

Hearing on Biomedical Research Related to Down Syndrome

Testimony from Congresswoman Cheri Bustos (IL-17), Co-Chair, Congressional Task Force on Down Syndrome

Thank you Chairman Cole and Ranking Member DeLauro for hosting this hearing today.

Back home in rural Illinois, we teach our sons and daughters to lift each other up – to build strong communities and make sure everyone has a chance to succeed, no matter where they come from.

And so it's very important to me that we treat every American with the value and respect that they deserve.

I'm a co-chair of the Congressional Task Force on Down Syndrome because I think this is the right thing to do.

And I'm honored to join you here today.

I've met some amazing families and wonderful children with Down Syndrome through this Task Force.

One of my favorite stories is of a girl I met named Brianna who was in town to see Congress pass the ABLE Act, which gave tax advantages to the savings account of people with disabilities.

Her family was visiting Washington and one of my colleagues brought her onto to the House floor as we voted on this bill.

I fell for her right away.

I swiped my voting card and told her she should press the button to vote for me. As she pressed the button, the entire gallery erupted in cheers and applause.

She had just cast the vote that passed the bill.

To this day I am in touch with Brianna and her family.

There are some things about people with Down Syndrome that I'm sure everyone knows:

They light up any room they walk into.

They love unconditionally.

And they often live long, happy, successful lives.

But here's some other facts about Down Syndrome.

It's the leading cause of developmental delay in the United States.

It's becoming more common.

And while National Institute of Health funding has seen tremendous growth over the last 20 years, the funding for Down Syndrome research has remained relatively flat.

Just yesterday I spoke with Briana's father, Brad. He shared that the whole family was diagnosed with Lyme Disease six months ago.

Everyone else has recovered, but Brianna is still having a rough go of it.

Six months after her diagnosis, she is still struggling to walk.

Brad has to carry her to and from the kitchen table, the bathroom, and her bed.

That's because people with Down Syndrome have weaker immune systems.

There's very little research into that aspect of the condition.

Today's testimonies will show why it's so important to fix that.

Folks with Down Syndrome have some remarkable differences in their health compared to the rest of us.

They are nearly immune to some of the most common health threats that the rest of us deal with.

They are naturally resistant to almost all forms of cancer. They almost never suffer heart attacks.

And high blood pressure is virtually unheard of.

Developing a better understanding of Down Syndrome may help scientists find breakthroughs to fight cancer and heart attacks, which affect so many of our loved ones.

Additionally, we must do more to help those with Down Syndrome lead longer and healthier lives.

I'm sure all of us have seen a family member or close friend deal with the impact of Alzheimer's or dementia.

Right now, close to one hundred percent of folks with Down Syndrome will display signs of Alzheimer's by their forties.

And we must make solving this challenge a top priority. We need more research into Down Syndrome, not less.

With a stronger commitment from Congress to support Down Syndrome Research throughout the National Institute of Health, we could be even closer to solving the great health problems of our time.

And make a big difference in the lives of families like Briana's who deal with the challenges of Down Syndrome every day.

Thank you. I yield back.