

INVESTMENT IN RESEARCH SAVES LIVES AND MONEY

Down syndrome

Down syndrome, also known as trisomy 21, is a genetic condition that occurs when an individual is born with three copies of chromosome 21 instead of two.¹ The condition is associated with a number of physical, developmental, and cognitive delays, but people with Down syndrome have a wide range of abilities and skill levels. Research has the potential to improve medical care and health outcomes, and elongate lifespan for people with Down syndrome.

TODAY

Down syndrome affects approximately

1 out of every 700

infants born in the U.S.²

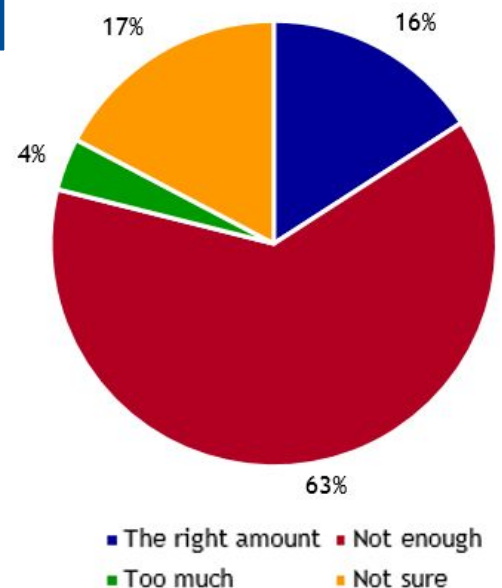
About **50%** of infants with Down syndrome in the U.S. are born with congenital heart defects that require surgery. Due to research and advances made in pediatric heart surgery and access to medical care, the vast majority of these heart defects are correctable.³

Individuals with Down syndrome face an increased risk of numerous diseases and disabilities, including hearing loss and ear infections, obstructive sleep apnea (OSA), vision issues, childhood leukemia, and thyroid disease.³

COST

On average, parents of children with Down syndrome pay an **additional \$84 per month** for out-of-pocket medical expenses compared to parents of children without Down syndrome.⁴

The U.S. spends about 5 cents of each health dollar on research to prevent, cure and treat disease and disability. Do you think that this is too much, the right amount, or not enough?



Research Paving the Way for Care

People with Down syndrome are **highly predisposed** to certain diseases (e.g. Alzheimer's disease, thyroid conditions, leukemia, and others),^{5,6} yet are **highly protected** from developing other diseases such as solid tumor cancers and certain heart attacks and stroke.^{7,8,9} By studying people with Down syndrome, we can not only improve their health but that of millions of other Americans as well.

A recent, groundbreaking study conducted by the Linda Crnic Institute for Down Syndrome at the University of Colorado School of Medicine Anschutz Medical Campus showed that Down syndrome can be understood in large measure as an immune system disorder.¹⁰ The findings provide an important clue as to why nearly all people with Down syndrome are susceptible to autoimmune disorders like thyroid disease, and why they are protected from developing solid tumors such as breast and prostate cancer.

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2019.

Down syndrome

Then. Now. Imagine.

THEN

In 1983, the average lifespan of a person with Down syndrome was 25 years.¹¹

NOW

Today, due to ongoing research efforts, increased access to care, and improved medical care, the current average lifespan for those with Down syndrome in the U.S. is 60 years.¹²

IMAGINE

Fully closing the life expectancy gap for individuals with Down syndrome.

Spotlight on Collaborative Research

In June 2018, the National Institutes of Health (NIH) launched the **INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome)** project in support of a Congressional directive calling for a new trans-NIH research initiative on critical health and quality-of-life needs for individuals with Down syndrome. An important support tool for INCLUDE is the NIH Down syndrome registry called DS-Connect® that connects individuals with Down syndrome and their families to scientists and their research.¹³

INCLUDE will investigate conditions that affect individuals with Down syndrome and the general population and will:

- **Conduct targeted, high-risk, high-reward basic science studies on chromosome 21.**
- **Assemble a large study population of individuals with Down syndrome.**
- **Include individuals with Down syndrome in existing clinical trials.**

Increased Health Risks for People with Down Syndrome

Figure 1: Comorbidities and medical complications of 1,108 children treated in the Site Center for Down syndrome at Children's Hospital Colorado

Co-Occurring Condition	%
GI Diagnosis	69.1%
Obstructive Sleep Apnea	66.1%
Cardia defects	64.4%
ENT: Tonsillectomy and/or adenoidectomy	47.1%
Autoimmune diagnosis	36.9%
Feeding problem	28.8%
Hypothyroidism	27.3%
Aspiration	12.2%
Autism	3.4%
Infantile Spasms	2.7%
Leukemia	1.5%

SOURCE: Hickey F, Wolter-Warmerdam K, Hickey E, Yoon J, Daniels D (2017) Pediatric Comorbidities and Medical Complications Identified in Children with Down Syndrome. J Down Syndr Chr Abnorm 3: 124. doi:10.4172/2472-1115.1000124

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Research!America 241 18th St S, Arlington, VA 22202 | 703.739.2577
www.researchamerica.org | info@researchamerica.org

The Albert and Mary Lasker Foundation is a founding partner in this series of fact sheets. www.laskerfoundation.org

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