

**Opening Remarks  
Chair Cathy McMorris Rodgers  
Health Subcommittee Markup  
May 16, 2024**

**Telehealth**

Good morning, and thank you Chair Guthrie.

Today we will consider bipartisan legislation to extend telehealth flexibilities that are set to expire at the end of this year.

While continuing these flexibilities for seniors will require an investment by Congress, it is crucial that we continue to allow seniors to access health care via telehealth if they choose.

The bills we are considering today will protect seniors access to telehealth for an additional two years.

They improve upon the bipartisan work of past Congresses by adding new program integrity safe-guards, and some of the bills will also expand how seniors can benefit from telehealth.

I commend Representatives Carter, Joyce, Balderson, James, Bilirakis, and the many other members on both sides of the aisle for their continued hard work on advancing these policies.

Telehealth has proven to be vital for patients across the country—especially in rural areas, like my district in Eastern Washington.

I look forward to advancing this legislation today...  
....and am committed to continue working to address any outstanding concerns, and to ensuring the legislation is fully paid for, before we consider them at the full committee.

## **Public Health**

I am also pleased we are considering several bipartisan bills to support and build upon efforts to increase access to care, raise awareness, and improve coordination across our federal government for programs related to autism and lung cancer.

## **FDA**

Lastly, the committee is working on a six-year reauthorization of the rare pediatric disease priority review voucher program ahead of its Sept. 30 expiration.

We've heard testimony on the importance of this program, and this week the Dion [DEE-ON] family has been meeting with offices to share their story.

When Peter and Maggie Dion [DEE-ON] were born, they were each discharged from the hospital with a clean bill of health and initially seemed to hit their developmental milestones.

Peter loved to fish for tuna with his dad. Maggie enjoyed dance and running with her mom.

Everything changed when Peter was almost 10 and was struggling to climb up a set of stairs.

Peter was diagnosed with a form of muscular dystrophy, limb-girdle type 2C.

Later that year, his then six-year-old sister Maggie was also diagnosed with the same disease.

This type of muscular dystrophy is a rapidly progressive muscle wasting disease, and there is currently no cure.

As their father put it, there are so many genetic variations, doctors ran out of letters in the alphabet to identify the condition.

The prevalence of the disease is low as is.

And with over 30 subtypes of the disease, each requiring a different gene replacement therapy, spurring the much-needed research and development proves challenging without additional incentives.

Without the Rare Pediatric Disease Priority Review Voucher Program, Maggie and Peter's parents say their chances of getting treatments for their kids becomes almost impossible.

For anyone who doubts why this program is needed, I urge you to consider the Dion [DEE-ON] family and their story.

And, sadly, it is a story known to many families.

Just this week, the National Organization of Rare Diseases, which represents patients with rare diseases and their families, released analysis of the importance of the P-R-V program.

It is clear from their analysis that the program is successful, but the report also provides important insights on how long it can take to see that success.

Drugs take years—and hundreds of millions...or even billions of dollars—to develop.

While the rare pediatric P-R-V program was started in 2012, more than half of the designations, awards, and voucher redemptions came in the last four years.

I want to thank Mr. Bilirakis, Ms. Eshoo, and many others for all their work on the rare disease legislation being considered today.

These bills will strengthen the orphan drug pathway, make sure drugs are studied for children battling cancer, and continue the important PRV program.

## **CONCLUSION**

I am proud of all the work and patient voices reflected in the legislation before us today.

I also know that more can and should be done.

This subcommittee has heard testimony on many other proposals, such as my legislation to improve access to home and community-based services in Medicaid.

I look forward to continuing to work with members to move those forward in the future.

Thank you, and I yield back.