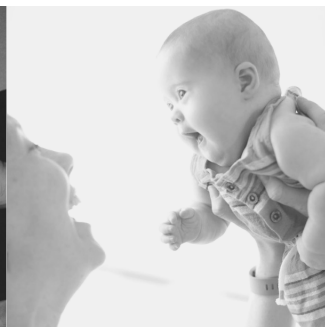
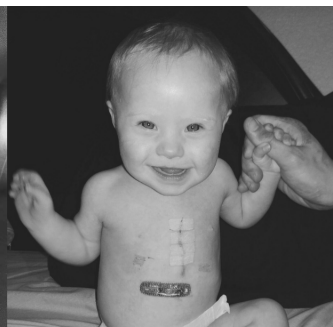


2018 ANNUAL REPORT

Together We Are Stronger



Dear Members and Friends,

As we start 2019, we are amazed at the growth that Down Syndrome Diagnosis Network has experienced these past five years. Our membership has increased exponentially--proof of the impact that DSDN is making in the lives of our families.

One of our strategic goals is to reach more families, especially underserved families, with the information, support, and connections they need. In 2018 we were thrilled to welcome the Black Families Down Syndrome Network to our organization, and we were equally excited by the growth in our Rockin' Moms en Español group, serving our Spanish-speaking families. Our Rockin' Dads group grew by leaps and bounds as well!

On the medical outreach side, we continue to work to change the diagnosis experience for our families. Our Medical Outreach team will be attending twelve medical conferences in 2019, including numerous ACOG division conferences and the ACOG and ACMG national conferences.

We are grateful for our members, donors, and volunteers who continue to support the work that DSDN is doing. We wish you all the best in 2019!

Heather Bradley

President

Jenny Di Benedetto

Vice President

Cathleen Small

Secretary

Jill Ulrich

Treasurer

MISSION: To connect, support, and provide accurate information to families with a Down syndrome diagnosis.

VISION: 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.



DSDN

support & connect



DSDN serves more than 8,000 families in our Rockin' Mom™ and Rockin' Dad online communities, which support parents beginning in pregnancy and through adulthood. Part of our three-year strategic goal is to capture 15 percent of families in our network and reach more underserved families. In 2018, we reached 14 percent of those with a new diagnosis, dramatically increased membership in the Rockin' Dads group and the Spanish-speaking group, and welcomed the Black Families Down Syndrome Network to our organization.



"From the very first package in the mail to the Mom's retreat and everything in between, I don't know what I would do without DSDN. Daily I am able to get on FB and talk to all my friends and those that have been there before me about anything we could be going through." ~ Crystal Kent



2018 Group Highlights

- Added more than 1,200 parents into our private, birth-club Rockin' Mom groups; 650 of these were moms with a baby under age one.
- Added 300 new dads .
- Captured 14 percent of families with a new diagnosis.
- Expanded our subgroups from twenty-three to forty-five to allow families with common interests and backgrounds the ability to connect.
- Provided complete comprehensive support training for our group moderators and trained more than fifty admins.

*"You've got this
and we've got you."*

support

Our Rockin' Family Fund supported more than 850 families with welcome gifts, scholarships, care gifts, and memorial gifts in 2018. DSDN also began offering a congratulations gift for parents joining our pregnancy group. We also celebrated Down Syndrome Awareness month with a Local Support Rocks campaign highlighting all of the important work local organizations do for families.

In 2019, we will be adding welcome gifts for new dads and those joining the Black Families Down Syndrome Network, to help better connect these groups.

WELCOME - SUPPORT - HONOR - EMPOWER

2019 Rockin' Family Fund Goals

- **Send 750 welcome gifts**
- **Send 150 care packages**
- **Provide 12 scholarships**
- **Add dad and black family welcome gifts**



2018 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 windchimes in memory of their child.
- Honored the work of local groups in October with three \$2,100 prizes given away to celebrate Local Support Rocks.
- Partnered with Down syndrome organizations in Arizona to provide more than 400 welcome gifts.
- Increased scholarship giving for 2019 to include:
 - Two for the Rockin' Dad Retreat
 - Five for the Rockin' Mom Retreat
 - Five for the NDSC Annual Convention

connect

Our 2018 Rockin' Mom Retreat surpassed our attendance expectations, and we welcomed 400 moms to Phoenix.

Our 2019 Rockin' Mom Retreat will take place at the Gaylord Opryland in Nashville in September. Also, we have opened up the event to moms with children of any age with Down syndrome. We will be welcoming about 800 moms to our fifth annual event!

Our event goals remain to help moms connect and recharge while also giving them opportunities to give back to new and expectant parents.



2018 Rockin' Mom Retreat Highlights

- Four hundred moms attended our fourth annual retreat.
- Bethany Van Delft and Brian Donovan gave inspiring keynote addresses.
- Partnered with Arizona Down syndrome organizations and assembled welcome gifts for new families.
- Sponsorship and exhibitor participation grew, with revenues exceeding goals.

connect. inspire. recharge

connect

2018 Rockin' Dad Retreat Highlights

In 2018, we also held our first annual Rockin' Dad Retreat! In this first year, we welcomed fifteen dads in Chicago to connect and recharge. In addition to sightseeing and taking in a Chicago White Sox game, the men spent time talking and planning for growing DSDN's dad-focused programming and services. The 2019 event will host sixty dads in Denver, Colorado!



- Dads attended a Chicago White Sox game, gathered for meals, and did some sightseeing in Chicago.
- Created a plan for further growth of programs and services for DSDN dads.

New Connections

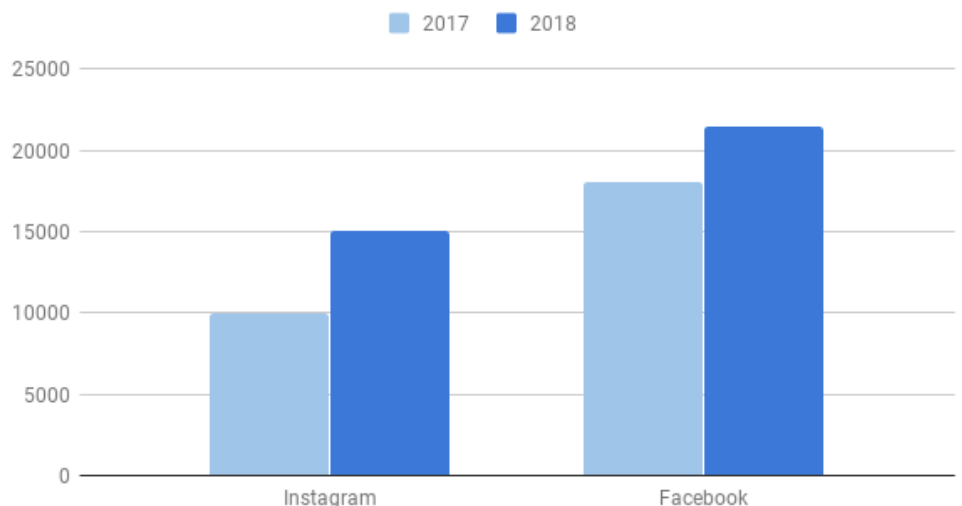


To continue to grow our network of support for families and further reach the goals in our three-year strategic plan, DSDN connected with a group of moms in 2018 with a goal to better serve black families in the Down syndrome community. The group began with a closed Facebook group, and we can't wait to see what is in store for 2019—including a meetup during our annual Rockin' Mom retreat!

inform

In 2018, our communication and social media teams worked to refine how and what we share with our followers, members, and donors, to ensure that we're providing the most useful content for our DSDN families and supporters.

DSDN SOCIAL MEDIA FOLLOWER GROWTH



This year, our Facebook followers increased by more than 3,000, and more than 6,000 new followers joined our Instagram account. That makes DSDN one of the most followed Down syndrome organizations on IG!

DSDN is continuing to work toward providing more content in Spanish to our followers on social media and our blog.



2018 Communications Highlights

- Reached more than 9,000 new followers on social media.
- Utilized microblogs on social media posts to better share our members' stories.
- Refined the process for reaching members and donors most effectively.

inform

In 2018, DSDN continued to provide our resources and information to local organizations. Due to incredible fundraising efforts by our families, we significantly expand our outreach to medical professionals. DSDN attended and presented two posters at the Down Syndrome Medical Interest Group symposium during the NDSC convention. We also exhibited at the Down Syndrome Affiliates in Action conference.

In the fall, we held a medical outreach workshop to train our first team of 20 moms to share their stories and talk with medical providers at nearly a dozen medical conferences in 2019.



2018 Outreach Highlights

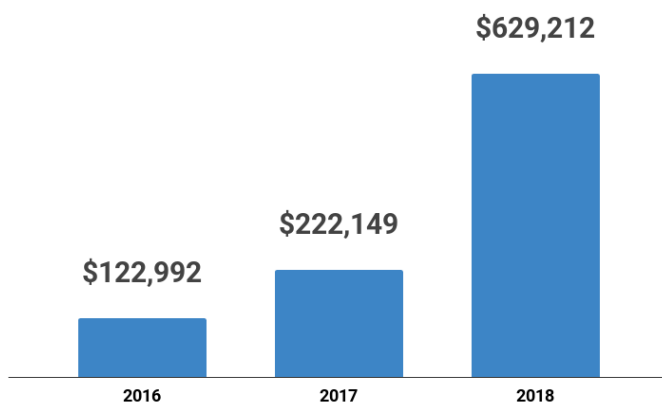
- Added new local organization partners, bringing DSDN's total partners to more than 100.
- Sent 18,252 free brochures to local organizations and medical providers.
- Trained our first medical outreach team to represent DSDN at national and regional medical conferences in 2019.
- Exhibited at the National and District II Academy of Obstetrics and Gynecology (ACOG) events.
- Exhibited at the Down Syndrome Affiliates in Action annual conference.
- Presented two posters at the annual Down Syndrome Medical Interest Group symposium.



financials

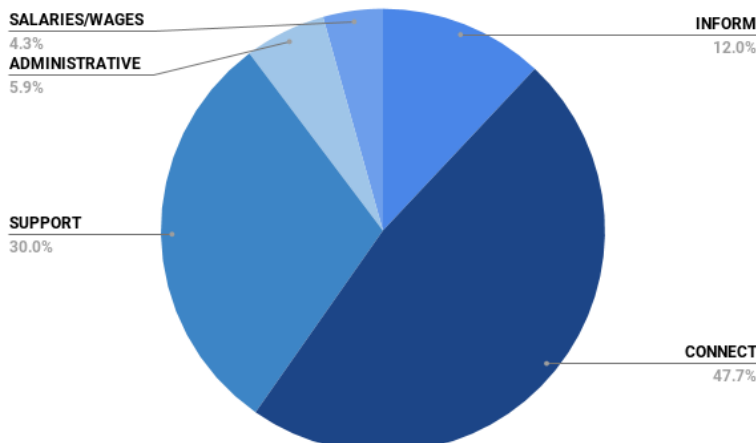
Financial support from donors, grants, and sponsors enabled DSDN to have a very successful 2018. Our partnership with Network for Good provided our members a wonderful and fruitful fundraising avenue. The financial strides we've made as an organization have allowed us to exhibit at twelve medical conferences in 2019. We are thrilled to be able to further our efforts toward improving the diagnosis conversation for families, thanks to the financial support of our donors, sponsors, and grantmakers.

Revenue Comparison



Income sources in 2018 included individual donations, unrestricted grants, retreat ticket sales, retreat sponsorships, and merchandise sales.

Expense Comparison



INFORM	\$43,537
<ul style="list-style-type: none">• Medical Outreach• DSDN Material Distribution	
CONNECT	\$173,239
<ul style="list-style-type: none">• Annual DSDN Retreats• National Conferences	
SUPPORT	\$108,899
<ul style="list-style-type: none">• Rockin' Family Fund (scholarships, welcome, care and memorial gifts)• Fundraiser Prizes	
ADMINISTRATIVE	\$21,505
<ul style="list-style-type: none">• Insurance, filing fees, postage, etc.	
SALARIES/WAGES	\$15,783
TOTAL EXPENSES	\$362,964

Board of Directors

Heather Bradley
President & Co-Founder
Stillwater, MN

Jenny Di Benedetto
Vice President
Antioch, IL

Cathleen Small
Secretary
Clayton, CA

Jaime Erickson
Outgoing Treasurer
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Joe Scott
Altoona, PA

Jill Urich
Incoming Treasurer
Avon, OH

Kelli Caughman
Incoming
Fort Lee, VA

Bethany Van Delft
Incoming
Boston, MA

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Executive Director & Co-Founder
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Communications
Melissa Chambers &
Alli Martin

Fundraising
Jessica Pace

Local Partnership
Kristin Moss, Beth Swanson
& Lauren Young

Medical Outreach
Jenny Di Benedetto &
Hannah Pascucci

Rockin Family Fund
Paula Ferrari & Sharon Sabol

Rockin' Mom Retreat
Mandy Ramzan, Amy Sherrard,
Michelle Steffen & Katie Williams

Rockin' Dad Retreat
Andrew Hilgart

Social Media
Crystal Tillman

Support
Melissa Shutwell &
Cassie Bexten

Volunteers

Facebook Lead
Shannon Prausa

Instagram Lead
Stefani Settlemyre

Pinterest Lead
Crystal Staley

Twitter Lead
Diane Hill

Rockin' Family Fund
Hap and Marcia Steed,
Natalie Palin &
Nancy Landess

Parent Advisory Council

Heather Bedinger
Amanda Brunning
Kelli Caughman
Beth Crain
Danielle Davidson
Sara Davis
Kristina DeRobertis
Maureen Gladding
Amy Harrill
Chrissy Hood
Zachary Johannsen
Mary Kenion
Jessica Schuster
Mahala Turner
Yami Johnson-Walker
Nicole White
Jessica Wooten

Medical Advisory Team

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

Advisors

Social Media
Jillian Benfield

Marketing
Tara Barnes

Design
Sheri Selph

MEDICAL OUTREACH SNAPSHOT 2019



Because of parent fundraising, our medical outreach team is able to attend TWELVE medical conferences this year

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.



ACMG National Conference
April 3-5
Seattle, Washington



ACOG District AFD
September 7-11
San Diego, California



ACOG National Conference
May 3-6
Nashville, Tennessee



ACOG Districts IV, VII, XI
September 27-29
New Orleans, Louisiana



AWHONN National Conference
June 8-12
Atlanta, Georgia



ACOG Districts V, VIII, IX
October 3-5
Kapalua, Hawaii



CREOG Education Retreat
July 25-26
Pittsburgh, Pennsylvania



ACOG Districts V, VIII, IX
October 4-6
Rockport, Maine



ACOG District XI
August 2-4
Lake Geneva, Wisconsin



ACOG Districts V, VIII, IX
October 18-20
Manhattan, New York



ACOG District XII
August 9-11
Orlando, Florida



NSGC
November 7-8
Salt Lake City, Utah

ACMG: American College of Medical Genetics **ACOG:** The American College of Obstetricians and Obstetrics

AWHONN: The Association of Women's Health, Obstetric and Neonatal Nurses

CREOG: The Council on Resident Education in Obstetrics and Gynecology **NSGC:** National Society of Genetic Counselors



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Down Syndrome
Diagnosis Network



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DSDN Rockin' Moms