August 31, 2020

The Honorable Alex Azar Secretary U.S. Department of Health & Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Secretary Azar,

On behalf of the scientific, medical, and patient communities dedicated to advancing human health, we write to express ongoing concerns about the NIH Human Fetal Tissue Ethics Advisory Board and its final report that would block funding for all but one research proposal seeking to use human fetal tissue. Given the unbalanced composition of the Ethics Advisory Board, we are concerned that the final report reflects a pre-determined objective that is impeding promising biomedical research that has the potential to save lives and reduce human suffering. Considering the medical and scientific significance of research using human fetal tissue, we urge you to use your authority under 42 U.S. Code § 289a–1(b) to reject the Ethics Advisory Board's recommendations to block specific research projects. Additionally, we ask that you immediately revoke the HHS policy restricting federal funding for biomedical research involving fetal tissue.

The evaluation process for publicly funded research must be insulated from politics and allowed to impartially identify promising research proposals that are ethically sound and scientifically and technically rigorous. This is fundamental to the meritocracy of American science that is envied around the world. In this case, each of the research proposals reviewed by the NIH Human Fetal Tissue Ethics Advisory Board had been peer-reviewed and deemed meritorious with the potential to advance scientific discovery to improve human health.

According to the Washington Post, five of the 15 members of the Ethics Advisory Board are affiliated with a single special interest group that advocates against using fetal tissue in research and that has no standing or expertise otherwise in the scientific community. We believe the lack of diverse perspectives and unbalanced composition of the Ethics Advisory Board prevented it from objectively evaluating most of the research proposals. The justification for the Ethics Advisory Board's recommendations were not adequately explained in the report, inhibiting public scrutiny of the rationale behind the recommendations. Additionally, the Ethics Advisory Board did not include a patient representative, a critical perspective for evaluating ethical considerations for research. In contrast, the review of fetal tissue research convened by President Ronald Reagan in 1988, led by a federal judge, included a diversity of perspectives from distinguished scientists and clinicians, patients, and multiple religious views. The Reagan panel ultimately supported fetal tissue research by an 18 to 3 vote and concluded in a detailed report that research using legally obtained human fetal tissue was ethical.

We are deeply concerned that the immediate and chilling effect of the Ethics Advisory Board's recommendations will limit the ethical use of an indispensable biomedical research tool and undermine medical advances in the United States. As our coalition noted during HHS's fetal tissue review, human fetal tissue has unique and valuable properties that cannot be replaced by other research materials or animal models. Cells from fetal tissue are more flexible and less specialized than cells from adult tissue and can be more readily grown in culture. This is part of the reason why fetal tissue was crucial for the development of vaccines against polio, rubella, measles, chickenpox, adenovirus, rabies, and treatments for debilitating diseases such as rheumatoid arthritis, cystic fibrosis, and hemophilia. Human fetal tissue remains necessary for ongoing research against viral diseases, understanding human development and its impact on disease, and research on potential treatments for Amyotrophic Lateral Sclerosis (ALS), spinal cord injury, and Parkinson's disease. As our coalition noted in March, which was also noted in the Ethics Advisory Board Report, fetal tissue research may be the key to discoveries that could help end the COVID-19 pandemic.

As organizations representing institutions, scientists, clinicians, and patients driven by a desire to improve the health and well-being of all, we hope you will make the health and safety of all Americans a priority. We urge you to immediately reject the recommendations of the NIH Human Fetal Tissue Ethics Advisory Board that would block funding for important research, and we ask you to revoke the HHS policy that restricts research using human fetal tissue. Thank you for considering our views.

## Sincerely,

AIDS Action Baltimore

AIDS Foundation Chicago

Alliance for Aging Research

American Academy of HIV Medicine

American Academy of Neurology

American Academy of Pediatrics

American Association for Anatomy

American Association for the Advancement of Science

American Association of Colleges of Pharmacy

American Brain Coalition

American College of Obstetricians and Gynecologists

American Institute of Biological Sciences

American Society for Cell Biology

American Society for Reproductive Medicine (ASRM)

American Society of Hematology

American Thoracic Society

Association of Public & Land-Grant Universities

Association of American Medical Colleges

Association of American Universities

Association of Independent Research Institutes

AVAC

Axis Advocacy

**Boston University** 

**Brown University** 

Coalition for the Life Sciences

Columbia University Irving Medical Center

Council on Governmental Relations

**Duke University** 

**Equity Forward** 

GLMA: Health Professionals Advancing LGBTQ Equality

Global Healthy Living Foundation

Harvard University

HealthHIV

**HIV Medicine Association** 

HIV+Aging Research Project-Palm Springs

Infectious Diseases Society of America

International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)

International Society for Stem Cell Research

ISCT, International Society for Cell & Gene Therapy

Jacobs Institute of Women's Health

Johns Hopkins University

Mass General Brigham Incorporated

Medical Students for Choice

**NASTAD** 

National Alliance on Mental Illness

**NMAC** 

Princeton

Research!America

Rutgers, The State University of New Jersey

Society for Maternal-Fetal Medicine

Society of Family Planning

Society of Toxicology

Stanford University

State University of New York

Stony Brook University

Texans for Cures

The Michael J. Fox Foundation for Parkinson's Research

The New York Stem Cell Foundation

Treatment Action Group

**Tulane University** 

UC San Francisco

UCLA

Union of Concerned Scientists

United States People Living with HIV Caucus

University at Buffalo

University of California San Diego

University of California System

University of California, Davis

University of California, Irvine

University of Massachusetts Medical School

University of Oregon

University of Pittsburgh

University of Rochester

University of Washington

University of Wisconsin-Madison

Weill Cornell Medicine

Yale University