Sabol

**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**
Cassie Bexten
Laura Gordon

**Social Media**
Crystal Tillman

## Additional Support

**Fundraising**
Amira Lawrence
Mary Beth Norton
Danielle Wood

**Retreat**
Hap and Marcia Steed
Gary and Deb Ushakow

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

**Shipping**
Nicole Kunkel

**Social Media**
Facebook
Shannon Prausa

Instagram
Stefani Settlemire

Pinterest
Crystal Staley

Twitter
Diane Hill

* Co-Founder

## Medical Outreach Team

Torri Attebury
Marie Bacsik
Jillian Benfield
Amanda Dickinson
Paula Ferrari
Vanessa Kale
Kristen Moss
Cara Neil
Troy Remick
Scotti Renee
Kelly Kulzer-Reyes
Erin Ribar
Jaclyn Skalnik
Amber Smith
Ayesha Stachula
Jackie Weldon
Karen Wollman
Kimberly Wyse

## Medical Advisory Team

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

## Online Birth Club and Subgroup Support Team

Mayfe Almeida-Zurita
Heather Ascherl
Marie Bacsik
Mekel Akins
Bergschneider
Heather Bessman
Holly Bishop
Amberly Blevins
San Bodeau
Nichole Brooks
Rachel Brown
Amanda Brunning
Allison Buescher
Kira Burton
Michelle Caldwell
Melissa Call
Mary Cardle
Becky Carey
Kelli Caughman
Laurie Cepkauskas
Carolyn Chase
Christy Cooper
Beth Crain
Harmon Davis III
Jeff Dice
Megan Dodd
Mike Demers
Marissa Dunn
Sophie Dykes
Aaron Ecker
Michelle Fagala
Paula Ferrari
Shelby Gasior
Bethany Glyde
Amy Hardeman
Caitlin Heberlein
Jordan Heberlein
Angela Hedican
Heather Hicks
Jen Jacob
Amy Jansen
Sarah Jorgensen
Sharon Kendrick
Crystal Kent
Jennifer King
Cassie Krzoska
Kaitlyn Lampley
Brianna Lardie
Kristin Leann
Wantanesha Lee
Amy Luke
Jennifer Lynn
Marissa Mahon
Erica Manning
Fernanda Martinez
Angela McCarty
Lauren McWhorter
Sarah Milbratz
Candace Nugent
Lauren Olachek
Natalie Palin
Sarah Petrone
Randy Pippen
Shannon Prausa
Nelly Pujalt
Yadira Regla-Cuevas
Peg Ricardo
Allie Richmond
Rebecca Roberts
Lara Segrest
MalloryShuck
Tanesha Shumpert
Leah Silverman
Roxanne Skonetski
Cathleen Small
Sarah Smith
Ayesha Stachula
Britney Stewart
Melissa Stoltz
Jennifer Sutton
Beth Swanson
Crystal Tillman
Stephie Trimble
Jennifer Tough
Sierra Tran
Heidi Ann Van Kirk
Deborah Vance
Elizabeth Vance
Christine Wiebe
Karen Wollman
Lauren Zwick

# MEDICAL OUTREACH SNAPSHOT
## 2020

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK
inform • connect • support

*Because of parent fundraising, our medical outreach team will be able to attend FOURTEEN medical conferences in 2020.*

**Parents are a powerful voice in ensuring the diagnosis conversation goes well. As part of our mission to ensure that all medical professionals provide current, accurate, up-to-date information to parents with a new diagnosis, we have trained a team to be onsite at medical conferences with practitioners to discuss diagnosis guidelines in their work.**

**SMFM National Conference**
**February**
Texas

**CREOG & APGO Annual Meeting**
**February**
Florida

**ACMG National Conference**
**March**
Texas

**ACOG Annual Meeting**
**April**
Washington

**CREOG Retreat**
**June**
**California**

**ACOG District XII**
**August**
Florida

**ACOG District I, V, VI**
**August**
Montreal

**ACOG Districts VII, VIII, IX**
**October**
Hawaii

**AAP Annual Meeting**
**October**
California

**ACOG District AFD**
October
Washington

**ACOG Districts IV**
**October**
Virgina

**ACOG District XI**
**October**
**Texas**

**ACOG District II**
**October**
Manhattan, New York

**NSGC**
**November**
**Tennessee**

**AAP:** The American Academy of Pediatrics **ACMG:** The American College of Medical Genetics
**ACOG:** The American College of Obstetricians and Obstetrics **CREOG:** The Council on Resident Education in Obstetrics and Gynecology
**NSGC:** The National Society of Genetic Counselors **SMFM:** The Society of Maternal Fetal Medicine

info@dsdiagnosisnetwork.org

Down Syndrome Diagnosis Network
PO Box 140
Stillwater, MN 55082
(612)460-0765
www.dsdiagnosisnetwork.org

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@TheDSDN
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DSDN Rockin' Moms