



June 12, 2019

OFFICERS

The Hon. Michael N. Castle, Chair
The Hon. John Edward Porter, Chair Emeritus
The Hon. Kweisi Mfume, Vice Chair
Mary Woolley, President
E. Albert Reece, MD, PhD, MBA, Secretary
Sudip S. Parikh, PhD, Treasurer

BOARD MEMBERS

Tenley E. Albright, MD
Georges C. Benjamin, MD
Nancy Brown
Susan Dentzer
Victor J. Dzau, MD
Susan Fitzpatrick, PhD
Jay A. Gershen, DDS, PhD
The Hon. Bart Gordon
William N. Hait, MD, PhD
Larry Hausner, MBA
Mary J.C. Hendrix, PhD
Martha N. Hill, RN, PhD
Rush D. Holt, PhD
Elizabeth Baker Keffer
Debra R. Lappin, JD
Alan I. Leshner, PhD
James L. Madara, MD
Lucinda Maine, PhD, RPh
Mark McClellan, MD, PhD
Herbert Pardes, MD
Harold L. Paz, MD, MS
Guillermo Prado, PhD
Derek Rapp
Gary M. Reedy
Amy Comstock Rick, JD
Laing Rogers
Larry J. Shapiro, MD
Gregory Sorensen, MD
Keith R. Yamamoto, PhD
Elias A. Zerhouni, MD

The Honorable Mark Pocan
1421 Longworth House Office Building
Washington, D.C. 20515

Dear Representative Pocan,

On behalf of Research!America, the nation's largest nonprofit alliance advocating for science, discovery and innovation to achieve better health for all, thank you for spearheading an amendment to the Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act, 2020 (H.R.2740) that would prevent a bureaucratic roadblock to life-saving medical research.

We appreciate your commitment, and that of the amendment's esteemed cosponsors, to the wellbeing of individuals facing debilitating and deadly health threats.

The federal government has funded fetal tissue research since the 1950s. Decades of thoughtful deliberation surrounding this research have produced an ethical framework under which valuable medical research has progressed, leading to critical new knowledge and the discovery of profoundly important medical advances. Unfortunately, the policy changes the Trump Administration announced on June 5 ignore this framework and the crucial and unique role fetal tissue research plays. Instead these changes erect roadblocks to current and future fetal tissue research, squandering progress at the expense of patients now and in the future.

We greatly appreciate your efforts to reduce the negative impact of the June 5 policy changes by offering an amendment that would prevent funding from being used to single out and disadvantage fetal tissue research studies, subjecting these studies to an additional, stultifying level of review regardless of their significance in advancing medical progress.

241 18th Street South
Suite 501
Arlington, VA 22202

P 703.739.2577

F 703.739.2372

E info@researchamerica.org

The positive impact of fetal tissue research is vast:

- It has contributed to the development of vaccines against polio, rubella, measles, chickenpox, adenovirus and rabies; treatments for debilitating diseases such as rheumatoid arthritis, cystic fibrosis and hemophilia; and a therapeutic regimen to prevent the transmission of HIV.
- Because of its critically important properties such as unique immune response and rapid cell replication, fetal tissue has been, and continues to be, particularly important in research focused on transplantation and regeneration. Clinical trials are underway using cells from fetal tissue as treatments for Amyotrophic Lateral Sclerosis (ALS), spinal cord injury, and Parkinson's disease.
- Fetal tissue research is also unique in revealing how human tissues develop and are impacted by disease. Using fetal tissue allows researchers to more fully understand congenital defects such as those of the heart or nervous system, and how viruses like Zika impact fetal development. In fact, the use of donated fetal tissue has been critical for understanding how Zika virus impacts human brain development.

The examples above are representative, but certainly not exhaustive. Fetal tissue research has contributed in profoundly important, unique ways to life-saving progress for decades. It is at work now bringing about crucial new insights and advances. The June 5 policy changes will bring broadly beneficial medical research to a halt. Patients across our nation and world do not have the luxury of time implied by these policy changes. They need research that delivers answers, and that's what fetal tissue research does.

Thank you again for taking a stand for patients by working to prevent harmful barriers to fetal tissue research.

Sincerely,

A handwritten signature in cursive script that reads "Mary Woolley".

Mary Woolley
President and CEO, Research!America

CC The Honorable Ted Deutch
The Honorable Suzan DelBene
The Honorable Jackie Speier
The Honorable Jamie Raskin
The Honorable Jerrold Nadler
The Honorable Diana DeGette
The Honorable Barbara Lee
The Honorable Zoe Lofgren
The Honorable Ro Khanna