



STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

Office for Genetics and People with Special Health Care Needs

Down syndrome Information for Providers

Brighter Tomorrows (www.brightertomorrows.org)

This site (for medical professionals: www.brightertomorrows.org for expectant parents: www.brightertomorrows.org) provides simulation training for health-care professionals who deliver a prenatal diagnosis to expectant couples; the webpage also provides information, in English and Spanish, about Down syndrome to new and expectant couples. The project was funded by federal grants; efficacy was researched and published in peer-reviewed journals. Developed by the National Center for Prenatal and Postnatal Down Syndrome Resources at the University of Kentucky's Human Development Institute (www.downsyndromediagnosis.org).

The National Institutes of Health –The Down Syndrome Consortium (<http://downsyndrome.nih.gov>)

In 2011, the National Institutes of Health (NIH) joined with organizations interested in Down syndrome to form the Down Syndrome Consortium. The goal of this effort is to encourage the exchange of information about Down syndrome research, support, and care among all of the groups in the Consortium. The Consortium meets two to three times each year to discuss research findings and progress toward achieving research, management, infrastructure, and other goals set out by the NIH after consultation with national organizations and agencies interested in Down syndrome. The Down Syndrome Consortium has compiled a list of resources on its Resources page, which includes the Lettercase *Understanding a Down Syndrome Diagnosis* that is funded by the Joseph P. Kennedy Jr. Foundation.

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 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.

2013 American College of Medical Genetics & Genomics statement on noninvasive prenatal screening for fetal aneuploidy https://www.acmg.net/docs/nips-GiM_galley_text_130301.pdf

Skotko, B., Kishnani, P., & Capone, G. for the Down Syndrome Diagnosis Study Group (2009). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics, Part A*, 149A: 2361-2367. <http://www.brianskotko.com/images/stories/Files/ajmgprenatalguidelinesfinal.pdf>

NSGC 2011 Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome: Recommendations of the National Society of Genetic Counselors

<http://www.guideline.gov/content.aspx?id=34434>

This guideline was written for genetic counselors and other healthcare providers regarding the communication of a diagnosis of Down syndrome to ensure that families are consistently given up-to-date and balanced information about the condition, delivered in a supportive and respectful manner.

Understanding a Down Syndrome Diagnosis (www.lettercase.org).

[Understanding a Down Syndrome Diagnosis](#) 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 (www.downsyndromediagnosis.org). Additional publications available are *Delivering a Down Syndrome Diagnosis* bi-fold and *Understanding Prenatal Screening and Testing for Chromosome Conditions*.

TREATMENT AND CARE

American Academy of Pediatrics Clinical Report for Practitioners: Health Supervision Guidelines for Individuals with Down syndrome (<http://pediatrics.aappublications.org/content/128/2/393.full.html>)

American Academy of Pediatrics, "Health Care Information for Families of Children with Down Syndrome" (<http://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx>)