

2019 ANNUAL REPORT



**LETTERCASE NATIONAL CENTER FOR
PRENATAL AND POSTNATAL RESOURCES**

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lettercase.org

MISSION

To ensure that families and medical professionals have the resources and training tools they need to provide accurate, up-to-date and balanced information about genetic conditions at the moment of diagnosis.

NATIONAL CENTER FOR PRENATAL AND POSTNATAL RESOURCES PROGRAMS

LETTERCASE

Resources for expectant parents first learning about genetic conditions during pregnancy. All materials reviewed by representatives of national medical, genetics & advocacy organizations. Also offers disability training for medical providers & medical outreach training for advocacy organizations.

www.lettercase.org

DOWN SYNDROME PREGNANCY

Resources for new and expectant parents preparing for the birth of a baby with Down syndrome. Also offers resources for loved ones and covers special topics for new and expectant parents.

www.downsyndromepregnancy.org

MESSAGE FROM THE DIRECTOR

Dear Colleagues and Friends,

For the past decade, we've been working to support families by providing accurate, balanced, and up-to-date information during that vulnerable moment of diagnosis. Our work focuses on new and expectant parents and the health professionals caring for them.

Thanks to ongoing support from our wonderful funders like the Joseph P. Kennedy, Jr. Foundation and the Human Development Institute, as well as the Down Syndrome Diagnosis Network, Flourish Network, private donors, and generous collaborators, we've been able to develop a robust library to support families and providers with free online and print materials and apps.

Our challenge in the next decade is to ensure that these resources get into the hands of health providers so that we can make sure every family is getting the information they need at that critical moment of diagnosis.

Thanks to a generous grant from the Administration on Community Living to address healthcare disparities for people with disabilities, we have more momentum to expand this work. We can look forward to a bright future where everyone has a better understanding of the improved outcomes for people with disabilities!

Stephanie Meredith
Director of the National Center for Prenatal & Postnatal Resources

SPOTLIGHTS

TRAINING MODULE FOR MEDICAL PROFESSIONALS

In September, Lettercase released an *online training module (PHT 201)* for medical and genetics professionals and students on the history of disability rights and providing accurate, up-to-date, and balanced information following a diagnosis of Down syndrome.

This module includes video podcasts and learning activities about communicating a prenatal diagnosis and improving longterm patient outcomes.

The module is also included as an available lecture in the database of resources for the Association of Genetic Counseling Program Directors.



NEW PRADER-WILLI SYNDROME RESOURCE

Lettercase created a *Prader-Willi syndrome resource* for expectant parents receiving a prenatal diagnosis in 2019. This resource was funded by the Joseph P. Kennedy, Jr. Foundation and developed with input from representatives of the American College of Medical Genetics and Genomics, the American College of Obstetricians and Gynecologists, the American Academy of Pediatrics, the National Society of Genetic Counselors, the Association of University Centers on Disabilities, the Prader Willi Association of the USA, and the Foundation for Prader-Willi Syndrome Research. See the new resource at www.understandingpraderwillisyndrome.org!

NATIONAL COUNCIL ON DISABILITY REPORT AND RESPONSES

In October, the National Council on Disabilities released a report in their bioethics series on *“Prenatal Testing and the Rush to Perfection”* and included a case study on the collaborative work done by Lettercase. Correspondingly, the National Society of Genetic Counselors wrote a response and also cited the collaborative work between NSGC and Lettercase. The Key Recommendations and ensuing conversations about bioethics are very helpful for anyone interested in these issues.

In March, our staff also co-authored a peer-reviewed publication, *Adherence of cell-free DNA noninvasive prenatal screens to ACMG recommendations* published in *Genetics in Medicine* with Dr. Brian Skotko as the lead author to determine how closely commercial labs were following the ACMG guidelines. See the *HDI Research Brief* or the *Prenatal Information Research Consortium table* for more details.

LETTERCASE BY THE NUMBERS IN 2019

NUMBER OF MEDICAL
PROFESSIONALS TRAINED
ONLINE & IN-PERSON:

913

NUMBER OF DOWN SYNDROME
PREGNANCY PRINTED BOOKS
DISTRIBUTED:



2,815

NUMBER OF LETTERCASE
BOOKS DOWNLOADED:

3953



NUMBER OF DOWN SYNDROME
PREGNANCY WEBSITE VISITORS:

41,076



TOTAL # OF PRINTED
LETTERCASE BOOKS
DISTRIBUTED:

3182

OF BOOKS DONATED BY
LETTERCASE TO PATIENTS &
PROVIDERS:

1629

MEDICAL CONFERENCE
PRESENTATIONS 2019:

- American Society of Human Genetics and Genomics
- George Washington University
- ACOG Electronic Health Records Meeting
- American College of Osteopathic Obstetricians & Gynecologists:

MEDICAL CONFERENCE
EXHIBITS 2019:

- American College of Medical Genetics and Genomics
- National Society of Genetic Counselors



GENETIC COUNSELING PROGRAMS TRAINED:

- University of Utah
- University of South Carolina Columbia
- Wayne State University
- University of Texas Houston

NUMBER OF CONFERENCES ATTENDED IN 2019:

 11

NUMBER OF ADVOCACY ORGANIZATIONS TRAINED TO DO MEDICAL OUTREACH:

45



ADVOCACY CONFERENCE PRESENTATIONS

- Club 21 Pasadena
- Down Syndrome Guild of Greater Kansas City
- Down Syndrome Affiliates in Action
- Down Syndrome Diagnosis Network
- Association of University Centers on Disabilities



PRODUCTS ADDED IN 2019:

- *Understanding Prader-Willi Syndrome*
- *Breastfeeding and Down Syndrome: A Comprehensive Guide for Mothers and Medical Professionals in Partnership with Julia's Way*
- Arabic Translation of *Understanding a Down Syndrome Diagnosis*
- Lettercase iTunes app

DOWN SYNDROME PREGNANCY RESOURCES

Throughout 2019, Down Syndrome Pregnancy provided the following resources for expectant parents who are preparing for the birth of a baby with Down syndrome, including a new book about breastfeeding and Down Syndrome:

- *New! Breastfeeding and Down Syndrome: A Comprehensive Guide for Mothers and Medical Professionals*

A book we distribute in partnership with Julia's Way about breastfeeding babies with Down syndrome.

- *Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome* (English & Spanish)

A book for expectant parents preparing for the birth of a baby with Down syndrome.

- *Welcoming a Newborn with Down Syndrome* (English & Spanish)

A book for new parents preparing whose baby was just born with Down syndrome.

- *Your Loved One is Expecting a Baby with Down Syndrome* (with Spanish chapter)

A book for friends and family whose loved ones find out they are expecting a baby with Down syndrome.

- *Coping with Loss: Down Syndrome*

A book for families who may experience miscarriage, stillbirth, or the loss of a child with Down syndrome.

- *The Congratulations Project*

A book we distribute in partnership with Camp Pals with letters from people with Down syndrome to new and expectant parents.



“RECEIVING A PRENATAL DIAGNOSIS CAN BE OVERWHELMING FOR FAMILIES, LEAVING THEM WONDERING WHAT LIFE IS LIKE FOR PEOPLE LIVING WITH THE CONDITION. ‘UNDERSTANDING A DOWN SYNDROME DIAGNOSIS’ IS OFTEN DESCRIBED AS A LIFELINE FOR FAMILIES LEARNING ABOUT A DIAGNOSIS, AND I BELIEVE, AS DID MY MOTHER, THAT EXPECTANT PARENTS NEED THAT SUPPORT AND INFORMATION RIGHT AWAY.”

—TIM SHRIVER, PHD

GRANT SPOTLIGHTS

LETTERCASE RESOURCES

We are constantly updating resources to create an accurate, up-to-date, and balanced library that clinicians can use to support families with an unexpected diagnosis. All materials can be found at resources.lettercase.org:

- **New! Lettercase iTunes app for tablets**
- **New! *Understanding a Prader-Willi Syndrome Diagnosis***
- *Understanding a Down Syndrome Diagnosis* (English, Spanish, Japanese, Chinese, Korean, Vietnamese, Russian, Somalian, Canadian French & **New! Arabic**)
- *Understanding a Turner Syndrome Diagnosis* (English & Spanish)
- *Understanding a Jacobsen Syndrome Diagnosis*
- ***Understanding a 47XYY Diagnosis in development for 2020***
- *Delivering a Prenatal or Postnatal Diagnosis*
- *Understanding Prenatal Screening and Testing for Chromosome Conditions* (English & Spanish)

Training modules can be found at lettercase.org/education:

- **New! PHT 201: Medical Professionals: Improving the Prenatal Diagnosis Experience and Long-Term Patient Outcomes with Accurate, Up-to-Date, and Balanced Information about Genetic Conditions**
- ***PHT 202: Prenatal Medical Outreach Training for Advocacy Organizations in development for 2020***
- ***PHT 203: Training for Prenatal Medical Outreach Representatives in development for 2020***

JOSEPH P. KENNEDY, JR. FOUNDATION

In January, the Joseph P. Kennedy, Jr. Foundation awarded Lettercase a \$10,000 grant to create a resource about Klinefelter syndrome/47XYY. This book will be available summer of 2020 and will be the 5th genetic condition in our library thanks to the Foundation!

HDI FUND FOR EXCELLENCE

In March, HDI provided Lettercase a \$10,000 grant to create training modules for medical professionals to better understand disabilities and for advocacy groups to build better relationships with health professionals.

ADMINISTRATION FOR COMMUNITY LIVING

In October, ACL awarded a collaborative grant to establish a Center for Dignity in Healthcare for People with Disabilities, and the Lettercase program at the University of Kentucky's Human Development Institute is responsible for the prenatal strand. As part of that grant, we will perform a gap analysis, establish prenatal screening protocols, and share resources. [Read article](#) for more details.

DOWN SYNDROME DIAGNOSIS NETWORK

In December, DSDN provided Lettercase a \$10,000 grant to fund training and resources for 4 local Down syndrome advocacy organizations in 2020! Application coming soon.



LETTERCASE STAFF

Stephanie Meredith, Program Director

Harold Kleinert, Director of Operations

Mark Leach, Bioethics Director

Nancy Iannone, Support Director

Connor Ensign, Shipping Clerk

114 Mineral Industries Building
University of Kentucky
Lexington, KY 40506

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Visit lettercase.org
Email info@lettercase.org

This program is part of the University of Kentucky's Human Development Institute, a University Center for Excellence in Developmental Disabilities.