



# Chairman Tom Cole

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

**Hearing: Down Syndrome: Update on the State of the Science and Potential for Discoveries  
Across Other Major Diseases  
October 25, 2017  
Opening Statement As Prepared**

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Good morning. It is my pleasure to welcome you all to the Subcommittee on Labor, Health and Human Services and Education for a hearing to discuss the state of the science for Down syndrome research. This hearing is timely, as October is Down Syndrome Awareness Month, which is a time to expand awareness of the accomplishments and abilities of people with Down syndrome.

Today, we will have two panels of witnesses. The first panel includes three fellow members of Congress who are tireless advocates for improving the lives of individuals with Down syndrome. The second panel includes researchers and advocates who are committed to expanding our knowledge about Down syndrome and related disorders and improving the quality of life for Americans with Down syndrome.

Research on Down syndrome is increasingly important because as the number of births of babies with Down syndrome increases and the life span of individuals with Down syndrome expands, we are likely to see a large increase in the number of Americans living with Down syndrome. Research targeted at further understanding this disorder will contribute to improving the lives of individuals with Down syndrome.

Additionally, recent discoveries suggest that Down syndrome research has the potential to contribute to our knowledge of a variety of other diseases and disorders that affect all Americans. We will hear more about this exciting research today.

I'm pleased to introduce the witnesses on our first panel.

Mr. Pete Sessions is the Chairman of the House Committee on Rules and is the proud father of a young man by the name of Alex, who has Down syndrome. Mr. Sessions has been a passionate advocate and leader in Congress for people with disabilities. As the lead sponsor, he worked tirelessly to enact the Family Opportunity Act in 2006, which gives states the option to create a Medicaid "buy in" for low- to moderate-income families of children with disabilities. He is a co-chair of the Congressional Down Syndrome Caucus, serves as an Advisor to the President for Special Olympics Texas, and has served as a board member of Best Buddies International.

Ms. Cheri Bustos represents Illinois' 17<sup>th</sup> Congressional District and is the Co-Chair of the Democratic Policy and Communications Committee. She is also a co-chair of the Congressional Down Syndrome Caucus.

Ms. Cathy McMorris Rodgers is Eastern Washington's chief advocate in Congress. As Chair of the House Republican Conference, she is the fourth highest-ranking Republican in the House and the highest-ranking woman in Congress. In 2007, she gave birth to Cole Rodgers. Cole was born with Trisomy 21 and inspired McMorris Rodgers to become a leader in the disabilities community. She is also a co-chair of the Congressional Down Syndrome Caucus and played an instrumental role in securing final passage of the ABLE Act in 2014, which created tax-free savings accounts to empower individuals with disabilities to save and invest in their futures.

After that, we will welcome our second panel.

Ms. Michelle Sie Whitten is the Co-Founder, President, and CEO of the Global Down Syndrome Foundation, as well as the Executive Director of the Anna and John J. Sie Foundation, which is the largest private funder of grants for Down syndrome-related research and programs.

Dr. Joaquin Espinosa is the Executive Director of the Linda Crnic Institute for Down Syndrome. He is also a Professor in the Department of Pharmacology at the University of Colorado Anschutz Medical Campus School of Medicine.

Dr. William Mobley is a Distinguished Professor and Chair of the Department of Neurosciences at UC San Diego. He also serves as the Executive Director of UCSD's Down Syndrome Center for Research and Treatment and is the Florence Riford Chair of Alzheimer's Disease Research.

Mr. Frank Stephens was awarded the Quincy Jones Excellence in Advocacy Award by the Global Down Syndrome Foundation in 2016. As an advocate, he has spoken all over North America and Europe promoting the inclusion of individuals with intellectual disabilities.

As a reminder to everyone, we will abide by the 5 minute rule so that we will be able to keep closely to the schedule we outlined for Members. Before we begin, I'd like to turn to my Ranking Member for any remarks she'd care to make.

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