DIAGNOSIS TO DELIVERY: REACHING OUT TO OBSTETRIC MEDICAL PROVIDERS SUPPORTING EXPECTANT PARENTS

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HUMAN DEVELOPMENT INSTITUTE – UNIVERSITY OF KENTUCKY
The National Center for Prenatal and Postnatal Down Syndrome Resources at the University of Kentucky’s Human Development Institute oversees three medically reviewed programs that complement each other in providing important resources and information for new and expectant parents learning about a diagnosis of Down syndrome: Brighter Tomorrows, Lettercase, and Down Syndrome Pregnancy. These programs also offer valuable resources for medical professionals delivering those diagnoses.

The National Center provides this clearinghouse of professionally recommended resources so that medical practitioners, expectant parents, and new parents have access to accurate, up-to-date, and balanced information about Down syndrome. The activities of the National Center include the dissemination of free resources to medical providers and their
• University of Kentucky’s Human Development Institute
• Brighter Tomorrows
• Lettercase
• Down Syndrome Pregnancy
PREGNANCY TIMELINE: LAYERS OF SUPPORT
For prenatal and postnatal parents:

• **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
For expectant parents first receiving a diagnosis

- The Kennedy Foundation’s “Understanding a DS Diagnosis” and “Delivering a DS Diagnosis” available in print and as free digital downloads in English and Spanish. Over 30,000 copies distributed nationwide and used by over 100 local organizations and Ariosa.

- Created in 2008 and selected in 2009 as the NDSS/NDSC First Call gold standard

- Revised with assistance in 2010 from representatives of the American Congress of Obstetrics and Gynecology (ACOG), the National Society of Genetic Counselors (NSGC), the American College of Medical Genetics and Genomics (ACMG), the National Down Syndrome Society (NDSS), and the National Down Syndrome Congress (NDSC)

- Endorsed by scholars and physicians as “the most balanced material that healthcare providers should provide to expectant parents following a prenatal diagnosis.”
DOWN SYNDROME PREGNANCY
DOWNSYNDROMEPREGNANCY.ORG

Website for expectant parents throughout pregnancy

• Includes the medically-reviewed books *Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome* (2010) and *Your Loved One is Having a Baby with Down Syndrome* (2012), available as free downloads and through Woodbine House Publishing Company.

• Website created in late 2010 includes constantly updated online resources and information for expectant parents, local Down syndrome organizations, medical providers, friends and family, and the community.

• Site viewed by nearly 90,000 visitors worldwide and book downloaded by nearly 2500 expectant parents, medical providers, and others. About 760 distributed to expectant parents per year = over 15% of expectant parents nationwide.
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
REACHING OUT TO MEDICAL PROFESSIONALS
MEDICAL OUTREACH GOALS

• Build relationships of trust and respect between medical providers and Down syndrome community.

• Convey professionalism and credibility of local organization.

• Provide up-to-date information about Down syndrome.

• Track materials distributed.
UNDERSTANDING MEDICAL PROFESSIONALS

- OB/GYN's
- Perinatologists/Neonatologists
- Genetic counselors
- Midwives/Doulas
- Nurse practitioners
- Social workers
- Nurses
UNDERSTANDING MEDICAL PROFESSIONALS

• What is the difference between prenatal and postnatal outreach?

• What obstacles confront a medical professional delivering a prenatal Down syndrome diagnosis?

• How can you respect those concerns?

• What obstacles confront the Down syndrome community seeking to establish relationships with medical professionals?

• How can you address those concerns?
The board/staff of an organization trains volunteers as Down Syndrome Reps for medical outreach. Each Down Syndrome Rep is assigned a medical office or offices to visit quarterly and do the following:

• Act as an organization representative.

• Develop relationships with medical offices.

• Distribute materials.

• Report a quarterly contact log to the organization/Medical Contact Supervisor.
DOWN SYNDROME REP PROGRAM

- Conduct training. MedicalOutreachTraining.pdf

- Practice script with DS Reps and distribute conduct policy. Script.doc and ConductPolicy.doc

- Make staff and volunteer assignments to local OB/GYN offices and hospitals.

- Provide notebook, print materials, promotional materials, business cards, and introduction letters.

- Instruct DS Reps to visit medical provider’s office to deliver organization intro letter. DSRepIntro.doc

- Follow up with DS Reps quarterly about contact log. contact-log.xls
VISITING MEDICAL PROFESSIONALS

Being professional

• Discussion: What tactics can DS Reps use to approach a physician’s office?

• Discussion: Which characteristics of a pharmaceutical rep. can DS Reps use?

• Discussion: Does the Prenatally and Postnataally Diagnosed Conditions Awareness Act require medical providers to provide information about Down syndrome?

• Discussion: Why do discussions about prenatal testing and abortion rates undermine your credibility?

• Discussion: Identify other topics of discussion which establish credibility and undermine credibility.
VISITING MEDICAL PROFESSIONALS

Lose credibility:

• Emotional pleas. Give example.

• Religious references. Give example.

• Political discussions. Give example.

• Judgmental comments. Give example.

• Generalizations about Down syndrome, physicians, and hospitals. Give example.

• Misinformation.

• Tardiness.

• Long stories.
VISITING MEDICAL PROFESSIONALS

Establish credibility:

- Emphasize that you have been trained.
- Give professional and credible materials.
- Use introduction letter, business cards, etc.
- Offer information about local resources, credible materials.
- Give brief stories about child.
- Give positive stories about physicians.
- Use language carefully and precisely.
- Choose materials that convey your message.
DISTRIBUTING MATERIALS

- Benefits of using materials that are medically reviewed, accurate, balanced, up-to-date, and featured in journals.

- How do the materials reflect the concerns of the Down syndrome community/medical community?
OFFICE RESOURCES FOR EXPECTANT PARENTS

Print

• National Center promotional postcards

• “Understanding a Down Syndrome Diagnosis”

• “Diagnosis to Delivery: A Pregnant Mother’s Guide to DS”

• NDSAN Brochure

Online

• lettercase.org

• downsyndromepregnancy.org

• brightertomorrows.org

• National Down Syndrome Adoption Network: ndsan.org

• NDSS, NDSC, and local organizations
OFFICE RESOURCES FOR MEDICAL PROFESSIONALS

Print

• Delivering a Diagnosis bi-fold at www.lettercase.org

Online

• Online tutorials for CME credit at brighter-tomorrows.org

• National Down Syndrome Congress Physician’s Guide: ndscccenter.org/physiciansguide/

• Down Syndrome Guild of Greater Kansas City Informed Consent and Prenatal Testing Presentation (vimeo.com/16171909)
## CONTACT LOG FOR DS REPS

**Office:** Metro Women’s Center  
**Specialty:** OB/GYN  
**Address:** 544 Main St.  
**Phone:** 555-123-1233  
**Fax:** 555-123-1223  
**Email:** admin@metrowc.com  
**Contact Person:** Karen Smith  
**Medical Providers:** Susanna Gomez, Jason Martin,  

<table>
<thead>
<tr>
<th>Action</th>
<th>Date</th>
<th>Person Contacted</th>
<th>Result</th>
<th>Next Contact</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial Visit</td>
<td>7/20/10</td>
<td>Karen Smith</td>
<td>Wanted 10 booklets to start—evaluate again in 6 months.</td>
<td>10/20/10</td>
<td>SM</td>
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ONGOING SUPPORT FOR MEDICAL PROFESSIONALS

• Set up a presentation for the entire office. “Lunch and Learn” or breakfast an option. OfficeOutreachPresentation.pdf

• Make introductions when changing volunteers.

• Ask about other colleagues who might be interested in getting more information.
SUPPORTING EXPECTANT PARENTS
EXPECTANT PARENT SUPPORT GOALS

• Understand unique expectant parent needs

• Understand prenatal testing developments and available prenatal resources

• Offer a range of resources: online, print, and in-person

• Offer information about local resources
UNDERSTANDING EXPECTANT PARENTS

• Making decisions about pregnancy

• Four to six months of waiting

• Emotions: ongoing support, empathy, not linear - all over the map

• Questions: information, prenatal care, delivery plans, newborn issues

• Social: new terrain, unique in pregnancy
UNDERSTANDING EXPECTANT PARENTS

• Many are uncomfortable in person.

• Many will not approach a local group until further along.

• Many will not approach group until after baby's birth.

• Many may feel intrusive, especially with ongoing questions and emotional developments.

• Many are in need of professional counseling.

• Many will not be honest with you about the extent of their emotions.

• Many have questions about prenatal care, delivery, miscarriage.
“I have no motivation to contact the local DS group because I think to me that will finally be admitting that this is really happening. It is so much easier to just forget about it until our DD [Diagnosis Day] is actually here. Don't know, just feeling blue.”

“When we found out through amnio, I hardly told anyone anything at all, positive or negative. I shared my inner most thoughts (the dark, ugly ones) with my DH [Dear Husband] and about 2-3 people that already were in my inner circle. Everyone else got my ‘game face.’”

“I didn't share with anyone. I was raised with the example that you don't share things that hurt. I think I didn't share because I was afraid of what might have come spilling out and what people may have thought of me after hearing those things...”
"I still put on a happy face for most people and my DH and mom are the only ones I really let my guard down with, well and this board. I also don't really share with our local DS group, but we don't really know the families very well yet as we have only met them twice."

"I did not want people to see that. I did not want them whispering, "She's not handling it well." Because it was a prenatal diagnosis, I felt I had to try extra hard to contain it, lest someone think, ‘I don't know why she just doesn't take care of it. She obviously can't handle this.’"

"I think we are taught to put on brave faces, and as PPs have stated, that if we show a break that others will think we're not good mothers. We're supposed to love our children unconditionally. If we don't, there's something wrong with us."
UNDERSTANDING EXPECTANT PARENTS

“How can you adjust your support structure to accommodate these feelings?”

• **Understand**

  • some parents may not want to go to group activities.
  
  • group activities may not meet all of parents' needs
  
  • even private meetings may not meet all of parents' needs

• **Be willing**

  • to provide passive support (with information: website; books)
  
  • to follow-up and ask, “How is your state of mind?”

“Don't take non-participation as a rejection of the need for your support.”
DOWN SYNDROME PREGNANCY PROGRAM

• Books: “Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome” and “Your Loved One is Having a Baby with Down Syndrome.”

• Website with blog posts and comments from experienced parents

• BabyCenter Discussion Forum

• One-on-one email support

• Sample emails: Sharing the News, Letter to Doctor, Hurtful Language

• Match-up referrals (heart defects, duodenal atresia, fluid, referrals to experts)
DOWN SYNDROME PREGNANCY PROGRAM: EXPECTANT PARENTS

• Resources address unique concerns of expectant parents: emotions, social terrain - advice, prenatal care, miscarriage risks, telling siblings, breastfeeding, delivery plan, newborn medical issues, early intervention, insurance, SSI, etc., basic information

• Provide peer support and voices of experience

• Offer prenatal testing updates

• Provide constant accessibility: active/interactive (discussion boards, call, emails) and passive (book and website)
DOWN SYNDROME PREGNANCY PROGRAM: LOCAL GROUPS

• Free medically reviewed, quality resources for expectant parents

• Top Google search ranking for “down syndrome pregnancy”

• Direct online support

• Helping your members before they reach you

• Referring expectant parents to local groups
LOCAL GROUPS: SUPPORTING EXPECTANT PARENTS

• Be aware of what resources are available and prenatal testing advances

• Share resources with local medical providers via website and visits

• Share resources with expectant parents via website, direct support, and meetings

• Share resources with your membership via newsletters, website, social media

• Donate funds to support free online resources for expectant parents at the National Center

• Learn about the psychology of expectant parents

• Respect testing decisions

• Think about your language
LOCAL GROUPS: SHARING EXPECTANT PARENT RESOURCES

• Personally visit the National Center website: DSP, BT, and Lettercase

• Read book, blog, Facebook and Twitter updates at DSP and Lettercase and read the BabyCenter “Down Syndrome Pregnancy” discussion board

• Put DownSyndromeDiagnosis.org on your prenatal resource list

• Review local supplement info sheet and create online local supplemental information

• Create a “First Call” program (See presentation by Sarah Cullen.) Respond within 24 hours.

• Pass a prenatal testing info law in your state (See presentation by Sara Weir.)
UNDERSTANDING EXPECTANT PARENT EMOTIONS

<table>
<thead>
<tr>
<th>Stages of grief</th>
<th>Response</th>
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<tbody>
<tr>
<td>• Shock and denial (numb, alone, confused)</td>
<td>• Listen; Allow silence and time to adjust; Encourage eating and sleeping well</td>
</tr>
<tr>
<td>• Loss and anger (grief, bitterness, rejection)</td>
<td>• Listen; Redirect anger toward situation, Reassure; Provide resources; Write feelings</td>
</tr>
<tr>
<td>• Depression and despair (guilt, worry, sad)</td>
<td>• Listen; Reassure; Encourage communication; Keep daily routines and exercise; Get help</td>
</tr>
<tr>
<td>• Adaptation (acceptance, relief, excitement)</td>
<td>• Reiterate positive; Keep notebook; Give resources; Accept roller coaster</td>
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UNDERSTANDING EXPECTANT PARENT EMOTIONS

- Emotional growth not linear; up & down
- Often showing you “game face”
- Concerns are DS-related, but also:
  - pregnancy-related
  - NICU-related
  - relationship-related
  - concerns about comments received (heightened during pregnancy)
LOCAL GROUPS: SUPPORTING EXPECTANT PARENTS

- Information Expectant Parents need from local groups:
  - Prenatal support information
  - Contact person for prenatal support
  - A menu of available programs, and services
  - Local on-line discussion group or e-mail list - information to sign up
  - Local sibling programs
  - Parent to Parent, connections with parents with similarities (internal list)
LOCAL GROUPS: SUPPORTING EXPECTANT PARENTS

- Information Expectant Parents need from local groups about health care:
  - Recommendations of obstetricians in area (Not on your website, but available)
  - Recommendations of therapists in area (centered on perinatal depression) (Not on your website, but available)
  - Local lactation consultants or breastfeeding support groups experienced with Down syndrome
  - Local hospitals for delivery
  - Local Children's Hospitals information
  - Local Trisomy 21 or Down Syndrome clinic information
LOCAL GROUPS: SUPPORTING EXPECTANT PARENTS

- Information Expectant Parents need from local groups about local services:
  - State services: insurance programs (CHIP) information
  - State services: rules for Medicare, SSI
  - State services: early intervention structure
  - Local services: early intervention structure
LOCAL GROUPS: SUPPORTING EXPECTANT PARENTS

Language:

• Same discussion principles as for medical professionals.

• If you are equating testing with termination, then expectant parents are hurt, defensive

  Think:

  • “I didn't have any testing, because we would love the baby regardless.”

  • “I didn't want to risk my baby's life because of some idea about ‘preparing.’”

  • “I skipped all screenings: as far as I was concerned, this was my baby.”
LOCAL GROUPS: SUPPORTING EXPECTANT PARENTS

“When I got the news that my baby girl had Down syndrome, my world turned upside down. Downsyndromepregnancy.org launched within weeks of getting Ellie’s diagnosis. I was able to share the website and book with family members and close friends; connect with other women; learn more about Down syndrome; and find hope from experienced parents who talked me through both of my daughter’s major surgeries. I cannot fathom how difficult my pregnancy would have been without the voices of other parents providing hope.

I now have a happy, healthy eight month old daughter. When she arrived, we were able to celebrate because we were prepared for her extra chromosome with community, information, and resources.”

Megan Landmeier

Friday, January 18, 13
THE NATIONAL CENTER
DOWNSYNDROMEDIAGNOSIS.ORG

• University of Kentucky’s Human Development Institute
• Brighter Tomorrows
• Lettercase
• Down Syndrome Pregnancy

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