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RANKING MEMBER

ONE HUNDRED EIGHTEENTH CONGRESS  
**Congress of the United States**  
**House of Representatives**  
COMMITTEE ON ENERGY AND COMMERCE  
2125 RAYBURN HOUSE OFFICE BUILDING  
WASHINGTON, DC 20515-6115  
Majority (202) 225-3641  
Minority (202) 225-2927

April 16, 2024

Ms. Michelle Whitten  
President, CEO, and Co-Founder  
Global Down Syndrome Foundation  
3239 East 2nd Avenue  
Denver, CO 80206

Dear Ms. Whitten:

Thank you for appearing before the Subcommittee on Health on Wednesday, February 14, 2024, to testify at the hearing entitled “Legislative Proposals to Support Patients and Caregivers.”

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and (3) your answer to that question in plain text.

To facilitate the printing of the hearing record, please respond to these questions with a transmittal letter by the close of business on Wednesday, May 1, 2024. Your responses should be mailed to Emma Schultheis, Legislative Clerk, Committee on Energy and Commerce, 2125 Rayburn House Office Building, Washington, DC 20515 and e-mailed in Word format to [Emma.Schultheis@mail.house.gov](mailto:Emma.Schultheis@mail.house.gov).

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,



Brett Guthrie  
Chair  
Subcommittee on Health

cc: Anna Eshoo, Ranking Member, Subcommittee on Health

Attachment

## **Attachment — Additional Questions for the Record**

### **The Honorable Robert Latta**

1. People with Down syndrome are the largest population with a genetic predisposition to Alzheimer's disease yet for decades were not included in this vital research. Can you share in more detail how the INCLUDE initiative and the legislation before the committee today will advance science and lead to the discovery of Alzheimer's disease treatments for people with Down syndrome and typical Americans?
2. Prior to INCLUDE, there were few if any Down syndrome clinical trials and most clinical trials excluded people with Down syndrome from participating. In the six years since INCLUDE was established, there are now at least 12 clinical trials that include repurposed drugs to treat autoimmune diseases, Alzheimer's, cognition deficit, and Regression Disorder. Can you explain the role that INCLUDE has played in this turnaround and how the bill will continue this important work?
3. It is my understanding that people with Down syndrome may not respond to certain FDA approved treatments that are prescribed for typical people and in some instances FDA approved treatments for certain chronic diseases can even be harmful for people with Down syndrome. Can you share more detail on the types of drugs and conditions that GLOBAL is studying and what your scientists are learning as a result of support provided as part of INCLUDE?
4. People with Down syndrome are highly protected from developing solid tumors – like breast cancer or prostate cancer – yet are highly predisposed to certain blood cancers like acute megakaryoblastic leukemia (AMKL) and acute lymphoid leukemia (ALL). Can you explain the connection and how INCLUDE supported research is unlocking these secrets and pointing us in the direction of new treatments?

### **The Honorable Gus Bilirakis**

1. Thank you for your support of the Congenital Heart Futures Reauthorization Act of 2024. Can you provide any insight or recommendations for how you believe we can improve the existing Congenital Heart Defect program at the CDC and explain why we need to better educate the public about the challenges that persist for congenital heart patients, especially patients with Down Syndrome?

**The Honorable Neal Dunn, M.D.**

1. Genetic counselors play an essential role when there are genetic aspects to disease and conditions. They ensure patients and family members who would benefit from genetic testing gain access to appropriate testing and ensure physicians and their patients understand test results well. Genetic counselors also help navigate follow-up care and identify clinical trials that may be of benefit. Today, Medicare does not reimburse genetic counselor services. Should this policy change?