

Testimony of
R. Alta Charo
before the Select Investigative Panel
of the
Energy and Commerce Committee
U.S. House of Representatives
2 March 2016
Washington DC

Madam Chair, Ranking Member Schakowsky, members of the Select Investigative Panel, thank you for allowing me to address you on research using fetal tissue. My name is Alta Charo. I am an elected member of the National Academy of Medicine, and was a member of the National Bioethics Advisory Commission from 1996 to 2001. At present, I am the Warren P. Knowles Professor of Law and Bioethics, on the faculties of the Law School and the School of Medicine & Public Health at the University of Wisconsin.

I would like to note for the record that I am here in my personal capacity as a scholar of bioethics. I do not represent the University of Wisconsin or any of its units, and have used only my own personal funds to come here to speak with you.

Madam Chair, fetal tissue has been used in research in this country since the 1920s, and NIH-funded since the 1950s. It has been deemed ethical by federal review bodies going back a half a century, and has been specifically authorized for funding by Congress for a quarter-century, precisely because it has saved the lives of countless people, including children and infants. It continues to be ethical and it will

continue to save lives. In my view, supporting this research represents a commitment to helping today's patients and tomorrow's infants.

I say this for three reasons. First, this research serves a compelling public health purpose. Second, it operates within a framework of state and federal law. And third, support for it need not depend on one's views about abortion.

First, any discussion of fetal tissue research must begin with its unimpeachable claim to have saved the lives and improved the health of millions of people. Indeed, almost every American has benefited, in the form of vaccines for whooping cough, tetanus, chicken pox and German measles. Diseases do not discriminate, and the beneficiaries of this research come from every place on the political, religious, geographic and economic spectrum. You yourselves, and those whom you love, are undoubtedly among those whose lives have been made better by this research.

When work began nearly century ago, no one knew precisely where the research would lead. But over time it led to a Nobel Prize for developing a polio vaccine using cell lines from fetal tissue. Today's scientists also cannot say precisely which disease will benefit, or when. But HHS says that "fetal tissue continues to be a critical resource" for developing vaccines against dengue fever, HIV and Ebola, and for research on devastating diseases such as Huntington's chorea and Alzheimer's. And as of this year, Zika virus is also on that growing list.

Some people may find the dispassionate, technical language used by professionals to be startling. But one should never mistake that for callousness, particularly when talking about men and women who have devoted their lives to improving all of our lives through medicine and science. And the use of cadaveric tissue and organs, ranging from mature hearts to fetal tissue, can make some people uncomfortable about benefiting from material whose origins lie in complex situations. But it does not prevent us from accepting this life-saving gift. Critics have overwhelmingly partaken of the vaccines and treatments derived from fetal tissue, and give no indication that they will forswear further benefits. Fairness and reciprocity alone would suggest they should support the work, or at least, not thwart it.

Second, the use of fetal tissue in research has been specifically protected under American law for over 50 years. In the 1960s, the Uniform Anatomical Gift Act was drafted to include a provision that allowed fetal tissue to be donated just as other cadaveric tissue is donated for research and therapy. And in 1974, President Ford's commission on medical research also found that fetal tissue research is ethical.

In the 1980s, President Reagan created the Human Fetal Tissue Transplantation Research Panel, chaired by the late Arlin Adams: a Republican, a retired federal judge, an opponent of abortion rights and the author of a book entitled "A Nation Dedicated to Religious Liberty." Like the earlier Ford commission, the Reagan Panel found the research to be ethical, and declared there was no evidence that it had any effect on decision-making or on the number of abortions performed in this country.

To guard against even that hypothetical possibility, however, current practice follows its recommendations, and discussion about donation takes place only after a woman has definitively decided to terminate her pregnancy.

Fetal tissue research is subject to local oversight committees, state law, laboratory and tissue bank regulations, and various federal laws. These address everything from the consent process, to collection and storage, to confidentiality of records. Two separate GAO investigations found no violations, and found no sale of tissue, but only legally permitted reimbursement for expenses. And no violations have been found in any current investigations at the Federal or State level.

Third, support for fetal tissue transcends the debate about abortion rights. Federal review has repeatedly found that the option to donate tissue has no effect on whether a woman will choose to have an abortion. That is one reason why the Congress passed legislation by overwhelming, bipartisan margins that codified the recommendations of the Ford and Reagan committees, and authorized federal funding for this work. Some of the most passionate supporters recognized the difference between opposition to abortion rights and opposition to research using fetal tissue. Sen. John McCain, for example, was quoted as saying “My abhorrence for the practice of abortion is unquestionable. Yet, my abhorrence for these diseases and the suffering they cause is just as strong.”

In this country, women have a constitutionally protected right to safe and legal abortion services. They make their decisions for their own reasons. And after that, some of them choose to donate fetal tissue to research. We gain nothing when we turn our backs on the benefits of this research for people who are sick today, or will be sick tomorrow—to say nothing of the irony of halting research that improves our chance of preventing miscarriages, of preventing birth defects, and of saving infants' lives.

Thank you.