



## DEPARTMENT OF HEALTH

Wes Moore, Governor · Aruna Miller, Lt. Governor · Laura Herrera Scott, M.D., M.P.H., Secretary

### Office of Children and Youth with Specific Health Care Needs Informational Resources on Down syndrome for Families

#### ***Understanding a Down Syndrome Diagnosis*** ([www.lettercase.org](http://www.lettercase.org))

[Understanding a Down Syndrome Diagnosis](http://www.lettercase.org) has been identified by the American College of Medical Genetics and Genomics as the suggested resource to provide to expectant couples who have received a prenatal diagnosis of Down syndrome but have not yet made a decision regarding their pregnancy options. The book was prepared with assistance from the ACMG, the American Congress of Obstetricians and Gynecologists, the National Down Syndrome Society, and the National Down Syndrome Congress. Printed and digital copies are available in English and Spanish from the [National Center for Prenatal and Postnatal Down Syndrome Resources at the University of Kentucky's Human Development Institute](http://www.ndsc.org).

#### ***A Promising Future Together: A Guide for New and Expectant Parents***

<https://ndss.org/resources/promising-future-together-guide-new-and-expectant-parents>

This booklet was prepared by the National Down Syndrome Society, is available in English and Spanish for free download at [www.ndss.org](http://www.ndss.org). Printed copies are also available.

#### ***Down Syndrome: An Expectant Parents Guide*** <https://www.ndsccenter.org/wp-content/uploads/DS-expparent-guide.pdf>

Provided by the National Down Syndrome Congress on its website. Learn about FAQs, download “Down syndrome: An Expectant Parents Guide” as well as healthcare guidelines and videos with noted health professionals and self-advocates. Founded in 1973, the NDSC hosts the largest of-its-kind convention for families and professionals annually.

#### ***Down Syndrome Pregnancy*** <https://downsyndromepregnancy.org/>

Down Syndrome Pregnancy is a program administered by the National Center for Prenatal and Postnatal Down Syndrome Resources at the University of Kentucky's Human Development Institute to provide information and support to expectant parents who are preparing for the birth of a baby with Down syndrome. The book *Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome* is available for free download through [downsyndromepregnancy.org](https://downsyndromepregnancy.org/)

#### ***DS-Connect: The Down Syndrome Registry*** (<https://dsconnect.nih.gov/>)

The NIH-supported Down Syndrome Registry, DS Connect™, will allow people with Down syndrome and their family members, researchers, and parent and support groups to share information and health history in a safe, confidential, online database. Users will be able to create and edit their customizable online profiles, share their profiles with other DS Connect™ users, and set reminders for medical care and other appointments and events. DS Connect™

will also provide access to general information about Down syndrome, as well as de-identified statistical data based on user responses to survey questions.

***Prenatal Testing and Screening for Chromosome Conditions***

<https://www.understandingprenataltesting.org/>

This online prenatal testing information tool provides the contents found in the Lettercase “Prenatal Screening and Testing for Chromosome Conditions” pamphlet, as well as links to additional resources and more detailed information about chromosome conditions. “[Prenatal Screening and Testing for Chromosome Conditions](#)” is also available as a printed pamphlet. This pamphlet was prepared with assistance from representatives of The National Society of Genetic Counselors with funding provided by the U.S. Administration on Intellectual and Developmental Disabilities (AIDD).

***Health Care Information for Families of Children with Down Syndrome***

[https://downloads.aap.org/HC/Down\\_Syndrome/1\\_Introduction\\_HealthCare\\_Information\\_for\\_Families\\_of\\_Children\\_with\\_down\\_Syndrome.pdf](https://downloads.aap.org/HC/Down_Syndrome/1_Introduction_HealthCare_Information_for_Families_of_Children_with_down_Syndrome.pdf)

This information was prepared by the American Academy of Pediatrics based on their clinical report [Health Supervision for Children with Down Syndrome](#)