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 18, 2024

Dr. Alexander Bassuk, M.D., Ph.D. Physician-in-Chief, University of Iowa Stead Family Children's Hospital Chair and Professor, Stead Family Department of Pediatrics 200 Hawkins Drive Iowa City, IA 52242

Dear Dr. Bassuk:

Thank you for appearing before the Subcommittee on Health on Thursday, February 29, 2024, to testify at the hearing entitled "Legislative Proposals to Support Patients with Rare Diseases."

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 Thursday, May 2, 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.

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

Sincerely,

Brest Author

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. By improving the process for enabling an out of state provider to enroll as a participating provider in the State Medicaid program for purposes of being reimbursed for treating children with deadly cancers like brain tumors, will these pediatric patients have a better chance of accessing state of the art care and clinical trials?

The Honorable Gus Bilirakis

- 1. As medicine gets more personalized with innovative cell and gene therapies, how will the Accelerating Kids Access to Care Act help alleviate regulatory barriers to ensure these new innovations are available to rare disease patients that need it?
- 2. What are some additional ways we can reduce regulatory barriers beyond Medicaid, such as at the FDA or elsewhere in the health care system, to help pediatric rare patients?

The Honorable Larry Bucshon, M.D.

1. Do you think Medicare provider status and reimbursement of genetic counselor services would improve your patient care?