

C O N G R E S S W O M A N

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**RODGERS**

PROUDLY REPRESENTING EASTERN WASHINGTON



**Testimony Before the United States House of Representatives**

**Committee on Appropriations**

**Subcommittee on Labor, Health and Human Services, Education, and Related  
Agencies**

Down Syndrome: Update on the State of the Science and Potential for Discoveries  
Across Other Major Diseases

Testimony of:

Representative Cathy McMorris Rodgers (WA-5)

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Thank you Chairman Cole and Ranking Member DeLauro for holding this hearing highlighting the tremendous potential of Down syndrome research -- not just for those with Down Syndrome -- but for millions of others who could benefit from what we learn.

Ten years ago, our oldest son Cole was born and tested positive for an extra 21st Chromosome known as Trisomy 21 or Down syndrome. Today, Cole is a happy, healthy 5th grader. He's mastered his multiplication table such that classmates want him to be on their team for quizzes. He's in Cub scouts and loves to play basketball. Without medical research, children like Cole wouldn't have the opportunities that they have today.

Down syndrome's discovery began with Dr. John Langdon Down in 1866. This brilliant English doctor of the Royal London Hospital laid the groundwork for what would become a rich history of dramatic medical breakthroughs.

In the 1950s, it led to the discovery that humans have 46 chromosomes in each cell, but an individual with Down syndrome has 47. And in 2000, an international team of scientists successfully identified and catalogued each of the approximately 329 genes on chromosome 21.

As a mom and a member of Congress, I have dedicated my time to advocating for **more** research to **improve** outcomes and **increase** opportunities for those born with Down syndrome. Today, there's still more we can discover.

Consider this:

Fifty percent of babies with Down syndrome are born with congenital heart defects although there's no case of someone with Down syndrome suffering from a heart attack.

Children with Down syndrome have a higher likelihood of developing juvenile leukemia although those with Down syndrome do not have solid tumor cancers.

And, thanks to improved medical care, eighty percent of adults with Down syndrome live beyond sixty years compared to 1960, when on average, a person would live to be only ten years old. This is a dramatic increase in life expectancy; however, almost every individual develops Alzheimer's or dementia.

Even though Congress has substantially and consistently increased the NIH budget in recent years -- in large part thanks to the work done on this very subcommittee --

funding for Down syndrome research makes up less than one hundredth of a percent of the total budget. The year Cole was born, the NIH provided \$16 million dollars for Down syndrome research. Today, it is approximately \$28 million dollars. With more than 400,000 Americans living with Down syndrome, that's less than \$100 of research per individual.

By comparison, approximately 1.5 million people live with Autism, which receives \$243 million.

Cystic Fibrosis receives \$91 million -- and affects nearly 30,000.

And, Fragile X research is funded at \$46 million with an estimated 50,000 people living with the disease across the nation.

With additional funding, more new and innovative research could take place. A great example is Global Down Syndrome's Human Trisomy Project -- an ambitious longitudinal and cross-sectional study of several layers of genomics information from 1,000 individuals with Down syndrome and 500 typical individuals. This research will help us understand why individuals with Down syndrome are protected from some medical conditions and diseases, while highly predisposed to others. The results won't just help those with Down syndrome, but also millions of others with life-threatening diseases through the potential development of new diagnostic and therapeutic tools.

**Therefore, my question to this committee is why aren't we dedicating more research to continue to unlock these mysteries of the 21st chromosome?**

I urge my colleagues to consider increased NIH funding for Down syndrome research, especially studies that incorporate much needed cross-institute collaboration. The history of research related to Down syndrome and the 21st chromosome is rich with breakthroughs and dramatic outcomes. Let's go unlock some more. Thank you.