

# Power Boost Your Medical Outreach Program with Free Online Training and Resources

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DSCNW

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## Basics of Prenatal Medical Outreach

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- Build relationships of trust and respect between medical providers and advocacy community.
- Convey professionalism and credibility of local organization.
- Provide presentations and distribute up-to-date information about genetic conditions.
- Track materials distributed.

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## Understanding the Prenatal Outreach Representative Program

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### Prenatal Outreach Representative Program

Overview: The Prenatal Outreach program generally consists of a contact for each OB/GYN group in the region. The Prenatal Outreach Representatives replicate the model of a pharmaceutical representative.

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### Prenatal Outreach Representative Program Overview

Each Prenatal Outreach 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.
- Offer presentations.
- Provide referrals to your organization
- Offer business cards with contact information to medical professionals and are available via telephone calls or in person. *Make sure business cards come from your local Down syndrome organization and identify the role of the Prenatal Outreach Representative.*
- Report a quarterly contact log or Qualtrics survey to the organization/Medical Contact Supervisor.

Find all materials at Lettercase.org.

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### Importance of Prenatal Outreach Program

- Prenatal Outreach Representative training is offered so that representatives understand the organization and focus of the program. The training also instructs parents about how to act as representatives of your organization and how to navigate complex territory.
- Importance of professional trained parents for medical outreach and for parent-to-parent support: each person is representing your organization
- A strong professional collaboration with health care professionals will ensure more positive, supported diagnosis experiences and more referrals to your program and growth of your organization and more families will be connected and supported
- Share information on how referrals can be made to org to support for patients

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### Prenatal Outreach Representative Program Benefits

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- Key to credibility with health care professionals
- Consistent standards for volunteers
- Allows different opportunities for volunteer parents where they will be the best fit
- Importance of specialized prenatal training
- Grants

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### Office Resources for Expectant Parents

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#### Print

- National Center/Lettercase brochure
- Understanding Prenatal Screening and Testing bi-fold
- Delivering a Prenatal or Postnatal Diagnosis brochure
- Delivering a Diagnosis of Down Syndrome (DSDN) postcard
- "Understanding a Down Syndrome Diagnosis" booklet
- "Diagnosis to Delivery: A Pregnant Mother's Guide to DS" English and Spanish book

#### Online

- lettercase.org
- downsyndromepregnancy.org
- National Down Syndrome Adoption Network: ndsan.org
- Down Syndrome Diagnosis Network
- NDSS, NDSC, and local organizations

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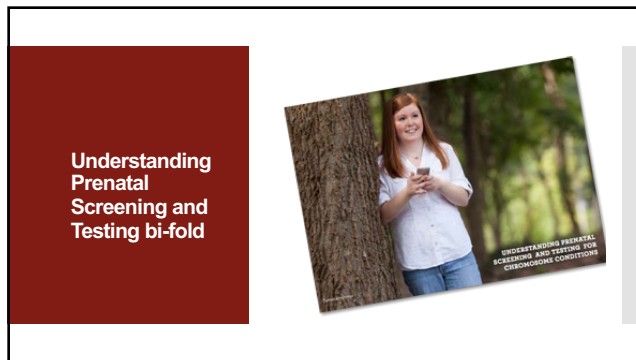
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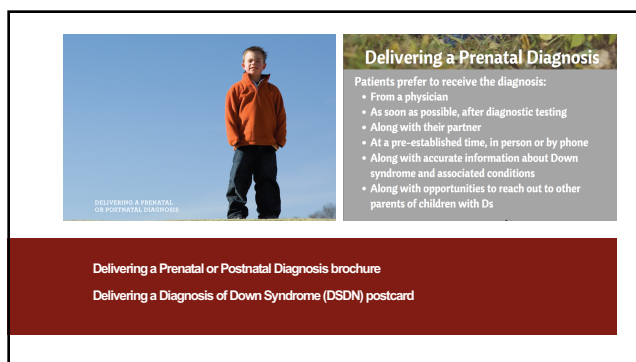
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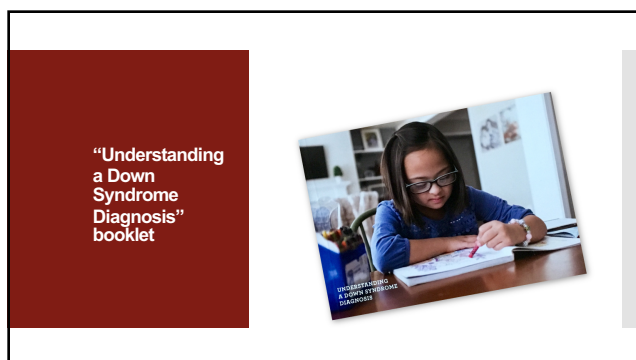
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**“Diagnosis to Delivery: A Pregnant Mother’s Guide to DS”  
English and Spanish book**



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**National Down Syndrome Adoption Network Brochure**



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**Down Syndrome Diagnosis Network Brochure**



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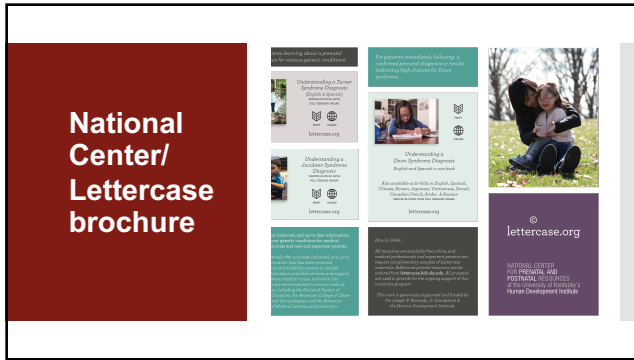
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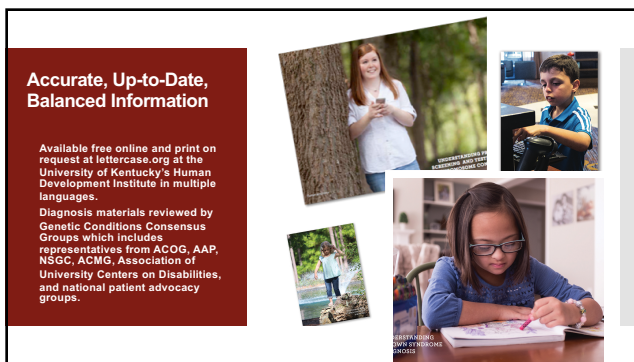
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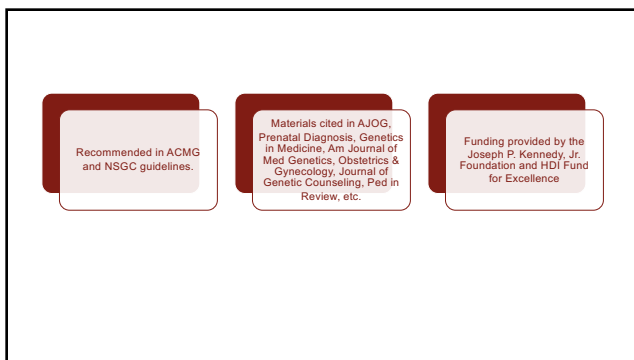
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Live training by Lettercase Trainers

Live training by the Local Organization Trainer with technical assistance from Lettercase Trainers

Online training with the Lettercase online module for Prenatal Outreach Representatives

Live training with the online module for Prenatal Outreach Representatives offered in person by the Local Organization Trainer

Options for Training

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**PHT 202: Prenatal Medical Outreach Training for Advocacy Organizations Education Module**

**PHT 203: Prenatal Medical Outreach Training for Trainees**

Description Target Audience: Volunteers and staff at local

Prenatal Outreach Representative Training  
<https://www.lettercase.org/education/advocacy-organizations/>

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**Prenatal Outreach Supplemental Material**

<https://www.lettercase.org/education/advocacy-organizations/>

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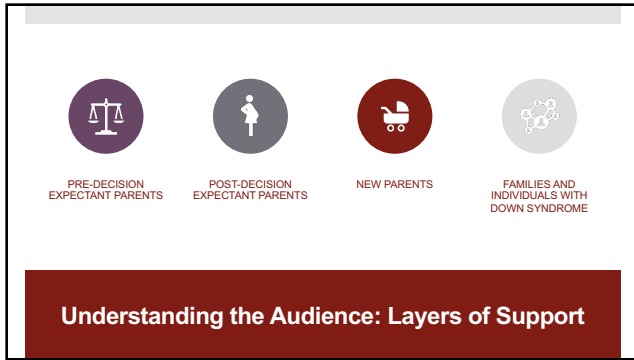
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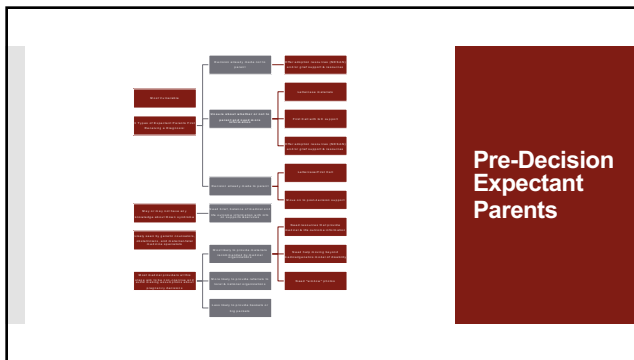
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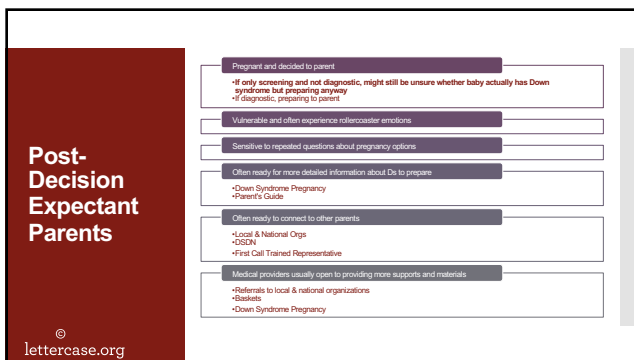
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# New Parents Postnatal

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New parent

- Received a post-natal diagnosis: may experience more shock and grief
- Received a pre-natal diagnosis: may be more prepared

Vulnerable and often experience rollercoaster emotions

Often ready for more detailed information about DS to prepare

- Down Syndrome Pregnancy: Welcoming a Newborn
- New Parent's Guide

Often ready to connect to other parents

- Local & National Orgs
- DSDN Groups
- First Call Trained Representatives

A small percentage of parents might be considering not parenting

- Refer to NCSAN

Medical providers usually open to providing more supports and materials

- Referrals to local & national organizations
- Baskets
- Down Syndrome Pregnancy

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# Families and Individuals with Down Syndrome

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If a local organization exists, any new & expectant parent outreach should be connected to the local org so that families make a connection across the lifespan

Because the moment of diagnosis is a flashbulb memory, local orgs need to make the connection as soon as possible. First point on the life course.

Need ongoing local support

- Play and social groups
- School
- Medical
- Employment
- More

Ongoing online connections like DSDN Birth Club Groups

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MEDICAL PROVIDERS WITH NEGATIVE BIAS

MEDICAL PROVIDERS WITH UNCONSCIOUS BIAS

NEUTRAL MEDICAL PROVIDERS

MEDICAL PROVIDERS WITH POSITIVE BIAS

# Understanding the Audience: Prenatal Medical Providers

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**Prenatal Medical Providers with Negative Bias**

A minority of medical professionals will be negative no matter what you do




**Prenatal Medical Providers with Unconscious Bias**

Many medical providers will strive to be neutral and not recognize their unconscious bias about disabilities

Quintessence and recommended resources are most helpful for this group

Medical model of disability common. Need to expand view

Most likely to benefit from Lettercase: PHT 201 Learning Module & Delivering a Diagnosis materials, Training & Lunch and Learn Presentations




**Neutral Prenatal Medical Providers**

Many medical providers strive to be neutral—provide balanced information & also not make presumptions about pregnancy decisions

Some families may perceive them as being biased when they are trying to follow guidelines and present reproductive options

Help them to be more balanced by sharing available resources & support. Often willing to provide recommended resources at the moment of diagnosis but might be unaware

Benefit from Lettercase: PHT 201 Learning Module & Delivering a Diagnosis materials, Training & Lunch and Learn Presentations



**Prenatal Medical Providers with Positive Bias**

Some medical providers will be positive with or without your outreach, but they might still be unaware of available resources and supports

Benefit from Lettercase: PHT 201 Learning Module & Delivering a Diagnosis materials, Training & Lunch and Learn Presentations

**Understanding the audience: Prenatal Medical Providers**

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**Professional guidelines:**

- Offer screening
- Discuss reproductive options.

**Ethics of healthcare:**

- Provide patient education and support based on peer-reviewed research
- Respect patient autonomy
- Might be concerned about advocacy organizations being coercive or pushing an agenda

**Laws:**

- Information Acts
- Reproduction Laws
- Wrongful Birth
- Wrongful Life

**Lack of training about genetic conditions/disabilities**

- Lack of specialists to support
- Lack of resources
- Often feel overwhelmed and anxious about discussing a diagnosis perceived as "bad news"

**Concerns: Prenatal Medical Providers**

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**Professional guidelines:**

- Provide resources that are medically-reviewed and are also recommended in guidelines

**Ethics of healthcare:**

- Provide educational resources and supports that are accurate, balanced, up-to-date, and cite peer-reviewed research
- Be professional and respectful

**Laws:**

- Provide materials and support that do not conflict with applicable laws and that are mentioned in the Information Act for your state as applicable

**Lack of training about genetic conditions/disabilities**

- Offer training opportunities through online modules, presentations, and lunch-and-learns
- Provide clinicians with patients resources, Delivering a Diagnosis bi-folds, and training to feel more comfortable discussing disability

**Addressing Concerns: Prenatal Medical Providers**

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Bad Diagnosis Experiences	Reproductive Decisions & Impact on Community	Negative Bias about Disabilities	Building Relationships with Medical Community/Overcoming Skepticism
<ul style="list-style-type: none"> <li>For every 1 positive prenatal diagnosis experience, there are 3 negative prenatal diagnosis experiences.</li> <li>A bad diagnosis experience causes trauma</li> </ul>	<ul style="list-style-type: none"> <li>Worried about termination rate and impact on number of births</li> <li>33% reduction in babies born with DS</li> <li>74% termination rate of those who opt for amnio or CVS</li> </ul>	<ul style="list-style-type: none"> <li>Historic societal bias against people with disabilities (institutionalization, segregation, and forced sterilization)</li> <li>Medical model of disability vs. social model of disability</li> <li>Ableism</li> </ul>	<ul style="list-style-type: none"> <li>Might face medical professionals who are skeptical that advocacy organizations have an agenda or unrealistic view about the condition</li> <li>Might have a difficult time getting through the door and making contacts</li> <li>Perceived as "mom and pop" org</li> </ul>

**Concerns: Advocacy Community**

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Bad Diagnosis Experiences	Reproductive Decisions & Impact on Community	Negative Bias about Disabilities	Building Relationships with Medical Community/Overcoming Skepticism
<ul style="list-style-type: none"> <li>Providing resources, support, and training for clinicians can improve diagnosis experiences for families.</li> </ul>	<ul style="list-style-type: none"> <li>In medical outreach, your primary concern is for the patient, the diagnosis experience &amp; patient/provider education.</li> <li>To build relationships with most medical providers, the goal can not be to influence pregnancy decisions</li> </ul>	<ul style="list-style-type: none"> <li>Offer resources, training, and support that show current outcomes and that do not contain outdated negative language or assumptions about disabilities</li> <li>Provide training and presentations that highlight the progress for disability rights</li> </ul>	<ul style="list-style-type: none"> <li>Be professional, respectful, reliable &amp; consistent</li> <li>Provide resources &amp; support that are accurate, balanced &amp; up-to-date &amp; are included in guidelines</li> <li>Avoid making assumptions about them &amp; make relationship building the goal.</li> </ul>

**Addressing Concerns: Advocacy Community**

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Update on the Center for Dignity in Healthcare for People with Disabilities	
<ul style="list-style-type: none"> <li>Gap Analysis: <a href="https://centerfordignity.com/wp-content/uploads/2021/02/CDHPD-Gap-Analysis-Report.pdf">https://centerfordignity.com/wp-content/uploads/2021/02/CDHPD-Gap-Analysis-Report.pdf</a></li> <li>Prenatal Recommendations to Enhance Equity for People with Disabilities</li> <li>Research Study (DSDN and ACL): 12 Local Down Syndrome Organization Medical Outreach Pilot Sites</li> </ul>	<ul style="list-style-type: none"> <li>Research Study: Expectant Parents (January 1, 2016-July 1, 2022)</li> </ul>

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## Research Update

- Parents want online and print products.
- OBs least likely to provide state DPH resources and life outcome information
- OBs most likely to provide comprehensive prenatal care, pregnancy options, and information about medical conditions
- GCs more likely than OBs to provide information about supports and services and life outcomes
- Parents want information at all stages before screening, after screening, and after diagnostic testing. Most important following NIPT.

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## Spotlight on Affiliate Success at GRADSA

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## Spotlight on Affiliate Success at MCDSIG

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## Spotlight on Affiliate Success at Down Syndrome Connections of the NW

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## Prenatal Outreach Representative Program

Developing Your Medical Outreach Plan

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## Know the Numbers

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**Determine the contents of packets for providers and parents**

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**Prenatal Pre-Decision/ "First Diagnosis" Packets for Parents**

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- Lettercase Understanding a Down Syndrome Diagnosis
- If you are prepared to support pre-decision parents at this time: Letter/cards/brochure for expectant parents about what your organization can offer them.
- If not prepared for pre-decision support, request National Prenatal First Call Brochure
- Your Organization Brochure
- Provide one packet per OB office you plan to serve and 3-10 per MFM or GGC depending on the birth numbers in your area)*

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NDSAN Adoption Brochure	Your organization brochure	Lettercase Understanding a Down Syndrome Diagnosis	Lettercase Delivering a Prenatal or Postnatal Diagnosis	DSN Delivering a Prenatal Down Syndrome Diagnosis
DSN Delivering a Postnatal Down Syndrome Diagnosis	Lettercase Understanding Prenatal Screening and Testing for Chromosome Conditions	State Information Act?	Letter from your organization about what you offer new and expectant parents and providers	<i>Provide one per medical professional you plan to serve.</i>

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# Prenatal “Preparing for the Journey” Packets for Parents

Diagnosis to Delivery:  
A Pregnant Mother's  
Guide to Down  
Syndrome (follow-up  
visit or basket)

National First Call  
Brochure, if an  
organization needs  
extra support

Lettercards/brochure  
for new and expectant  
parents about what  
your organization can  
offer them.

OSDN Brochure

Lettercase Brochure

Explain to providers  
that these are  
additional materials for  
families who are  
preparing for the birth  
of their baby and want  
more information in a  
follow-up visit.

Other  
Resources/Books/Gifts  
or Expectant Parent  
Baskets

Your Loved One Is  
Having a Baby with  
Down Syndrome

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# New Parent Packets

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Letter/cards/brochure for new and expectant parents about what your organization can offer them.

DSDN Brochure

Lettercase/Down Syndrome Pregnancy Brochure

Other Resources/Books/Gifts or Expectant Parent Baskets

Welcoming a Newborn with Down Syndrome

Breastfeeding and Down Syndrome

Congratulations Project

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# Baskets for New Parents

Baskets may contain many  
resources and gifts to  
welcome new parents or  
expectant parents preparing  
for the journey. We have  
many organizations who can  
provide examples in  
Prenatal Outreach Program  
Facebook group and IDMTF  
email.

Jack's Basket is another  
great resource you can  
utilize.

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**Closest UCEDD as a source of interns and host for seminars**

<https://www.aucd.org/template/index.cfm>

Directory

UCEDD Programs by State

Browse by Search Programs

Search

Enter information to search by key word or select a position from the list.

Position

State

Country

First Name

Last Name

State

UCEDD Program Search


Search


Funded in part by the Administration on Intellectual and Developmental Disabilities


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**Identify Maternal Fetal Medicine Specialists and Genetic Counselors who serve your region**

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 <https://www.nsgc.org/page/find-a-genetic-counselor>


 <https://www.smfm.org/members/search>


 <https://clinics.acmg.net>

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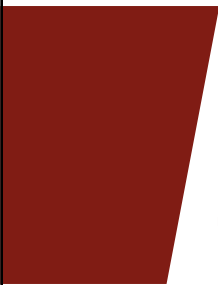
**Identify and connect with the largest birthing hospitals in your area**

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 Connect with perinatal social worker

 Head nurse at NICU

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## Understand your Down Syndrome Information Act

<https://www.lettercase.org/issues/state-laws/>

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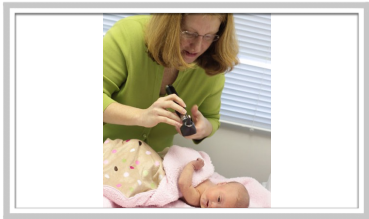
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Identify and collaborate with medical allies in your area

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Compile a list of all medical providers who could be delivering a diagnosis

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**Identify if you have a genetic counseling program in your area.**

<https://www.gceducation.org/program-directory/>




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**Determine how you are tracking data**

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 Excel spreadsheet
  Online database
  Other tool

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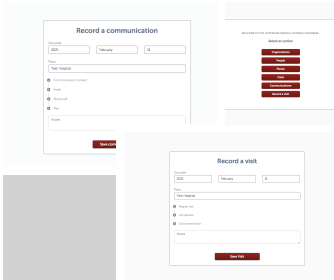
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**Lettercase Data Tracking Tool**

Record visits  
Record communications  
Admins can assign representatives to different medical practices.  
Admins can record notes about representatives.  
Representatives can input information on their phones. Only assigned medical practices appear when they log in.  
Representatives can record notes about locations.




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**Identify if your program will need to train representatives**

<https://www.lettercase.org/pht-203-prenatal-medical-outreach-training-for-trainees/>

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**Assess your website and branding:**

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**Audience of new and expectant parents**

Provide national resources  
List the programs your organization offers new and expectant parents

**Provider Audience**

Provide national resources  
Contact information for presentations  
Training resources

**Branding and name**

Convey professionalism

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**Website Examples**

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<http://dsaco.net/new-parents/>

<https://www.kcdsg.org/newparents.php>

<https://mdsc.org/programs/ParentsFirstCall.cfm>  
and name

<https://mcdsig.org/category/new-expectant-parents/>

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Identify resources for multicultural audiences?



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Identify 3-5 goals for the next 6 months, including one goal to outreach to a new clinician

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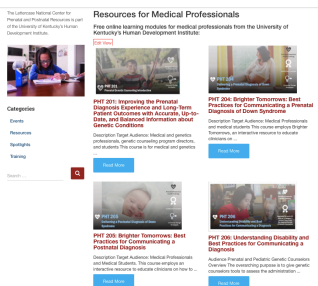
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Other Resources for Medical Professionals



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THE NATIONAL CENTER FOR PRENATAL AND  
POSTNATAL DOWN SYNDROME RESOURCES

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[twitter.com/lettercaseorg](https://twitter.com/lettercaseorg)  
[twitter.com/DownSynPreg](https://twitter.com/DownSynPreg)  
[downsyndromediagnosis.org](https://downsyndromediagnosis.org)

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