



Heal Without Harm

ETHICAL RESEARCH COALITION

Heal Without Harm is a coalition of organizations and citizens dedicated to working with the scientific community to encourage it toward ethical research. The coalition is composed of member organizations, including: Wisconsin Right to Life, Wisconsin Catholic Conference, Wisconsin Family Action and Pro-Life Wisconsin, among others.



Heal Without Harm Coalition – Wisconsin Catholic Conference, Pro-Life Wisconsin, Wisconsin Family Action, Wisconsin Right to Life

Senate Judiciary and Public Safety Committee

RE: The Heal Without Harm Legislative Initiative - SB 423 and SB 424

Thursday, November 2nd, 2017

Distinguished members of the Senate Judiciary and Public Safety Committee,

Thank you for the opportunity to testify today. The Heal Without Harm Coalition consists of four organizations: Wisconsin Right to Life – represented by its Legislative Director Chelsea Duffy, Wisconsin Catholic Conference – represented by its Executive Director Kim Wadas, Wisconsin Family Action – represented by its President Julaine Appling, and Pro-Life Wisconsin – represented by its Legislative Director Matt Sande.

The Need for SB 423 and SB 424

Heather Weininger, Executive Director for Wisconsin Right to Life, unfortunately could not join us today, but wishes to pass along the following remarks:

“Just last month was Pregnancy and Infant Loss Awareness Month. It is fitting today to talk about legislation that will provide families who experience the loss of an unborn child information about the final disposition of their baby, and the opportunity to donate their child’s remains to scientific research.

Christmas Eve, 2013, is a day my husband and I will remember forever. It was the day we lost our baby to a miscarriage. When this frantic situation occurred and we went to the hospital for help, I felt so alone and lost. We were given no information about what to do with the remains of our child, we had no resources to help us cope with our loss, and quite frankly, at this time, I really needed someone to tell me what to do next. Where could we turn for answers?

When a parent is faced with a sudden loss, the one thing you want the most is answers. We may not be able to explain why their child passed away, but the least we can do is give parents information about options for the final disposition and donation of their child's remains. As I look back at my experience, I wish I knew my options for the final disposition of my child. I wish I knew of my ability to donate my child's remains to scientific research.

Even if we can't give parents all the answers, we can give them the information that they need for some closure. We can reaffirm that their child was real, she existed, and she can be a gift to others.

SB 423 and SB 424 are about answers – answers to how we can protect vulnerable unborn children while also advancing scientific research, and answers to how we can provide parents with the information they need after a loss.”

Now, more than ever, the public is aware that aborted fetal body parts are being used in research. As a Coalition, we looked at the law in Wisconsin and wondered if there was a way to continue to champion research without the controversy that comes from the trafficking and use of aborted fetal tissue.

Our state needs to do a better job of supporting and promoting the use of ethical tissues. No patient should have to face the difficult choice of using or refusing an unethically-derived treatment. No one should have to ask, “*Do I help myself, or do I support the common good?*”

To aid us in this effort, we asked for the support and direction of two esteemed legislators, Senator Terry Moulton of Chippewa Falls and Representative Joel Kleefisch of Oconomowoc. As leaders, Sen. Moulton and Rep. Kleefisch have continually shown how they value family, ethics, and promoting the common good of all, including the most vulnerable among us. With their guidance, we forwarded this new initiative, unique to Wisconsin, which will allow our state to become a leader in both research and ethics.

We know the Heal Without Harm Legislative Initiative can make a lasting positive impact on the state. Senate Bills 423 and 424, along with their companions, Assembly Bills 549 and 550, will ensure that in Wisconsin, no researcher need operate under a cloud of controversy and no patient need to choose life over conscience.

If one looks at the history of scientific experimentation in the U.S., it is evident that self-regulation within the scientific community does not always adequately protect vulnerable human beings. One need only reflect on the Tuskegee Syphilis Study or the Willowbrook State School hepatitis study. These experiments led to community outcry, as well as local and federal action, including the creation of the National Research Act of 1974, the Civil Rights of Institutionalized Persons Act (CRIPA) of 1980, and the Americans with Disabilities Act of 1990. Members of the public and members of the Legislature have a vital role to play in establishing scientific standards that protect human life and dignity.

The dependence on tissue derived from the abortion industry legitimizes abortion, creates a demand for it, and further embeds it in our educational and medical institutions. This is simply wrong, just as it was wrong for researchers in the past to experiment on minorities and people with disabilities in the hope of finding cures. We can and must find a better way, and that is exactly what these bills do.

What SB 423 and SB 424 Accomplish

The Fetal Remains Respect Act (SB 423/AB 549) prohibits any person from knowingly acquiring, providing, receiving, or using fetal body parts obtained from induced abortions (i.e., where the child is directly and deliberately killed). The Act also requires a facility that provides an abortion to arrange for the final disposition of the aborted remains.

The Unborn Child Disposition and Anatomical Gift Act (SB 424/AB 550) requires that in every instance of an unborn child's death due to stillbirth or miscarriage (i.e., where the child dies naturally or accidentally) within a facility, the facility shall inform the mother that she may request her child's remains either for final disposition and/or to make an anatomical gift for research, experimentation, study, or transplantation.

These two bills represent a compromise, and a holistic solution to creating an ethical research environment in Wisconsin.

The Heal Without Harm Coalition listened carefully to the concerns raised last session regarding fetal tissue research. Therefore, the *Fetal Remains Respect Act* (SB 423/AB 549): 1) includes no criminal penalties; 2) requires civil forfeiture only for facilities, never individuals; and 3) does not impact existing cell lines or aborted fetal tissue procured prior to 2017.

In addition, by allowing for anatomical gifts and requiring final disposition for those who are stillborn or miscarried through *The Unborn Child Disposition and Anatomical Gift Act* (SB 424/AB 550), not only can we help families through a time of sorrow, we can also ensure ethical fetal tissue is available for research.

Finally, it should be noted that the Heal Without Harm Initiative follows the lead of the U.S. Congress, which is currently looking at ways to advance research that does not use aborted fetal tissue. The future of research funding is tied to ethical fetal tissue research.

Pro-Life Groups Are United, and Pro-Medical Research

The pro-life community is pro-medical research. We want to see medical research move forward in the hopes of discovering treatments for debilitating diseases, and we can move forward ethically so long as we do not degrade human life in order to potentially save it.

This package of bills is groundbreaking. All major pro-life groups in Wisconsin, representing tens of thousands of people across our state, support these pro-research bills. Parental donation of organs or tissue from stillborn or miscarried children is a life-affirming, ethical alternative.

While we know that research involving aborted fetal body parts represents only a small fraction of all scientific funding, we listened to the concerns raised by researchers. If researchers want to employ fetal tissue in their studies, they can under this legislation so long as the tissue is not derived from an aborted child. They can also use adult or adult-type stem cells. The clinical success of adult stem cells over a broad range of medical conditions is well documented and simply amazing. Adult type stem cells can be ethically derived from pregnancy-related tissues including umbilical cords, placentas and amniotic fluid.

We are confident that there is a sufficient supply of ethical fetal tissue to meet research needs. Nationally, the Centers for Disease Control (CDC) report that abortions are now about the same number as stillbirths/miscarriages. In Wisconsin, the DHS reports that in 2014, 317 stillbirths occurred after 20 weeks gestation. DHS also reports that in 2015, 359 abortions occurred

between 16-20 weeks and 56 after 20 weeks, for a total of 415 abortions. As with other organ and tissue donation, many people are not aware that the gift of their loved one's remains is possible. This is why this legislation is so vital.

When enacted, these bills will encourage new avenues of discovery and attract new researchers and biotech firms. This is precisely what happened with induced pluripotent stem cells, or iPS cells, which were discovered after a concerted effort to find an ethical alternative to the controversial embryonic stem cells.

Currently, students and researchers who conscientiously object to using aborted fetal tissue either have to leave their fields entirely or change their research projects. Wisconsin must attract and keep these researchers. We need to find a better way. Wisconsinites deserve the assurance that our state can build on its lead in biotechnology without compromising its bioethics. The Heal Without Harm Legislative Initiative helps provide this assurance.

Concluding Remarks

With limited floor periods left this year, and leadership in both chambers indicating that there will be an early end to session, the Heal Without Harm Coalition understands that time is short for these bills to be successful.

We thank you for this hearing today to publicly voice our support for ethical research in Wisconsin. We encourage a swift executive session on SB 423 and SB 424 to ensure there is adequate time for these bills to have the opportunity to reach the Senate floor. In fact, if these bills do not make it out of committee within the next twenty-four hours, there is little evidence that these bills will have any chance of passage this year. We are encouraging similar swift action in the State Assembly for companion bills AB 549 and AB 550, because the time to act is now.

Wisconsin has an extraordinary opportunity to lead the nation by championing research that is ethical, innovative, and effective. The Heal Without Harm Legislative Initiative, SB 423 and SB 424, would make our state a destination for ethical research.

Thank you for your time,
The Heal Without Harm Coalition