

**Cathy McMorris Rodgers**  
**House Energy and Commerce Committee**  
**Subcommittee on Health**  
**“The Path Forward: Advancing Treatments and Cures for**  
**Neurodegenerative Diseases”**  
**July 29, 2021**  
*As Prepared for Delivery*

**INTRO**

Thank you, Madam Chair.

I was thinking this morning of our work before the pandemic...

... and the many meetings we’ve all had to listen to advocates fighting for cures and treatments.

Hundreds of disease and rare disease groups came to the People’s House for the opportunity to share their stories with us.

Advocates like my friend from Spokane, Gail Gleason... Steve Gleason’s mom.

They—like millions of other people—have an extraordinary amount of hope in the promise of American innovation.

Whether it’s ALS, Alzheimer’s, Huntington’s, or another disease....

... the hope for lifesaving treatments and cures is here... **in America.**

We cannot forget that. We have led the world.

**America** is where hope becomes a reality.

## **H.R. 3**

That brings me to H.R. 3, Speaker Pelosi's radical government price controls for prescription drugs.

As one mom told this subcommittee, research will stall under H.R. 3.

She said countries with prices controls are quote, "innovation deserts" and "innovation deserts are relentless when you need access to a rare disease treatment to save your children."

Her son's name is Hunter. He has spinal muscular atrophy and he is alive today because of a breakthrough treatment.

For children like Hunter... it would be devastating if socialist price controls were jammed in the Democrat's reckless tax and spending spree.

It would lead to less innovation, fewer cures, and no hope for many people who deserve a fighting chance at life.

For that fighting chance, we should be working on bipartisan solutions like H.R. 19, the Lower Costs, More Cures Act.

## **DOWN SYNDROME**

In addition, we should be leading in a bipartisan way to fund more basic research...

... support research around the causes of diseases...

... and unleash the private sector just like we did for the COVID-19 vaccines.

This is very personal for me.

My son Cole has Down syndrome.

It's the most common chromosomal abnormality, yet there's still a lot we don't know about it and the extra 21<sup>st</sup> chromosome.

For example, the scientific community has acknowledged that 100 percent of people with Down syndrome will develop the brain pathology of Alzheimer's in their lifetime.

But, about only half will experience symptoms of dementia.

The reason for this is still not understood.

Imagine what it would mean if we unlocked the mysteries of the 21<sup>st</sup> chromosome?

It could lead to major medical discoveries—maybe even a cure for a disease like Alzheimer's.

That's why I was surprised to see the Biden budget propose to move the NIH's INCLUDE program from the Office of the Director to the National Institute of Child Health and Human Development, without any explanation. What problem does this reorganization

solve, and will the same cross institute center collaboration and coordination continue?

This program has been one of my top priorities, and I am disappointed that, if there were concerns with it, NIH didn't consult with Congress.

## **NIH**

I want to be very clear. I have historically been a champion for NIH.

But the NIH is on the verge of a trust crisis with this Committee and the American people.

This is a warning.

Proposing moving a program like INCLUDE with no consultation with authorizing committees in Congress is one thing.

Another is the lack of respect for congressional oversight for how NIH research money is received and spent.

To inform a scientific and objective investigation into the origins of COVID-19, I have made many requests to the NIH public servants to be transparent and provide documents.

We have received no documents, including for grant documents releasable to the general public under federal law.

This is unacceptable. I've told Dr. Collins this directly when we spoke about ARPA-H.

President Biden has requested more than \$6 billion dollars for ARPA-H with even less accountability and transparency than what we have now.

If I were to support this, I need more confidence and trust in the oversight and management of the \$44 billion in taxpayer funding going to NIH now... including a clear picture on how much of that goes toward research in China.

## **CONCLUSION**

I'll close by thanking our patients, families, caregivers, and researchers with us today.

I'm grateful that you are here.

I share in your mission to unleash American innovation, support clinical trials, and improve early diagnosis.

It's why I'm passionate about making sure NIH research dollars are spent wisely and with accountability...

.... and that we do all we can to enable the private sector to tackle diseases we are discussing today with the same sense of urgency we had with COVID-19.

I yield back.