<u>Home</u> > House Appropriations Committee Explores Link Between Down Syndrome and Finding a Cure for Alzheimer's Disease

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January 12, 2018 by Natalie Barry [2]

The House Appropriations Labor-HHS-Education Subcommittee held the first-ever Congressional hearing on Down syndrome research – focusing on a research project developed on the CU Anschutz Medical Campus. The October hearing gave lawmakers a chance to hear first-hand about the enormous scientific potential of the Human Trisome Project, an effort by CU's Linda Crnic Institute for Down Syndrome [3] to build a cohort study of individuals with the condition that causes Down syndrome – Trisomy 21.

Among those who testified at the hearing were Dr. Joaquin Espinosa, PhD, executive director of the Crnic Institute and Michelle Sie Whitten, president and co-founder of the Global Down Syndrome Foundation [4], which funds and supports the Human Trisome Project (HTP) [5].

The hearing focused not only on how the HTP might lead to treatments that help people with Down syndrome lead a better life, but also how this scientific research may shed light on diseases that afflict millions of Americans. People with Down syndrome have extremely high rates of early-onset Alzheimer's disease, and researchers at CU Anschutz Medical Campus hope that understanding how Trisomy 21 leads to Alzheimer's will also help them find new cures and treatments. Likewise, people with Down syndrome have fewer solid tumors, lower rates of heart disease, and unusual rates of a number of other conditions that may be tied to Trisomy 21. Dr. Espinosa discussed the important opportunity represented by this work in his testimony [6].

Frank Stephens, a noted self-advocates for persons with Down syndrome, received a standing ovation from the entire committee as well as staff and guests in attendance.

Congressman Mike Coffman attended the hearing to introduce Ms. Whitten and Dr. Espinosa. Also attending the event were Representatives Cathy McMorris-Rodgers, Pete Sessions, and Cheri Bustos – all noted advocates for individuals with Down syndrome in Congress.

A C-Span video of the hearing can be found here [7].



House Labor-HHS-Education Appropriations Subcommittee Chairman Tom Cole, Down Syndrome self-advocate Frank Stephens, CU Anschutz's Dr. Joaquin Espinosa, and Global Down Syndrome Foundation President Michelle Sie Whitten

Global Down Syndrome Foundation

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