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Planned Parenthood Federation of America, Inc.

July 29, 2015

Director Francis Collins, M.D., Ph.D.  
National Institutes of Health  
9000 Rockville Pike  
Bethesda, MD 20892

Dear Director Collins:

In the last two weeks, Planned Parenthood has been attacked through a series of doctored videos for our role in helping women who want to donate fetal tissue for medical research.

By design, these attacks completely misrepresent our work and fail to acknowledge that our policies exceed the applicable legal standards. But they won't deter us in any way from providing essential medical care to people around our nation and safeguarding a woman's ability to make her own deeply personal decisions about pregnancy.

It has become clear in the ensuing public debate, however, that there is widespread confusion about fetal tissue research and that government officials, medical researchers, health care providers, and the public could benefit from a review of the research and the procedures surrounding it by an independent expert panel. The last time such a review occurred was in 1988 during the Reagan Administration. We believe it may be time for another expert panel to examine these issues in light of the advancements achieved in medicine over the past 27 years.

While Planned Parenthood has been targeted to make our organization stand in for the field of fetal tissue research, in fact our role is limited. Planned Parenthood affiliates operate in all 50 states, but at this time affiliates in fewer than five states help women donate tissue. We participate in fetal tissue donation and occasionally partner in research not because this research is a core part of our mission, but because we are supporters of medical research and serve women who chose to make donations. The primary entities engaged in fetal tissue research are the researchers themselves, who are often the nation's leading medical institutions. The National Institutes of Health also plays an important role because it provides funding for this research, which is why we are sharing our views with you.

The panel appointed by the Reagan Administration in 1988 provided a tremendous public service when it considered the medical ethics of using fetal tissue for transplantation research. The panel was chaired by Arlin Adams, a retired federal judge

opposed to abortion. Its final report stated: “a decisive majority of the panel found that it was acceptable public policy to support transplant research with fetal tissue.”

The panel separated the question of the ethics of abortion, about which the panel members had differing views, from the question of the ethics of using fetal tissue from legal elective abortions for medical research. The panel supported fetal tissue research for two primary reasons: (1) “abortion is legal” and “would occur regardless of their use in research” and (2) “the research in question is intended to achieve significant medical goals.” The panel made a series of recommendations to ensure that any research followed appropriate guidelines.

The panel recommended that “the decision to terminate a pregnancy ... should be kept independent from the retrieval and use of fetal tissue” so that “a woman’s abortion decision would be insulated from inducements to abort to provide tissue for transplant research and therapy.” The panel recommended that “payments ... associated with the procurement of fetal tissue should be prohibited, except payment for reasonable expenses” so that there would be “no offer of financial incentives or personal gain to encourage abortion or donation of fetal tissue.” And the panel recommended that “no abortion should be put off to a later date nor should any abortion be performed by an alternate method entailing greater risk to the pregnant woman in order to supply more useful fetal materials for research.” The panel’s recommendations were limited in scope to fetal tissue used in transplantation research.

The work of the panel won broad bipartisan support. In 1993, Congress overwhelmingly passed legislation codifying the key recommendations of the panel into law. Prominent Republicans in Congress were among the leaders in the effort to pass the law, including Senator Strom Thurmond and Senator Alan Simpson. Senate Majority Leader Mitch McConnell voted for the legislation.

An important provision of the 1993 law (42 U.S.C. 289g-2) prohibits the acceptance of any payment for a fetal tissue donation other than “reasonable payments associated with the transportation, implantation, processing, preservation, quality control, or storage of human fetal tissue.” We require Planned Parenthood affiliates to follow all state and federal laws and have given them specific guidance for complying with this requirement.

Another section of the law (42 U.S.C. 289g-1) imposed additional provisions – such as informed consent requirements and limitations on alterations in timing or method – to federally funded “research on the transplantation of human fetal tissue for therapeutic purposes.” A common assumption is that these provisions apply to the tissue donations made by Planned Parenthood affiliates. In fact, they do not apply to any tissue donations made in the United States because NIH is no longer funding transplantation research and has not done so for many years.



Instead, research has moved into other areas that do not involve transplantation. Currently, fetal tissue research receives around \$76 million from the National Institutes of Health each year. We understand this research is being done to advance vaccine development and clinical knowledge and treatment options for life-threatening diseases, chronic conditions, and genetic disorders, such as Parkinson's, Alzheimer's, Down syndrome, ALS, immunologic disorders, spinal cord injuries, hemophilia, leukemia, sickle cell anemia, and diabetes, as well as specific maternal and infant health conditions. Our affiliates in a small number of states have chosen to support women who want to make donations to further this important research.

Although we are not legally required to follow the provisions in the 1993 law applicable to fetal tissue transplantation, we are doing so voluntarily. Our internal policies and procedures incorporate guidelines based on the substance of the federal requirements. We have taken this step because whether we are under a legal obligation or not, we want to make sure we meet the highest medical and ethical standards.

This has led to an unusual situation: Planned Parenthood is currently under attack for violating the 1993 law on fetal tissue research, when in fact we go above and beyond its requirements. As a result of a few doctored videos, Planned Parenthood is seemingly on trial for not complying with a law that does not apply to us, ignoring that our standards voluntarily adopt the substance and spirit of that law. The videos – and the three-year smear campaign behind them – clearly aim both to create revulsion at the process of collecting fetal tissue and to foment opposition to legal abortion and Planned Parenthood. The fact that Planned Parenthood participates in tissue donation in just a few states – and that we have always been committed to following all legal requirements – seems secondary to a group obsessed with inventing a problem, not uncovering one.

Unfortunately, the videos being released are just the most recent in an unending series of attacks on Planned Parenthood. We strongly denounce this latest attempt to strip federal funding from Planned Parenthood and deny essential health care to millions of women.

At the same time, we are first and foremost a health care provider – one that strives to meet the highest medical and ethical standards of compassionate care. We are constantly working to make sure that everything we do meets these standards. Tissue donation may not be part of our core mission, but we do offer this service in a few states to support the women who want to donate to research as a part of finding treatments and cures for devastating diseases and conditions. We want to ensure how we do so continues to meet our demanding standards.

As a result of a scurrilous campaign against Planned Parenthood, there is a renewed debate about the standards for fetal tissue research. A new review by a blue ribbon panel could help ensure the entire medical community is meeting the highest possible standards for this practice. In addition to Planned Parenthood, other health care

providers that make tissue donations could benefit from updated guidance. We are not in a position to speak for the medical researchers, who are the individuals most directly involved in fetal tissue research, but we suspect that they might also welcome a reexamination of the recommendations of the Reagan-era panel, which are now 27 years old.

It may be too much to hope that a new panel could reproduce the broad bipartisan consensus that the 1988 panel achieved. Politics today has become increasingly partisan and respect for science has seemingly diminished. But the inflammatory and misleading videos have pushed this issue into the national spotlight, and a thoughtful, careful review by leading medical and ethical experts could do a lot to help the public and policymakers think through this issue and reach informed conclusions.

It is essential that such a review protect the right of a woman to make her own decision about donation. In the midst of this politically saturated debate, women's voices need to be heard. Said one woman, Kate, about her decision to donate after ending her second, wanted pregnancy because of a fatal condition, "it gave me a little bit of closure to know I'm making a difference. I gave back a little. I did a little bit of good here. This shouldn't have to stop happening. People should always have this option."<sup>1</sup>

We are mindful of our limited role in fetal tissue research and respectful of the other voices that should be heard. We know you and federal medical researchers have valuable expertise and insights to share on this issue. We hope to contribute to a deliberative process rooted in medical facts and science that benefits our nation.

Sincerely,



Cecile Richards  
President  
Planned Parenthood Federation of America

cc: Secretary Sylvia Mathews Burwell

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<sup>1</sup> Jennifer Gerson Uffalussy, "Why Women Do (and Don't) Choose Fetal Tissue Donation After Abortion," *Yahoo*, July 29, 2015, <https://www.yahoo.com/health/why-women-do-and-dont-choose-fetal-tissue-125341176512.html>.