

Opening Remarks
Chair Cathy McMorris Rodgers
Health Subcommittee Legislative Hearing: Proposals to
Support Patients and Caregivers
February 14, 2024
As Prepared for Delivery

INTRODUCTION:

Good morning.

As I've said many times before, this committee has a rich history of plowing the hard ground necessary to legislate.

I'm proud of our efforts so far this Congress—like *the Lower Costs, More Transparency Act*—which are fundamental to driving down the cost of care and fixing our broken health care system.

Today, we'll continue this work by considering 19 bipartisan bills that support patients, caregivers, and health care providers.

PUBLIC HEALTH TOPICS

Specifically, we will examine proposals to help improve our understanding of various diseases, disabilities, chronic conditions, and stillbirths.

We'll look at legislation to continue support for emergency medical services and health care providers...

... to reauthorize respite care resources for family caregivers...

...and to prevent organ transplant candidates from being denied a transplant based solely on having a disability.

I look forward to hearing from our witnesses about the importance of these programs.

INCLUDE ACT

I'm particularly excited that we are moving forward with the DeOndra Dixon INCLUDE Project Act of 2024 that I've introduced with Representatives Diana DeGette, Tom Cole, and Eleanor Holmes Norton.

My mission of improving the lives of individuals with disabilities is no secret and is deeply personal.

That's why I'm proud to champion this bill that would provide important Congressional oversight and direction for the INCLUDE Project at the National Institutes of Health.

Established by a Congressional directive in 2018, INCLUDE, also known as the Investigation of Co-occurring Conditions Across the Lifespan to Understand Down Syndrome Project, conducts research on critical health and quality-of-life needs for individuals with Down syndrome throughout their lives.

At the time INCLUDE was established, Down Syndrome was among one of the least studied and funded genetic conditions at

the NIH, despite it being one of the most common chromosome abnormalities.

I can't stress enough how important it was that Congress took action then to make studying Down syndrome a priority at the NIH.

Individuals with Down syndrome are affected by many of the same diseases and conditions that are the focus of the programs we are examining today.

However, those diseases may affect those with Down syndrome differently, require different strategies to treat, or may appear more often in those with Down syndrome than in the general population, as is the case with Alzheimer's disease.

For a neurological disease like Alzheimer's, it may take new tools and strategies to know if a treatment is working.

Individuals with Down syndrome are living longer than ever, and the NIH needs to help push forward meaningful research that will benefit those with Down syndrome and their families in all stages of their lives.

It is important that we also acknowledge this research could benefit the millions of people who battle conditions—like Alzheimer's, cancer, and heart conditions—that are common among, but hardly limited to people with Down syndrome.

Our bipartisan legislation directing the NIH to continue this important work will help us take Down syndrome research to new

heights and usher in a new era of innovation...

...to help everyone with Down syndrome—and their families—live their lives to their fullest potential.

CONCLUSION:

Given my recent announcement, I'd also like to thank everyone for the kind messages over the last few days. More than anything, my heart is filled with gratitude for having the chance to serve alongside all of you on the best Committee on Capitol Hill... as we work to deliver for the American people.

We still have a lot of work ahead, including these important bipartisan bills before us today, and I am looking forward to continuing our work over the rest of this Congress to improve the lives of the American people.

I thank the witnesses for being here today and look forward to your testimony.