3 types of Down Syndrome

1 - Trisomy 21 (95%)
2 - Translocation Down syndrome (4-5%)
3 - Mosaicism Down syndrome (1%)

Prevalence

- Down’s is 1 in every 800 babies born in the United States.
- Approximately 6,900 births in each year in the United States.
- About 250,000 people in the United States live with Down syndrome.

Health risks for people with Down Syndrome

- Congenital heart conditions
- Developmental problems, such as delayed language development
- Gastrointestinal problems, such as obstructions
- Eye problems, such as far-sightedness or near-sightedness
- Thyroid conditions
- Hearing loss, such as sensorineural hearing loss
- Problems with memory, concentration, and judgment

Cognitive characteristics for some children with Down Syndrome

- Modest-to-moderate intellectual disability
- Difficulty navigating social situations
- Short attention span
- Impulsivity
- Self-talk (talking out loud to him/herself)
- Difficulty with memory, concentration, and judgment
- Difficulty with motor coordination
- Difficulty with vision
- Speech problems, such as articulation
- Eyes, such as cataracts or glaucoma

Lifespan expectancy for people with Down Syndrome

- Ages 60 years: 45% between 1960 and 2007

Risk factors

- Advanced maternal age is the only known risk factor.
- Chance increases every year, especially after the mother is 35 years of age.
- Because younger women are more likely to have babies than older women, about 80% of babies with Down syndrome are born to women younger than 35 years of age.

Prenatal testing for Down syndrome

- All pregnant women over the age of 35 are offered an amniocentesis.
- Risk factors:
  - Maternal age: Older age increases risk.
  - Family history: Increased risk for Down syndrome in a family member.

Education is NEEDED about prenatal testing

- All forms of media should be involved in prenatal testing education, regardless of age.

Important education for clinicians about prenatal Down syndrome testing

Prenatal Diagnoses of Down Syndrome: Delivering Results in Our New Age of Genetic Testing

- Free, one-hour webinar that provides guidance for providers and families on the clinical management of Down syndrome.
- Watch the Webinar at www.mghacademy.org/downsyndrome

Other important Down syndrome organizations

- National Down Syndrome Society: 1-800-221-4602
- National Down Syndrome Congress: www.ndsc.org
- Massachusetts Down Syndrome Congress: www.ndsccenter.org
- Massachusetts Department of Public Health: www.mass.gov
- National Institutes of Health, National Institute of Child Health and Development: www.genetics.nichd.nih.gov
- American College of Obstetricians and Gynecologists: www.acog.org
- American Heart Association: www.heart.org
- National Down Syndrome Congress: www.ndss.org
- About Mass General Hospital: www.massgeneral.org
- About Massachusetts General Hospital: www.mgh.org
- Toronto Down Syndrome Research Foundation: www.tdsrf.org
- Educational Opportunities: www.rrrs.org
- Down Syndrome International: www.dsi-int.org
- National Down Syndrome Congress: www.ndsc.org

SOURCES / REFERENCES

1. National Down Syndrome Society
2. Genetics Home Reference, National Library of Medicine, NIH

Public Health Massachusetts Department of Health

www.ndss.org

Society

National Down Syndrome Congress

www.ndsc.org

Other important Down syndrome organizations

About Massachusetts General Hospital

For more information, please contact the Mass General media relations department at 617-726-4243 or massgeneral_media_relations@partners.org.

35% of Down Syndrome births occur in the age of 35+.

Regrettably, there are no known ways to prevent Down Syndrome.

60% of Down Syndrome births occur in women younger than 35 years of age.

With early diagnosis during pregnancy, many complications can be identified.

Postnatal testing for Down syndrome is only available to all women who are pregnant.

New Recommendation

- All forms of media should be involved in prenatal testing education, regardless of age.

Old recommendation

- All pregnant women over the age of 35 are offered an amniocentesis.

Importance of early diagnosis during pregnancy.

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1. National Down Syndrome Society
2. Genetics Home Reference, National Library of Medicine, NIH

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