

Congress of the United States
Washington, DC 20515

July 2, 2019

Honorable Alex M. Azar II
Department of Health and Human Services
200 Independence Ave S.W.
Washington D.C. 20201

Dear Secretary Azar,

As Members of Congress who value the critical role played by the National Institutes of Health (NIH) in advancing better health outcomes through cutting-edge research, we urge you to promote a full range of scientific research, which is why we are strongly opposed to the new restrictions on the use of fetal tissue.

Our message is simple: fetal tissue and cells that would otherwise be discarded play a vital role in modern, cutting-edge medical research. The limitations on intramural research at the NIH outlined in your announcement will obstruct research that is necessary for the development of new treatments for serious and incurable diseases that impact millions of patients, including research into treatment for Alzheimer's disease, eye disease, infant mortality and birth defects. The research terminated at the University of California at San Francisco (UCSF) was testing potential therapies to find a cure for HIV, ending a 30-year partnership between the NIH and UCSF.

In addition to our concerns over the limits imposed on intramural research, we are interested in learning more about how HHS intends to apply new levels of review through an Ethics Advisory Board to proposals for extramural funding. Rigorous legal and ethical oversight of fetal tissue research has been in place for decades. We are extremely concerned that these additional reviews will delay the development of new medical treatments needlessly extending the suffering of countless patients.

Research using fetal tissue has saved millions of lives through the development of vaccines for diseases that once ravaged communities across the world. Polio is now almost eradicated, and rubella, measles, chickenpox, and rabies are all preventable diseases because of fetal tissue research. Today, fetal tissue is still making an impact, with clinical trials underway using cells from fetal tissue to treat conditions including Parkinson's disease, ALS, and spinal cord injury. Fetal tissue is also being used to understand and to develop potential treatments for major global health problems such as Zika virus and HIV/AIDS. The elimination of long-standing federal funding will delay this critical research and set back the development of potential therapies for these and other infectious diseases.

To ensure Congressional oversight of this decision, we request answers to the following questions by July 12, 2019:

- HHS announced its new rules related to intramural and extramural research were developed through a policy process informed by an internal audit and comprehensive review of HHS research (initially launched in September of 2018). What did the audit and review entail? Where are the results of the audit and review?
- What other factors helped “inform the policy process that led to the administration’s decision to let the contract with UCSF expire and to discontinue intramural research?”
- The stated necessity of the audit and review was to “ensure consistency with statutes and regulations governing such research, and to ensure the adequacy of procedures and oversight of this research in light of the serious regulatory, moral, and ethical considerations involved.” What information was found from the audit and review? Did that information support the new rules?
- What are the names of staff from HHS who conducted the audit and review, and what are their scientific and legal qualifications?
- It was reported that HHS held “multiple listening sessions with various stakeholders [like] scientists, pro-life groups, ethicists, on this topic” as part of the audit and review process. What groups were in attendance during these sessions, what information was provided, where are the agendas from those meetings and what were the findings?
- Why were anti-choice advocacy groups consulted during the audit and review of scientific research, particularly as it relates to “consistency with statutes and regulations governing such research, and to ensure the adequacy of procedures and oversight”?
- What role did the September 2018 letter from anti-choice advocacy groups play in HHS’ decision to terminate the contract between Advanced Bioscience Resources, Inc. and the Food and Drug Administration, as well as launch the audit and review?
- Was there additional communication between HHS and anti-choice groups beyond the listening sessions throughout the audit and review process?
- Based on the information gathered through the audit and review, including the listening sessions, how will the new rules impact the development of important biomedical knowledge which cannot be obtained by other means for diseases impacting newborns, early child development, and incurable diseases like ALS, Spinal Muscular Atrophy, HIV, Parkinson’s Disease and Multiple Sclerosis?

The Administration’s action is a grave step backward for the millions of patients waiting for cures and treatments. We urge you to reconsider this policy shift and allow researchers to move forward with sound, responsible, and ethical science.

Sincerely,



Susan DeBene
Member of Congress



Jackie Speier
Member of Congress



Barbara Lee
Member of Congress



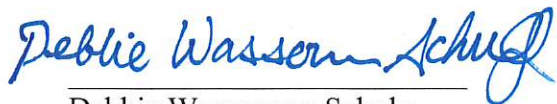
Jan Schakowsky
Member of Congress



Rick Larsen
Member of Congress



Peter Welch
Member of Congress



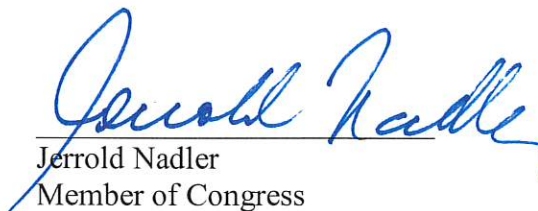
Debbie Wasserman Schulz
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Joe Neguse
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Robin L. Kelly
Member of Congress



Jerrold Nadler
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Ro Khanna
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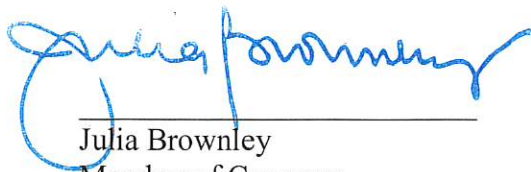
Eric Swalwell
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Kim Schrier, M.D.
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Ayanna Pressley
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Julia Brownley
Member of Congress



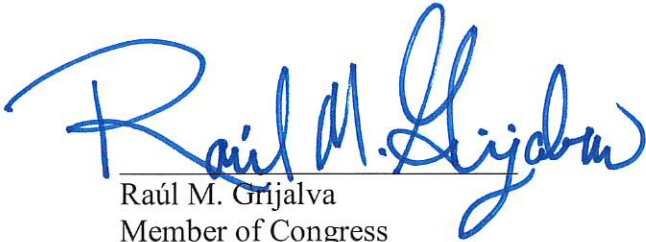
Katherine Clark
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Eleanor Holmes Norton
Member of Congress



Adriano Espaillat
Member of Congress



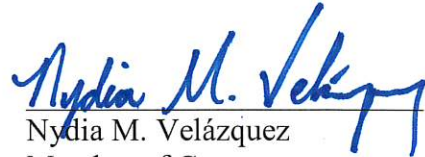
Raúl M. Grijalva
Member of Congress



Sean Casten
Member of Congress



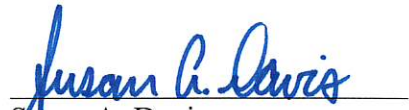
Sean Patrick Maloney
Member of Congress



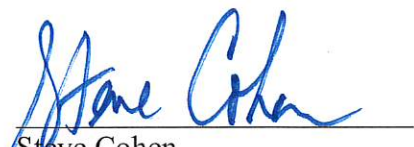
Nydia M. Velázquez
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Mark Pocan
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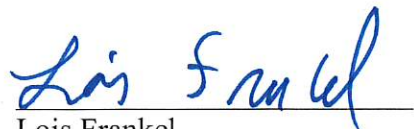
Susan A. Davis
Member of Congress



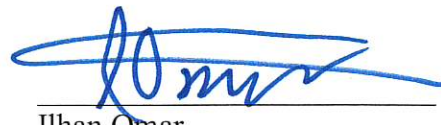
Steve Cohen
Member of Congress



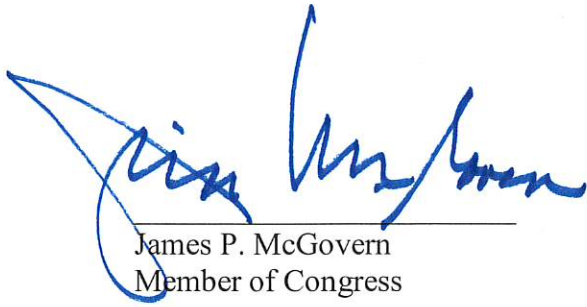
Bill Foster
Member of Congress



Lois Frankel
Member of Congress



Ilhan Omar
Member of Congress



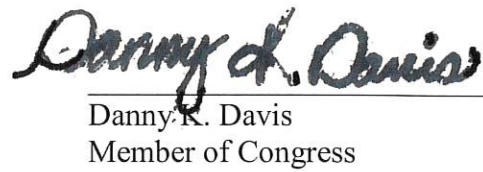
James P. McGovern
Member of Congress



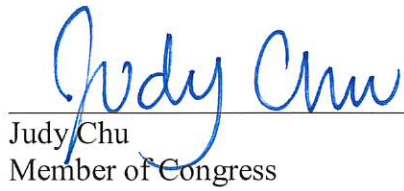
Denny Heck
Member of Congress



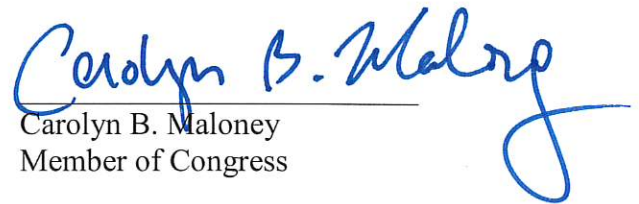
Jamie Raskin
Member of Congress



Danny K. Davis
Member of Congress



Judy Chu
Member of Congress



Carolyn B. Maloney
Member of Congress