



# Down SYNDROME

A Guide to Relevant Facts

## 3 types of Down syndrome <sup>1</sup>

**95%**

Trisomy 21

**4-5%**

Translocation Down syndrome

**~1%**

Mosaic Down syndrome



## Prevalence

- Occurs in **1 in every 830 babies** born in United States <sup>2</sup>
- Approximately **6,000 births each year** in the United States <sup>2</sup>
- About **250,000 people in the United States** live with Down syndrome <sup>2</sup>



## Health risks for people with Down syndrome



**Congenital heart conditions**



**Gastrointestinal problems, such as obstructions**



**Celiac disease**



**Problems with memory, concentration, and judgment**



**Hearing conditions such as sensorineural hearing loss**



**Eye problems, such as cataracts or far-sightedness**



**Thyroid conditions**

## Cognitive characteristics for some children with Down syndrome

- Mild to moderate intellectual disability
- Difficulty navigating social situations
- Short attention span
- Impulsivity
- Stubbornness, a desire for routine & order
- Angry outbursts
- Self talk (talking out loud to him/herself) as a way of understanding and processing information

## Life expectancy for people with Down syndrome

**~60 YEARS** **456%** between 1960 and 2007 <sup>4</sup>

## Support systems that help people with Down syndrome live fulfilling lives

- Quality educational programs that augment natural learning
- High-quality, specialized health care, like Down syndrome clinics
- Stimulating and supportive home environment
- Positive family members and friends



## Risk factors



**Age of Mom**

- Advanced maternal age** is the only known risk factor <sup>3</sup>
- Chance increases every year**, especially after the mother is 35 years of age <sup>3</sup>

**80%**

**Under 35**

- 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** <sup>3</sup>

## Prenatal testing for Down syndrome

### Old recommendation

All pregnant women over the age of 35 be offered an amniocentesis <sup>5</sup>



### New Recommendation

All forms of testing should be available to all women... regardless of age <sup>6</sup>



## Education is **NEEDED** about prenatal testing

**45%** 45% of ACOG fellows and junior fellows rated their residency training regarding prenatal testing for fetal aneuploidy as **"barely adequate or nonexistent"** <sup>7</sup>

**28%** Only 28% of ACOG fellows felt **"well qualified"** in general prenatal genetic counseling <sup>7</sup>

## 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 provides physicians, nurses, and other healthcare professionals on communicating with expectant parents about a prenatal diagnosis of Down syndrome.



Watch the Webinar at [www.mghacademy.org/downsyndrome](http://www.mghacademy.org/downsyndrome)

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## Other important Down syndrome organizations

**National Down Syndrome Society**

[www.ndss.org](http://www.ndss.org)

**National Down Syndrome Congress**

[www.ndscenter.org](http://www.ndscenter.org)

**Down Syndrome International**

[www.ds-int.org](http://www.ds-int.org)

**Massachusetts Department of Public Health**

[www.mass.gov/dph/downsyndrome](http://www.mass.gov/dph/downsyndrome)

**Massachusetts Down Syndrome Congress**

[www.mdsc.org](http://www.mdsc.org)



MASSACHUSETTS GENERAL HOSPITAL

ACADEMY

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Advanced teaching methods, an interactive learning format, and focus on solving real-world, practice-related challenges give the MGH Academy international recognition for helping providers effectively diagnose and treat a compendium of diseases and illnesses.

### SOURCES / REFERENCES

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Learn more at [www.mghacademy.org/downsyndrome](http://www.mghacademy.org/downsyndrome)