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Fetal Tissue Research: A Weapon and a Casualty in the War Against Abortion

By Heather D. Boonstra

HIGHLIGHTS

- *Medical research using human fetal tissue obtained from abortions has benefited millions of people worldwide and holds great promise for the continued advancement of basic science, as well as for the development of lifesaving vaccines and therapies.*
- *Since 1973, when abortion became legal nationwide, fetal tissue research has, time and again, become entangled in the abortion controversy.*
- *The current controversy—set off by a series of heavily edited and misleading videos—grew out of abortion opponents' long-standing campaign to vilify abortion and abortion providers, and it now threatens fetal tissue research itself.*

The debate over using human fetal tissue in medical research came roaring back on the national policy agenda last summer when a group of antiabortion activists began releasing deceptively edited videos about Planned Parenthood's handling of fetal tissue donations for this purpose. Fetal tissue research dates back to the 1930s, and has led to major advances in human health, including the virtual elimination of such childhood scourges as polio, measles and rubella in the United States.[1,2] Today, fetal tissue is being used in the development of vaccines against Ebola and HIV, the study of human development, and efforts to treat and cure conditions and diseases that afflict millions of Americans.

To ensure it meets the highest ethical standards, fetal tissue research has been subject to stringent laws and regulations for decades. Abortion foes are now accusing health care providers and researchers of violating these laws and ethical standards, in hopes of undermining the right to abortion and ending fetal tissue research. These attacks not only threaten sexual and reproductive health and rights, but also pose a threat to the large numbers of people who could benefit from fetal tissue research, given the wide range of conditions that such research might ameliorate. Any impediment to ongoing scientific inquiry in the field caused by the current controversy would have substantial consequences.

Importance of Fetal Tissue Research

Unlike embryonic stem cell research, which uses cells from days-old embryos created through in vitro fertilization, fetal tissue research uses tissue derived from induced abortion of pregnancies at or after the ninth week.[1,3] (Fetal tissue obtained from a miscarriage is often not suitable for research purposes because of concerns about potential chromosomal abnormalities that led to the miscarriage.[3]) Researchers most often acquire fetal tissue from a tissue bank or, sometimes, directly from a hospital or abortion clinic.[4]

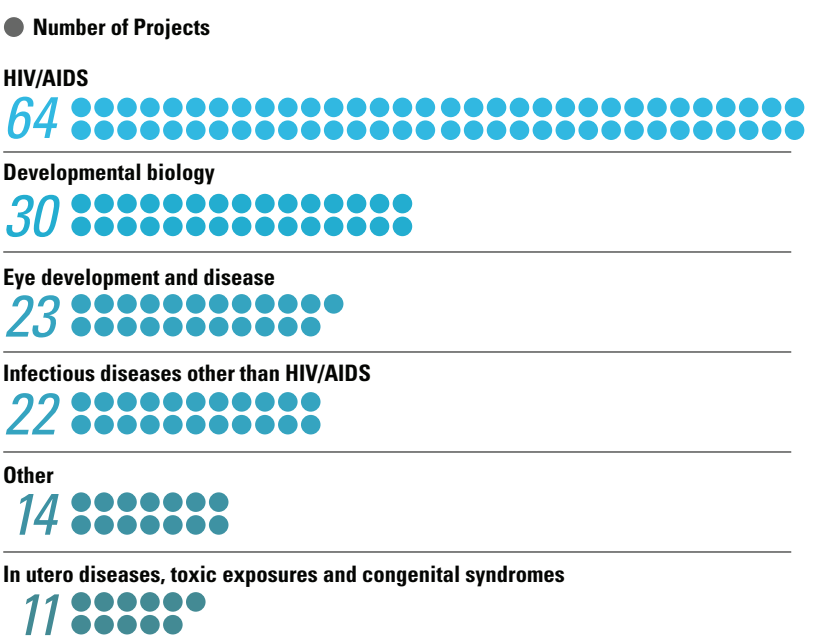
Because it is not as developed as adult tissue and is able to adapt to new environments, fetal tissue is critical to the study of a wide variety of diseases and medical conditions, according to the American Society for Cell Biology.[1] Researchers use fetal tissue—and cell cultures derived from such tissue, which can be maintained in a laboratory environment for decades—to study fundamental biological processes and fetal development. According to the U.S. Department of Health and Human Services, fetal tissue continues to be an important resource for researchers studying degenerative

eye disease, human development disorders such as Down syndrome, and early brain development (relevant to understanding the causes of autism and schizophrenia).[2]

Fetal tissue has also been used to develop vaccines that have saved and improved the lives of billions of people worldwide.[1,2,5] The 1954 Nobel Prize in Medicine was awarded for work using cell cultures originating from fetal tissue that led to the development of the polio vaccine. Vaccines for diseases such as measles, mumps, rubella, chickenpox, whooping cough, tetanus, hepatitis A and rabies were also created using fetal cell cultures, and researchers are now using fetal cells to develop vaccines against other diseases, including Ebola, HIV and dengue fever.

WIDESPREAD APPLICATIONS

The National Institutes of Health provides grants for a wide array of fetal tissue research projects.



Note: Data are for fiscal year 2014. *Source: Nature.*

In addition, researchers use fetal tissue in transplantation research. Fetal tissue has several unique properties that make it particularly suitable for transplantation. Not only do fetal cells grow at a much faster rate than adult cells, they also elicit less of an immune response, which lowers the risk of tissue rejection.[6] Clinical trials transplanting fetal cells are currently underway for people with spinal cord injury, stroke and ALS (Lou Gehrig's disease), and may soon begin for those with Alzheimer's disease, Parkinson's disease and multiple sclerosis.[1]

The National Institutes of Health (NIH) has been supporting research using fetal tissue since the 1950s, and in FY 2014, NIH provided roughly $76 million for this work.[3] According to an analysis of NIH research grants published in *Nature*, NIH funded 164 projects using fetal tissue in 2014, most often for research on infectious diseases, eye function and disease, and developmental biology (see chart).[7,8]

Many of the nation's leading academic medical centers are involved in fetal tissue research.[7,9,10] Researchers at the University of North Carolina at Chapel Hill are using cell cultures derived from fetal tissue for their work on hepatitis B and C—specifically, on how the viruses evade the human immune system and cause chronic liver diseases. At the University of Wisconsin-Madison, fetal cell cultures are used to study heart disease, including sudden cardiac arrest. At Stanford University, fetal tissue has been used to study Huntington's disease, juvenile diabetes, autism and schizophrenia. And scientists at Colorado State University are conducting HIV research using fetal tissue.

Federal Law and Regulation

Soon after the U.S. Supreme Court's *Roe v. Wade* decision in 1973 legalizing abortion nationwide, antiabortion leaders in Congress seized on fetal tissue research as a weapon in the war against abortion. Fetal tissue research was perhaps an inevitable target: It provided an aura of legitimacy to abortion itself and, at the same time, could be easily exploited to show how abortion "dehumanizes"

the fetus.[11] Accordingly, antiabortion activists employed graphic visuals to shock members of Congress, try to personify the fetus, and demonize abortion providers and the procedure itself.

This first incarnation of the controversy coincided with public revelations about the infamous Tuskegee syphilis study—a study that enrolled black men living in Alabama to investigate the long-term effects of syphilis. In 1973, an ad hoc advisory panel convened by the Department of Health, Education and Welfare (now the Department of Health and Human Services) concluded that, in retrospect, the study was "scientifically unsound" and "ethically unjustified."[12] In response to the Tuskegee revelations, Congress felt pressure to create protections for human research subjects, and by 1974, Congress passed the National Research Act. The law created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research to develop guidelines on the ethical principles that apply to research on all human subjects, as well as on particular principles that apply to research involving fetuses and using fetal tissue.

The commission's report on research on the fetus, issued in 1975, led to the creation of regulations during the Ford administration that set out the rules of the road for federally funded fetal tissue research. The regulations—which are still in effect—specify that "no inducements, monetary or otherwise, will be offered to terminate a pregnancy." They also provide that "individuals engaged in the research will have no part in any decisions as to the timing, method, or procedures used to terminate a pregnancy."

Fetal tissue research receded as a political issue until the late 1980s, when a group of NIH scientists sought approval from the Reagan administration for a proposed project involving the transplantation of fetal tissue. After deliberating on the request, the administration appointed an advisory panel—which included a chair and several members who were well-known opponents of abortion rights—to examine the ethical, legal and scientific questions raised by this type of research. In 1988, the panel issued its report and, despite its mixed composition, it concluded that "in light of the fact that abortion is legal and that the research in question is intended to achieve significant medical goals…the use of such tissue [for research] is acceptable public policy."[13]

Key recommendations of the panel were later codified into law with the passage of the NIH Revitalization Act of 1993. The legislation won broad bipartisan support in Congress, including from several prominent senators with solid antiabortion records. Among them were Sens. Robert Dole (R-KS), a longtime advocate for people with disabilities, and Strom Thurmond (R-SC), who had a daughter with juvenile diabetes.[14,15]

The NIH Revitalization Act of 1993 added several provisions to the existing regulations governing fetal tissue research. One such provision prohibits anyone from accepting payment for human fetal tissue other than "reasonable payments associated with the transportation, implantation, processing, preservation, quality control, or storage of human fetal tissue." Thus, although individuals may be compensated for any costs they incur in the acquisition, receipt or transfer of fetal tissue, they are prohibited from making a profit from these activities, regardless of whether the project is federally funded or not.

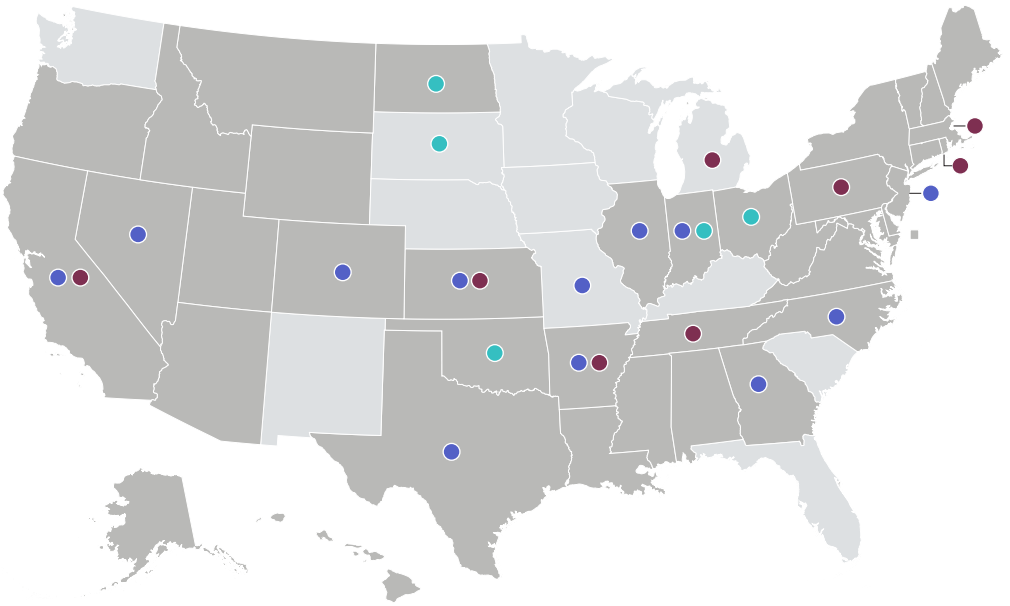
The law also imposes additional requirements when the donated tissue is used in federally funded research involving the transplantation of fetal tissue for therapeutic purposes. Among these are provisions for informed consent and prohibiting physicians and researchers from altering the timing or method used to terminate the pregnancy solely for the purposes of obtaining the tissue. Although all of these requirements technically apply only to federally funded transplantation research, as a practical matter, they set the standard for all research using fetal tissue. For example, the policies and procedures for fetal tissue donation issued by Planned Parenthood Federation of America and by the National Abortion Federation incorporate the substance of these federal requirements.[16,17]

State Policies

At the state level, fetal tissue donation is regulated by the Uniform Anatomical Gift Act (UAGA),

FETAL TISSUE POLICIES

In the states, fetal tissue donation is generally governed by the Uniform Anatomical Gift Act (UAGA). In addition, many states have specific statutes on fetal tissue donation and research.



- Donation explicitly permitted under UAGA **(TOTAL = 38+DC)**
- Donation not addressed under UAGA **(TOTAL = 12)**
- Prohibits profiting from fetal tissue donation or procurement **(TOTAL = 12)**
- Requires consent before fetal tissue is donated **(TOTAL = 8)**
- Bans all fetal tissue research **(TOTAL = 5)**

Note: Three additional states have laws that apply only to abortion after viability. Kentucky prohibits experiments using tissue from a postviability abortion. Nebraska and Wyoming prohibit "giving away, sale, transfer or distribution" of tissue from a postviability abortion.

versions of which are in effect in every state.[13,18] According to an analysis by the Guttmacher Institute, 38 states and the District of Columbia have UAGA laws that explicitly treat fetal tissue the same way as other human tissue, permitting it to be donated by the woman for research, therapy or education. The remaining 12 states have laws that are silent, neither allowing nor disallowing the donation of fetal tissue (see map). UAGA also prohibits profiting from the sale or purchase of anatomical gifts for transplantation or therapy.

Fetal tissue donation and research are also regulated in some states by specific statutes. Often, these statutes incorporate many of the same standards set by federal law and regulations. For example, 12 states prohibit making a profit from the donation or transfer of fetal tissue for research purposes, and eight states require the woman's consent for research.

Five states have laws that ban research using fetal tissue obtained from abortions throughout pregnancy. (Four other states also ban research using postabortion fetal tissue, but these laws have been struck down by the courts.) One of these states with a ban in effect, Indiana, also has a law that requires the disposal of postabortion fetal tissue in an established cemetery or by cremation, presumably precluding any possibility of donation for research.

Political Firestorm

The current furor over the use of fetal tissue in research ignited last summer, after the release of heavily edited videos purporting to capture undercover sting operations targeted at Planned

Parenthood. The series of videos—released in close cooperation with members of Congress who want to ban abortion[19]—show an antiabortion activist posing as a representative of what turned out to be a sham biomedical research company, in frank discussions with various Planned Parenthood officials about tissue donation policies and reimbursement.

The fallout from the videos has been swift, severe and wide-ranging. The stated targets are Planned Parenthood, abortion providers and the legitimacy of abortion. The videos also threaten to undermine fetal tissue research itself, however, by sowing confusion, and by using graphic descriptions and images to turn the public against this research.

The primary goal of this current campaign has been to portray Planned Parenthood as callous and its providers as possibly criminal. Antiabortion policymakers have accused Planned Parenthood of violating several provisions of the NIH Revitalization Act of 1993, such as profiting from the sale of fetal tissue and altering the abortion procedure solely for the purpose of obtaining tissue. Opponents of abortion have also accused providers of using a procedure that violates the so-called "partial birth" abortion ban. As an instigator of the videos, David Daleiden explained in an interview with *Politico*, "For me, the goal was to document and illustrate for the public really, really clearly how Planned Parenthood harvests and sells the body parts of the babies that they abort."[20]

Antiabortion elected officials ran with this narrative and immediately called for investigations of the organization. In October 2015, congressional leaders formed a special committee to carry out an official inquiry into Planned Parenthood—bringing the total number of investigations into Planned Parenthood in the House and Senate to five since the first video was released. In January 2016, the House's first substantive piece of business was yet another attempt to cut off funding for Planned Parenthood, one of several such efforts recently to scale back abortion rights and women's health care. Also, officials in 11 states have concluded investigations into claims that Planned Parenthood profited from fetal tissue donation, and each one of these investigations has cleared the organization of wrongdoing.[21]

Nonetheless, the grandstanding has continued unabated. Antiabortion leaders, lawmakers and all the Republican presidential candidates have used the opportunity to demonize abortion and paint a ghoulish picture of organ harvesting, all in an effort to gin up public disgust and attract public support for themselves and against abortion and Planned Parenthood. Indeed, the videos and the hype around them appear to have provoked at least four arson attacks on Planned Parenthood clinics since July 2015 and set the stage for yet another extreme act of violence in Colorado Springs over Thanksgiving weekend.[10] It was there that Robert Lewis Dear Jr. allegedly killed three people and injured nine others at a Planned Parenthood health center. During his arrest, Dear shouted "no more baby parts," suggesting that the constant barrage of inflammatory rhetoric around the fetal tissue issue over the prior months played a role in triggering his actions.[22]

High Stakes

Beyond the attacks on Planned Parenthood, however, the use of fetal tissue in research also is under direct attack. Since July, bills have been introduced in Congress and in several states that would make it more difficult to donate tissue or use fetal tissue in research. Other bills would ban fetal tissue research outright. This trend is almost certain to continue through 2016 as the issue is sure to be exploited in state and federal elections.

Meanwhile, the videos appear to have had a chilling effect on science. According to Theresa Naluai-Cecchini, a scientist at the Birth Defects Research Laboratory at the University of Washington (a federally funded entity that has served as a source of donated fetal tissue to researchers nationwide for more than 50 years), tissue donations have dropped dramatically since July 2015.[10] Naluai-Cecchini told *Mother Jones* that if this trend continues, research that may save lives would take considerably longer.

Some scientists involved in fetal tissue research have been afraid to speak out.[7] They have seen how abortion providers have been targeted,

and now they too fear for their personal safety. Others have spoken out strongly to defend the importance of their work, pointing out that tissue that would otherwise be discarded has played a vital role in lifesaving medical advances and holds great promise for new breakthroughs. In an October 2015 open letter to Congress, 41 scientists called for the end to political interference with science and research: "Fetal tissue research has already saved and improved the lives of countless people. [We] cannot allow political agendas to undermine our nation's legacy of leadership in medical and scientific innovation."[23] In another action, the Association of American Medical Colleges released a statement on January 6, 2016 signed by 59 academic medical centers, scientific societies and allied groups—from the University of Alabama School of Medicine to Duke University School of Medicine, from the University of Wisconsin-Madison to Tulane University School of Medicine.[24] The statement expresses "grave concerns" about the numerous legislative proposals now in play in Congress and in many states, and it calls on lawmakers to reject any proposals that restrict access to fetal tissue for research.

Ironically, in the wake of all the heightened focus on fetal tissue donation, Planned Parenthood officials report they have seen an uptick in the number of women obtaining abortion who request that the fetal tissue be donated to research. The role that Planned Parenthood plays in providing postabortion tissue to researchers, however, is small: Just 1% of the approximately 700 health centers that are part of the Planned Parenthood network are equipped for fetal tissue donation. And in another response to the disinformation campaign and to try to quell some of the controversy, Planned Parenthood announced in October 2015 that its clinics will no longer seek reimbursement for their costs related to fetal tissue donation, even though the practice is perfectly legal and commonplace.

Bioethicist R. Alta Charo has argued that enabling the use of fetal tissue to advance scientific research for the benefit of humankind must be seen as something of a moral imperative. "Virtually every person in this country has benefited from research using fetal tissue," she wrote in the *New England Journal of Medicine*. "Every child who's been spared the risks and misery of chickenpox, rubella, or polio can thank the Nobel Prize recipients and other scientists who used such tissue in research yielding the vaccines that protect us….Any discussion of the ethics of fetal tissue research must begin with its unimpeachable claim to have saved the lives and health of millions of people."[25]

As the full impact of the current firestorm surrounding fetal tissue research is still unfolding, it remains to be seen how much this research will continue be used as a weapon against abortion or become a serious target itself—or both. To be sure, the current controversy threatens not just access to safe and legal abortion and the providers who care for the women who seek this essential health service. It also threatens the millions of people globally who could benefit from fetal tissue research—and that includes nearly all of us, whatever our views on abortion rights may be. ■

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