GET ALL YOUR QUESTIONS ABOUT MEDICAL OUTREACH & PRENATAL AND POSTNATAL SUPPORT ANSWERED BY THE EXPERTS

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MASSACHUSETTS DOWN SYNDROME CONGRESS
PARENTS FIRST CALL PROGRAM

Sarah Cullen, Family Support Director
Parents First Call Program

- Supports new and expectant parents
- Provides accurate, up-to-date, balanced information
- Provides opportunity to speak with a trained parent mentor
Parents First Call program

*It is the heart and soul of your organization!*

- Privilege to support and welcome expectant and new families
- Grow your membership base
- Engage new families
- Families will give back in many ways
First Call position

- Outreach Coordinator
- First Call Coordinator
- Family Support Director
- Program Director

*A stipend or paid position reflects the Board and Organization’s commitment to the program*
## Growth of MDSC Parents First Call Program

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
<th>2015</th>
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<tbody>
<tr>
<td>First Call Program Budget (excluding salaries)</td>
<td>$1,000</td>
<td>$15,000</td>
</tr>
<tr>
<td>First Call parent volunteers</td>
<td>10</td>
<td>55</td>
</tr>
<tr>
<td>Trained <strong>Prenatal</strong> parent volunteers</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td># Prenatal Families Served</td>
<td>0</td>
<td>35</td>
</tr>
<tr>
<td># Families Served after the birth of their child</td>
<td>20</td>
<td>130</td>
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</tbody>
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*Growth of Parents First Call program correlated with growth of MDSC as an organization*
Make it easy to connect

- 800 number to cell
- Brochure
- Magnet
- Business cards
- Flyers
- FAX release forms
- Website
- Facebook
- Email
- Text
Develop the flow

- How referrals will be received
- Capturing key information on family
- Entering into database
- Sending materials *within 24 hours*
- Connecting them with a First Call parent *within 24 hours* (if requested)
- Tracking for Board reporting — keep the Board in the loop!
- Follow-up and opportunities to engage
Choose Expectant and New Parent Materials

Consider materials for:
- Prenatal pre-decision
- Prenatal post-decision
- Postnatal

Welcome Basket

Down Syndrome Pregnancy

DSDN

Project Linus
Providing Security Through Blankets
Parent Mentor Roles

- Postnatal Parent Mentors (Postnatal Diagnosis, Family just connecting now, New to area)

- Prenatal Parent Mentors – (Pre Decision)
  - Parents who found out prenatally themselves
  - Parents who are able to provide non-directive, nonjudgmental balanced support
  - Parents who support “pro information” regardless of their personal beliefs
  - Hand picked

- Prenatal Parent Mentors – (Post Decision)
Parent Mentor Roles

- **Resource Parents**
  - To support families (often a little further on in their journey) in a specific area of interest or geographical area
    - Home schooling or educational programs
    - Parents in a particular school district
    - Dual diagnosis (Down syndrome and ASD)
    - Adoption and foster care
    - Leukemia
    - Parents of teenagers or young adults
    - Parents of a medically complex child

- **Administrative Support**
  - Making welcome packets/folders
  - Mailing welcome packages and baskets
  - Maintaining database

- **Medical Outreach**
Develop/Strengthen your First Call team

- Language
- Geographic area
- Medical challenges (NICU, heart surgery, GI, etc.)
- Cultural diversity
- Religion
- Dads
- Twins

- Prenatal Pre-decision
- Prenatal Post-decision
Enhance Prenatal First Call Program:

Goal is that all pregnant women receiving the diagnosis will receive accurate, up-to-date, balanced information and the opportunity to speak with a trained prenatal mentor so they can make an informed decision.
Legislative Support

- June 2012: Governor Deval Patrick today signed H. 3825, “An Act Requiring Certain Information Relative to Down Syndrome be Provided to Certain Parents and Families.”

- The bill requires care providers to provide educational information to parents who receive prenatal and postnatal Down syndrome diagnoses.

- Specifically references the MDSC Parents First Call program as a key resource for families.
Training for parent mentors

- Your program
- Genetics of DS
- Non Invasive Prenatal Screening
- Guidelines for parent mentors
- Process of grief/emotional journey
- Listening skills
- Role playing/scenarios
- When to ask for help
- Quotes or brief sharing by a parent mentor and/or new family
- Resource binder of local and national resources
- Resources from statewide P2P group
Additional Prenatal Pre-decision Training

- Collaboration with Genetic Counselor

- Agenda:
  - Screening/Testing
  - Processing the diagnosis
  - Decision-making
  - Resources
  - Supporting Prenatal First Call parent mentors
Offer opportunities for expectant families to engage as they are ready!
Offer opportunities for new families to engage as they are ready!

- New Parent Socials
- Special invitations to Buddy Walk and conferences, with First Call table
- Assisting with outreach to health care community
- Multi-cultural group and events
- DADS group
More opportunities...

- New parent workshop at annual conference
- Grandparents group for parents and in-laws
- Hand picking new parents for future participation in your First Call program as parent mentors
- Local support groups or informal play groups within the organization
- Advocacy/legislative opportunities
- Volunteer opportunities
Helpful Resources in AIA Member Repository …
Importance of medical outreach

- Build trust, respect and credibility between medical providers and the Down syndrome community
- A strong collaboration with health care professionals will ensure more referrals to your program and growth of your organization and more families connected!!
Strengthen Health Care Professional Outreach

Reach out to your hospitals and physicians and community

- Drop First Call brochures or magnets in person
- Formal presentations, such as Grand Rounds (Dr. Brian Skotko)
- Host a symposium
- Down Syndrome 101
- Medical schools (Operation House Call)
- Genetic counseling programs
- Engage self-advocates
- Create “Resources for Medical Professionals”
- Befriend a medical professional to help support your program and build the network

Stephanie Meredith’s presentation 😊
DELIVERING A DIAGNOSIS OF DOWN SYNDROME
Brian G. Skotko, M.D., M.P.P., Massachusetts General Hospital

POSTNATAL
1. OBs and Pediatricians should coordinate their messaging. Ideally, they would meet together with parent(s) to deliver the news.
2. Inform parents of suspicion for Down syndrome immediately, even if diagnosis is not yet confirmed.
3. Deliver the diagnosis in a private room.
4. Parents should be informed together.
5. The infant with Down syndrome should be present and referred to by name.
6. Begin conversation with positive words, such as congratulations on the birth of the child.
7. Provide accurate, up-to-date information.
8. Limit discussions to medical conditions that the infant has or might develop within one year of age.

PRENATAL
1. Results from the prenatal screening should be clearly explained as a risk assessment, not as a “positive” or “negative” result.
2. Prior to CVS or amnio, discuss all reasons for prenatal diagnosis.
3. Healthcare professional(s) most knowledgeable about Down syndrome should deliver the news – most likely OB and genetic professional together.
4. If in-person visit not possible, news should be delivered over the phone at a pre-arranged time.
5. Answer: What is Down syndrome? What causes the condition?
6. Answer: What are realistic expectations for individuals with Down syndrome today? Offer connection with parent support groups (MDSC Parents’ First Call Program 800-664-MDSC or mdsc@mdsc.org).
7. Use non-directive language.
8. Offer up-to-date materials or bibliography (MDSC Parents’ First Call Program 800-664-MDSC or mdsc@mdsc.org).
9. Make follow-up appointments, including specialists, as needed.


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THE NATIONAL CENTER
FOR PRENATAL
AND POSTNATAL DOWN SYNDROME RESOURCES

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THE NATIONAL CENTER FOR PRENATAL AND POSTNATAL DOWN SYNDROME RESOURCES

DOWNSYNDROMEDIAGNOSIS.ORG
THE NATIONAL CENTER
 DownsSyndromeDiagnosis.org

- University of Kentucky’s Human Development Institute
- Brighter Tomorrows
- Lettercase
- Down Syndrome Pregnancy
SUPPORTING EXPECTANT PARENTS FOLLOWING A PRENATAL DIAGNOSIS OF A GENETIC CONDITION
BUILDING RELATIONSHIPS WITH THE MEDICAL COMMUNITY
SUPPORTING NEW AND EXPECTANT PARENTS LEARNING ABOUT DOWN SYNDROME
Print or Digital. Free.

The Joseph P. Kennedy, Jr. Foundation’s Understanding a Down Syndrome Diagnosis is an accurate, balanced, and up-to-date booklet for use when delivering a diagnosis of Down syndrome and is part of the National Center for Prenatal and Postnatal Resources at the University of Kentucky’s Human Development Institute (HDI). The booklet is the only prenatal resource to have been reviewed by representatives of the national medical and Down syndrome organizations and is available in both print and digital formats. You can request a printed copy through your medical provider or download an ePUB for your smartphone, tablet, or desktop.

Understanding a Down Syndrome Diagnosis covers the following:

- Available health and education services;
- Common medical conditions for babies with Down syndrome;
- Information about pregnancy options;
- Helpful resources about the condition;
- Spanish translation included in all booklets;
- Optimization for different reading levels.

Get the booklet now.
For expectant parents considering prenatal screening/testing or first receiving a prenatal diagnosis for a genetic condition:

- Online and print materials for expectant parents considering prenatal screening/testing or first receiving a prenatal diagnosis for a genetic condition.

- All materials reviewed by representatives of national medical and disability organizations.

- Accurate, balanced, and up-to-date information about a range of conditions.
For pregnant women before testing:

- “Understanding Prenatal Screening and Testing for Chromosome Conditions” in English and Spanish. Available in print and free online.

- Gives an overview of prenatal screening and testing (including cfDNA/NIPS/NIPT), states reasons why expectant parents might or might not want these tests, explains testing is optional, gives a brief summary of the different conditions that can be detected with prenatal screening, lists the national support organizations for each condition (sex chromosome and trisomy conditions and Spina Bifida, and shows photos of different conditions.

- Reviewed by professional advisory committee: scholars, genetic counselors, an OB/GYN, a geneticist, education experts, a pediatrician, legal experts, disability advocates, and patient support experts.

- Recommended by National Society of Genetic Counselors.
For expectant parents first receiving a diagnosis

- *Understanding a Down Syndrome Diagnosis* in English and Spanish. Available in print and free online. Medical professionals and expectant parents can request a free printed copy.

- Updated *Delivering a Diagnosis* bi-fold.

- Revised with assistance in 2010 from representatives of the American Congress of Obstetricians and Gynecologists (ACOG), the National Society of Genetic Counselors (NSGC), the American College of Medical Genetics and Genomics (ACMG), the national Down syndrome organizations. Updated in 2013 with new photos and data.

- Recommended in guidelines from NSGC, ACMG, and ACOG.

- Endorsed by 45 scholars and physicians as “the most balanced material that healthcare providers should give to expectant parents following a prenatal diagnosis.”
BRIGHTERTOMORROWS
BRIGHTERTOMORROWS.ORG
For parents learning about a prenatal or postnatal diagnosis of Down syndrome:

- **Free** online English and Spanish multi-media resource with information about testing, prenatal topics, and postnatal topics; videos; life glimpses; and free downloadable pamphlets reviewed by medical professionals to provide both prenatal and postnatal support.

- Funded by the National Center on Birth Defects and Developmental Disabilities, through a cooperative agreement with the Association of University Centers on Disabilities.

- Created in 2008 and updated in July 2012.
The articles below correspond to chapters and topics in the books, and they offer a wide variety of constantly updated online resources. The articles also share stories from parents about their experiences with issues ranging from breastfeeding to preparing siblings to dealing with comments.

50 Things to Do Instead of Worry
A list of 50 things to do instead of worrying during a pregnancy where test results indicate the baby might have or definitely has Down syndrome. The list includes fun activities for any baby like choosing possible name, and specific resources about life with Down syndrome.

15 Reasons to Contact Your Local Group
15 reasons why pregnant moms might want to contact their local Down syndrome groups for support following a diagnosis — and what services local groups often offer.

DOWN SYNDROME PREGNANCY
DOWN SYNDROME PREGNANCY

DOWNSYNDROPREGNANCY.ORG

For expectant parents preparing for the birth of a baby with Down syndrome and new parents and families adjusting to a diagnosis:

- Complete suite of books for new and expectant parents in English and Spanish and online articles about a range of topics, including breastfeeding, preparing siblings, etc.

- All resources available for free download, and print products are available for purchase now through the University of Kentucky (formerly Woodbine House).

- New books include: “Welcoming a Newborn with Down Syndrome” in English and Spanish and “Coping with Loss: Down Syndrome.”

- Provided online support to 250,000 families and professionals since 2010.

- Recommended by the National Society of Genetic Counselors and reviewed by top experts in the medical and Down syndrome communities.
DOWN SYNDROME PREGNANCY

DOWNSYNDROME PREGNANCY.ORG
DOWN SYNDROME PREGNANCY

NEW 2015

Hosted by Down Syndrome Pregnancy.org
THE NATIONAL CENTER

DOWNSYNDROMEDIAGNOSIS.ORG

National Center materials cited in:

• Genetics in Medicine
• American Journal of Medical Genetics
• American Journal of Obstetrics and Gynecology
• NSGC Guidelines for Delivering a Diagnosis of DS
• Journal of Midwifery and Women's Health
• Journal of Genetic Counseling
• Obstetrics and Gynecology
THE NATIONAL CENTER

DOWNSYNDROMEDIAGNOSIS.ORG

National Center program initiatives and distribution plans:

• All materials reviewed by top experts in medical and disability communities.

• Make presentations at major national medical/genetics and disability conferences and local conferences: SMFM, NSGC, ACMG, ASHG, AUCD

• Direct online and print distribution to thousands of medical providers, hospitals, medical offices, and expectant parents annually.

• Create new resources and translations as needed and regularly update materials.

• Provide support and resources to more than 80 local Down syndrome organizations in most states.
THE NATIONAL CENTER FOR PRENATAL AND POSTNATAL DOWN SYNDROME RESOURCES

Stephanie Meredith, MA,
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inform · connect · support

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK

inform support connect

www.dsdn.org
thedsdn@thedSDN
Our Mission

Connect, support and provide accurate information to families with a Down syndrome diagnosis
Our Goals

**Inform** – Provide families and medical professionals with up-to-date information and resources

**Support** – Support new and expectant parents in our online communities

**Connect** – Assist families in connecting with local groups and other families in their local area

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK

www.dsdiagnosisnetwork.org

thedsdr@theDSDN
Provide up-to-date information
www.dsdiagnosisnetwork.org
Shares resources with new and expectant parents

Congratulations on your new or expected arrival!
view our slideshow for facts and information

what is down syndrome?
Down syndrome occurs when there is a full or partial additional copy of the 21st chromosome. About one in every 1,000 babies in the United States is born with Down syndrome.
Currently there are about 256,000 Americans with the condition. Down syndrome occurs within all racial, cultural and economic backgrounds.
A Down syndrome diagnosis can present certain challenges, but advances in medical science, public attitudes and education have greatly improved the quality of life for those with the condition.
Go to link

guide for new and expectant parents
While most people have heard of Down syndrome, a lot of people are not familiar with what a diagnosis can mean for their child.
Please take a moment to learn more by reading a comprehensive guide called "A Promising Future Together" by the National Down Syndrome Society.

Dear Future Mom

Down Syndrome Pregnancy provides a free downloadable, practical guide for expectant moms, Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome, along with resources for family members.

www.dsdiagnosisnetwork.org
thedsdrr@theDSDN
DSDN Social Media Sites Provide Curated, Relevant Information

- Posts specifically selected to support new and expectant families
- Share resources from a diverse selection of reputable sources and professional organizations
- Post blog entries and articles from popular authors and new moms sharing their recent experiences
- Over 6000 followers; Post Reach up to 30,000
Physician Feedback Program

Your Feedback Counts
At DSDN, we believe that your first experiences in this new Down syndrome world can affect your path to acceptance. How the diagnosis for your child was delivered can having a lasting impact.

Commit to sending your medical provider feedback today to ensure future patients are equipped with valuable resources.

Learn more on the FEEDBACK page of our website: www.dsdagnosisnetwork.org

resources we provide
- "How to Deliver a Postnatal Diagnosis of Down Syndrome," a tool that includes a summary of peer-reviewed best practices for clinicians delivering a prenatal diagnosis
- "Delivering a Down Syndrome Diagnosis," a tool that includes a summary of peer-reviewed best practices for clinicians delivering a prenatal diagnosis
- "How to Deliver a Postnatal Diagnosis of Down Syndrome," a compilation of professional recommendations for delivering a birth diagnosis of Down syndrome. Only PDF version available.

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK
inform • connect • support

Visit us at dsdagnosisnetwork.org for more information.

www.dsdagnosisnetwork.org

"discussing down syndrome"
Unlike the Physicians Guide, developed by the National Down Syndrome Congress, for guidance in delivering both a prenatal and postnatal Down syndrome diagnosis.
Access to Diagnosis Stories

{Unexpected} Facts:

- Contains nearly 100 families prenatal and postnatal diagnosis stories
- Parents share their real and raw moments
- Over 25,000 pageviews and 10,200 users since WDSD 2014
- Over 200 print copies sold
- Available to view at no charge via DSDN’s Website
- eBook and print copies available through Amazon, Nook and Lulu Press
- Book project is supported by DSDN

{Unexpected}

We understand the fear and uncertainty that often come with a new Down syndrome diagnosis. To lovingly support families who have received a Down syndrome diagnosis, the book “Unexpected,” was written. This incredible memoir includes the personal, real-life accounts of more than 80 families who have received a Down syndrome diagnosis.

If you have received a prenatal diagnosis or have learned after birth that your baby was born with the extra chromosome, this candid, raw resource was written with you in mind.

Find a link to these stories on the DIAGNOSIS tab of our website:
www.dsdn.org
Or directly at: www.msiont21.com
Small, Private, Moderated Facebook Groups

DSDN supports over 2000 new and expectant parents in our multiple Facebook groups. Some facts about our groups:

- Prenatal group for expectant parents
- Birth-Club style so families can connect with those whose children are the same age
- Private and limited to 150 parents so families get to know one another
- Spanish Speaking Group
- Currently on track to capture 15% of all diagnoses in U.S. in 2016
inform · connect · support

BABY BORN!
- Welcome Gift
- BIRTH DIAGNOSIS
- Parent wants to learn/network
- Baby passes away
- Scholarship
- Care Package
- Surgery/extended NICU stay

Bereavement Gift

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www.dsdagnosisnetwork.org

thesdrr@theDSDN
The Rockin’ Family Fund

WELCOME
Gift baskets for parents who receive a diagnosis. Delivers a message of positivity and connection, introduces DSDN & services.

SUPPORT
Gift baskets/cards sent to parents when kids are in NICU/surgery. Shows support and connection, and reinforces Rockin’ Moms/DSDN link.

BEREAVE
Meaningful honorific gift for parents who lose kids (pre-natal or after birth).

EMPOWER
Scholarships or stipends for parents to attend Ds-related events or classes.
Rockin’ Mom Retreat

- Provides moms in groups an opportunity to connect, be inspired and get recharged
- Minneapolis 2015 Retreat a success
- 2016 Rockin’ Mom Retreat to be held in Dallas Sept 9-11
Local Connections Matter

DSDN helps families find local support

- We strongly encourage families to get involved in their local groups
- We facilitate meet ups between families with like experiences

[Image of a group of people]

Connect in Person

A strong support system can have a positive impact on raising a child with Down syndrome. Connecting to a local group or family in your area can be an enormous support. Let us help!

Fill out our connection form and indicate if you would like to find someone with a similar background or beliefs. We can even find someone nearby that has gone through similar health experiences with their child.

Join us now on the CONNECT page of our website: www.dsdiagnosisnetwork.org

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK

www.dsdiagnosisnetwork.org
thedsdr@theDSN
How can you leverage DSDN?

DATABASE: Complete our survey to build our database of local organizations to enable us to connect our moms to you.

COMMUNICATIONS: Send us information about programs or supports relevant to new and expectant families that we can share on our SM Sites.

WELCOME KITS: Include our brochure, Congratulations Card and {Unexpected} book or cards in your welcome packets/baskets to provide comprehensive support to your new and expectant moms (Spanish Brochure coming soon!)

MEDICAL OUTREACH: Utilize our “How to Deliver a Postnatal Diagnosis” brochure in your medical outreach.

www.dsdagnosisnetwork.org

thedsdnr@thedSDN
Organizations Partnering with DSDN