

# Ethics Controversies

Terri Schiavo Case

Abortion and PAS

Jeff Kaufhold, MD FACP

June 2023

# Hot Button Issues

- Terry Schiavo Case 2006.
- Abortion
- Cloning
- Stem Cell Research
- Physician Assisted Suicide

# Case Synopsis

- 26 y.o. female with Anorexia-Nervosa
  - Hypokalemia
  - Cardiac arrest with severe brain injury 1991
  - Feeding tube placed, transferred to ECF.
- In 1998, husband began asking for feeding tube to be removed.
- Parents of pt want to continue care.

# Complications to case

- Lawsuit for failure to diagnose A-N leads to \$ 1 million judgment in favor of pt.
- Parents allege that Terri may have been abused due to finding of fractures
- Husband has a girlfriend and they have children together.
- Vatican makes statement that “all life must be protected”
- Religious right protests outside Hospice
- Politicians pass “Terri’ s Law” .

# Why is this case so high profile?

- Withdrawal of feeding / life support happens every day in hospitals and ECF' s
- Usually the decision is consensus among family members and caregivers.
- No conflict means no headlines.
- This case had conflict between Parents and Husband, so came to attention of courts.

# Who Decides?

- By law and by convention / tradition, the spouse is spokesperson, unless there is a compelling reason to suspect they do not have best interest of pt at heart.
- Adult Children are next in line.
- Parents are next.

**WHO GETS TO DECIDE?** In most states, statutes give priority to the spouse as decision maker for an incapacitated person, assuming there are no advance directives or previously designated agents. Here are surrogate priorities by state:

- Spouse   ■ Physician and next of kin   ■ Consensus of "interested persons"   ■ Equal status for spouse and parent   ■ No priority specified



NOTE: Limits on what a surrogate can do vary from state to state

# First 10 years

- Husband is not contested as spokesperson,
- parents have visited every day.
- Numerous events occur requiring decision about care, no contests raised.



# 2001

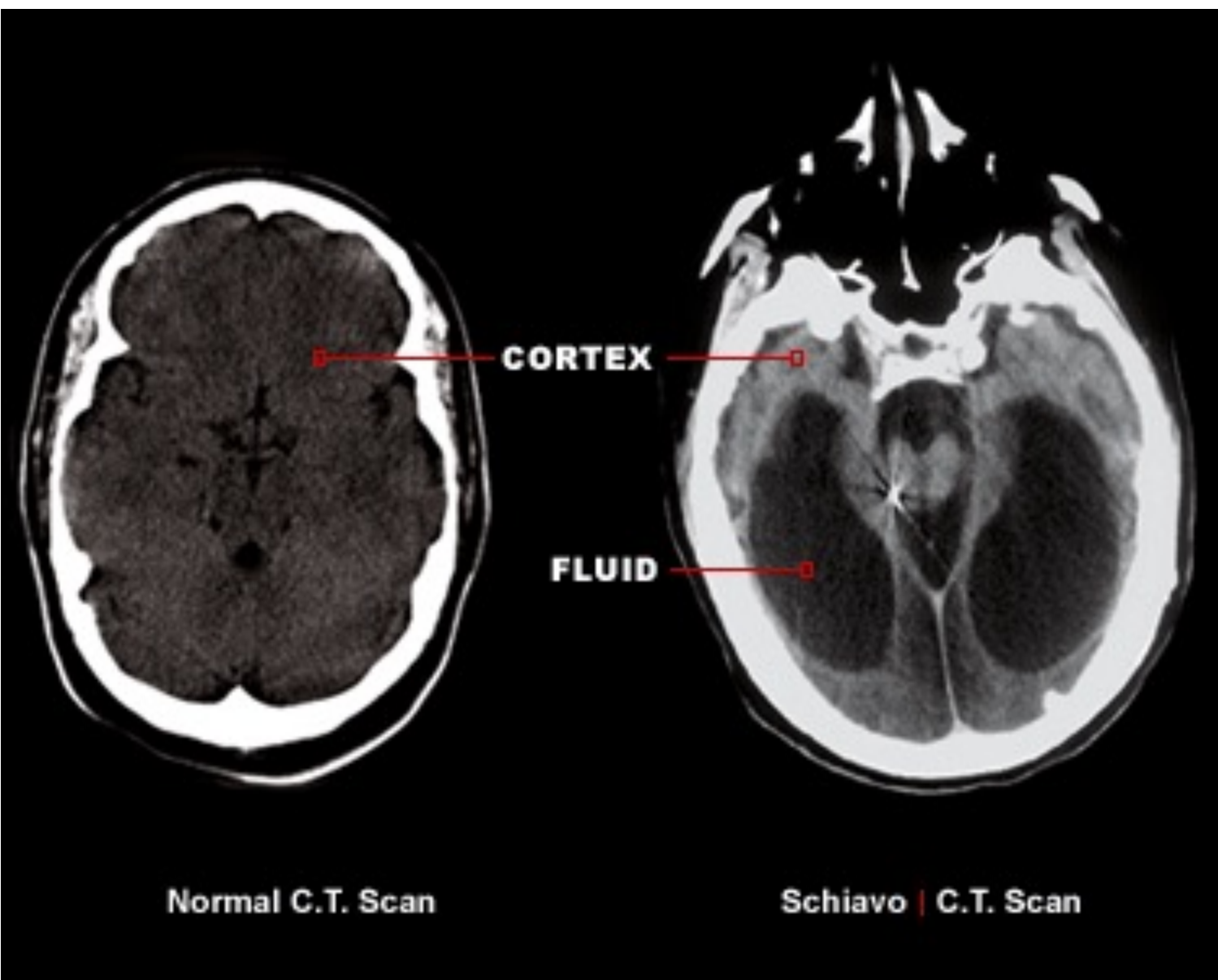
- Husband requests
  - Hospice Care
  - DNR-CC Status
  - Withdrawal of feeding
  - Removal of feeding tube
- Pt is moved to Hospice and tube removed.

# Case goes to Court

- Parents contest removal of tube/feedings
  - Tube reinserted
  - Pt remains DNR-CC arrest, in Hospice
- Husband appeals. In 2003, again granted motion to remove tube. Courts quickly overturn decision and tube is replaced.

# Appeals 2004/5

- Neurologist assigned for independent review of case.
  - No evidence that pt recognizes her surroundings or people, or interacts meaningfully.
  - MRI shows liquifactive necrosis of entire cerebral cortex. Midbrain and brainstem structure and function intact. (analogous to anencephalic infant)
  - Friends and family of Terri recall comments that “I wouldn’t want to be kept alive like that”
- State court allows tube to be removed, But....



# Florida State' s Interest

- State governments, as a rule, have an obligation to act in ways that protect and preserve life.
- However, there is no obligation to provide futile or inappropriate care.
- State can force standing in case, but this is *exceedingly rare*.
- Tube removal blocked by order of Governor and state legislature invoking Terri' s Law

# Latest Appeal

## This time to Florida Appellate Court

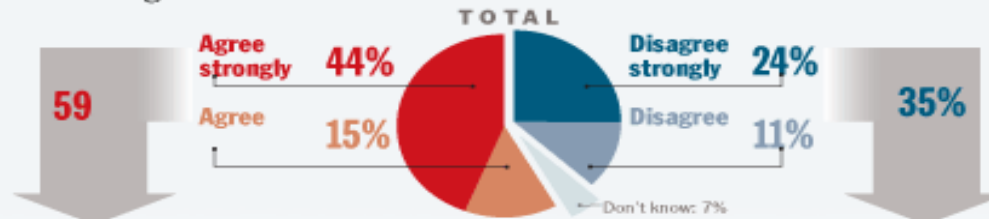
- Findings:
- “No clear evidence that Terri’s rights had been violated”. Lower court order upheld.
- Husband remains proper spokesperson.
- OK to remove tube and stop feedings/water. (for the third time)

# President and Congress Weigh In

- Why?
  - No standing in case
  - Political grandstanding for conservative base.
- Law permits Parents to ask Federal Appeals Court to review case.
  - US District Judge James Wittemore, Tampa.
- Supreme court doesn't review cases like this – would be a nightmare for their schedule, too slow for decision making. Don't want to set this precedent.

**Most Americans – even those who call themselves born-again or evangelical Christians – support the decision to remove Terri Schiavo’s feeding tube**

■ Do you agree with the decision to remove Schiavo’s feeding tube?

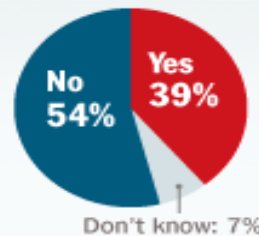


Those who agree strongly and somewhat:

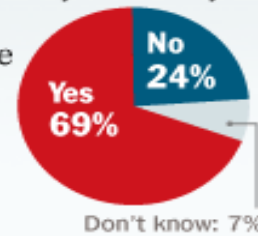


Those who disagree strongly and somewhat:

■ Do you think Schiavo’s parents should have the right to get a court to overrule the wishes of her husband?



■ If you were in Schiavo’s place, would you want your guardian to remove your feeding tube?





**The involvement of Congress and President Bush in the Schiavo case is overwhelmingly unpopular, and voters say they may punish those politicians in the next election**

■ Was it right for Congress to intervene in this matter?



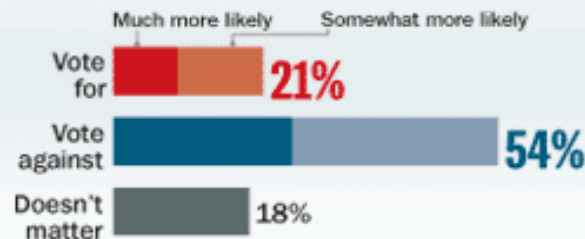
■ Was it right for President Bush to intervene in this matter?



■ Do you think that Congress's and the President's intervention had more to do with their values and principles or more to do with politics?



■ If your member of Congress voted to move the Schiavo case to the federal courts, would this make you more likely to vote for or against him or her?



# Fallout from Case

- Renew interest in living wills and DNR
- Get families to talk
- The real exercise in futility is trying to find the truth
- Terri dies after tube removed, in Hospice care, after 11 days.

# Controversies in Ethics

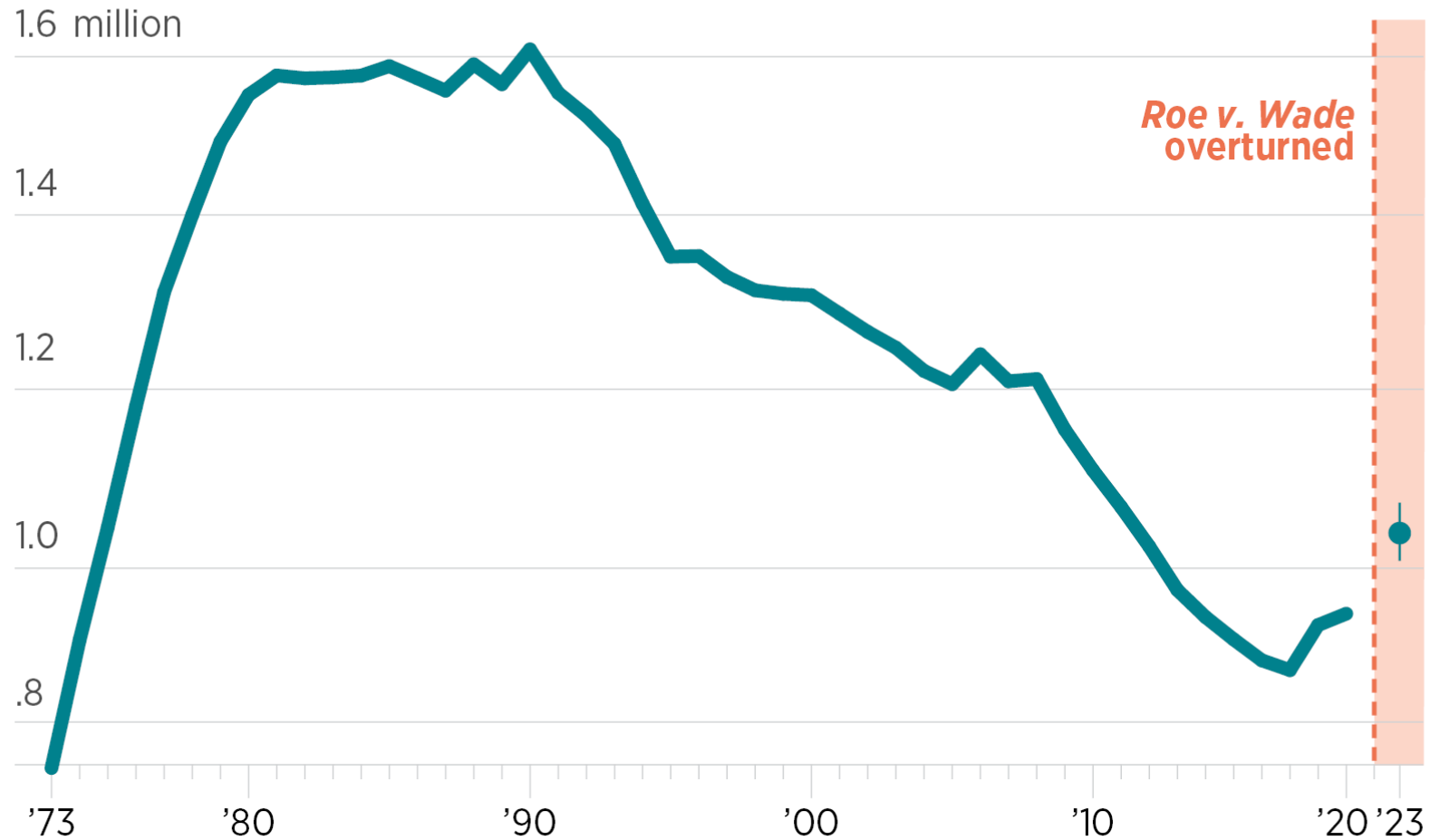
## Abortion

- Historical Background
  - Previously illegal for hundreds of years
  - Hippocratic Oath
  - Yet abortions have been available for hundreds of years.

# Abortion

- Legal since 1973.
- Rate peaked in 1981 at 29.3 per 1000 women (age 15-44)
- Actual # of abortions peaked in 1990 at 1.6 million.
- Rate as of 2023: 14.4 per 1000
  - Equates to 950,000 abortions that year!
- Total abortions since data could be collected is over 55 million.
- Number of abortion providers is declining.

# Estimated number of abortions provided in the formal health care system in the United States, 1973–2023



Notes: 2023 estimate shown with accompanying 90% uncertainty interval. No comprehensive data available for 2021 and 2022. Source: Guttmacher Monthly Abortion Provision Study.

# Roe v Wade

- Roe, a pregnant single women brought a class action suit challenging the constitutionality of Texas Abortion law.
- Dr Hallford, gynecologist who performed abortions,
- And the Does, a married couple served as plaintiffs.
- County District Attorney Wade was defendant.

# Roe v. Wade

- 1973 case decision which stood in face of supreme court review.
- Recognized that safe abortions were readily available to wealthy
  - “D&C’ s” in US hospitals
  - “European Vacations” euphemism
- Illegal Abortions available for a price to poor women
  - Had high mortality rate / complications.

# Roe v. Wade

- Conclusions:
  - Ban on abortions led to two levels of medical care, one for the wealthy, one for poor.
  - Level of care for the poor was unacceptable, and a result of the ban.
  - The decision was a medical decision between a woman and her Doctor, and the State has only limited right to interfere with Private decision.
  - Laws that criminalize abortion and do not take into account the stage of the pregnancy and other interests violate the Due Process Clause of 14<sup>th</sup> amendment.
  - Therefore, laws banning abortion were unconstitutional.



# Abortion Law

- Roe v Wade 1973.
  - One's philosophy, one's experiences, one's exposure to the raw edges of human existence, one's religious training, one's attitude toward life and family and their values, and the moral standards one establishes and seeks to observe, are all likely to influence and to color one's thinking and conclusions about abortion. ***Our task, of course, is to resolve the issue by constitutional measurement, free of emotion and of predilection.*** We seek earnestly to do this, and, because we do, we have inquired into, and in this opinion place some emphasis upon, medical and medical legal history and what that history reveals about man's attitudes toward the abortion procedure over the centuries.

# Abortion Law

- Roe v Wade 1973
  - The decision vindicates the right of the physician to administer medical treatment according to his professional judgment. [Until 3<sup>rd</sup> trimester] the abortion decision in all its aspects is inherently and primarily a medical decision, and basic responsibility for it must rest with the physician. If an individual practitioner abuses the privilege of exercising proper medical judgment, the usual remedies, judicial and intra-professional, are available.

# Abortion Law

- Once viability is reached, the State has an interest in the care and survival of the fetus.
- This interest may not supercede the mother's right to consent or refuse to consent to any medical treatment, or it may depending on state law.

# Roe v. Wade fallout

- Did not establish a “Right” to an abortion
- However, with abortion legal, activists on both sides started to push the envelope.
- Abortion became a covered benefit in health plans, Medicaid.
- When other methods of birth control were not covered / made available, abortion became the predominant way some women prevented unwanted births.

# How would you approach this problem?

- Option A: Ban abortion
- Option B: Limit abortion
- Option C: Freely available abortion with no questions asked.
- Option D: The hard, difficult to explain, but probably best approach, that will never be discussed in the media because you can't make a headline with it, and will be attacked by all.

# My opinion: recognize that abortion is a terrible but necessary choice

- Option D means:
  - Limit abortions
  - Make other contraception methods widely available, covered by insurance & Medicaid.
  - Educate women to lessen the demand for abortion
  - Reversible or permanently Sterilize repeat users / sex trade workers / drug abusers

# Issue: Abortions declining in nearly all states

## AP: Abortions drop even without new restrictions

Abortions have declined substantially in most states since 2010, whether or not those states have passed new laws to restrict access to abortion. The only states with an increase in abortions - Louisiana and Michigan - were among the states enacting multiple restrictions; many of the states with the biggest decreases did not pass new restrictions.

Percentage change for each state



States are here listed top-to-bottom by the number of abortions in 2012 to 2014. A = <2,000, B = <5,000, C = <10,000, D = <20,000, E = <50,000, F = <100,000. No data for five states.

SOURCES: State health departments, The Guttmacher Institute

Associated Press, as Reported in AOL June 7 2015

# Abortion rate declining

- States with the biggest decrease had not closed any clinics
- Teen pregnancy rate decline closely follows the decline in abortions
- Due to expanded coverage of long term birth control methods as a result of Expanded Medicaid and Affordable Care Act (ACA).
  - AP June 8 2015.



# Excluding Access To Contraception in Employee Health Insurance Plan

- Hobby Lobby Stores Inc v Burwell
  - Employer's objection based on Religious beliefs
  - Owners filed suit against Secretary of HHS 2012
  - Asked for exemption from the ACA requirement
  - Wanted relief from penalties for noncompliance with ACA
  - Claimed violation of Free exercise Clause of 1<sup>st</sup> Amendment and Religious Freedom Restoration Act of 1993.

# Excluding Access To Contraception in Employee Health Insurance Plan

- Hobby Lobby Stores Inc v Burwell
  - Decided in favor of Hobby Lobby 2014
  - Owners can be exempt from regulation on religious grounds
  - No specification of what a religion is
  - Established that “Corporations are People too”

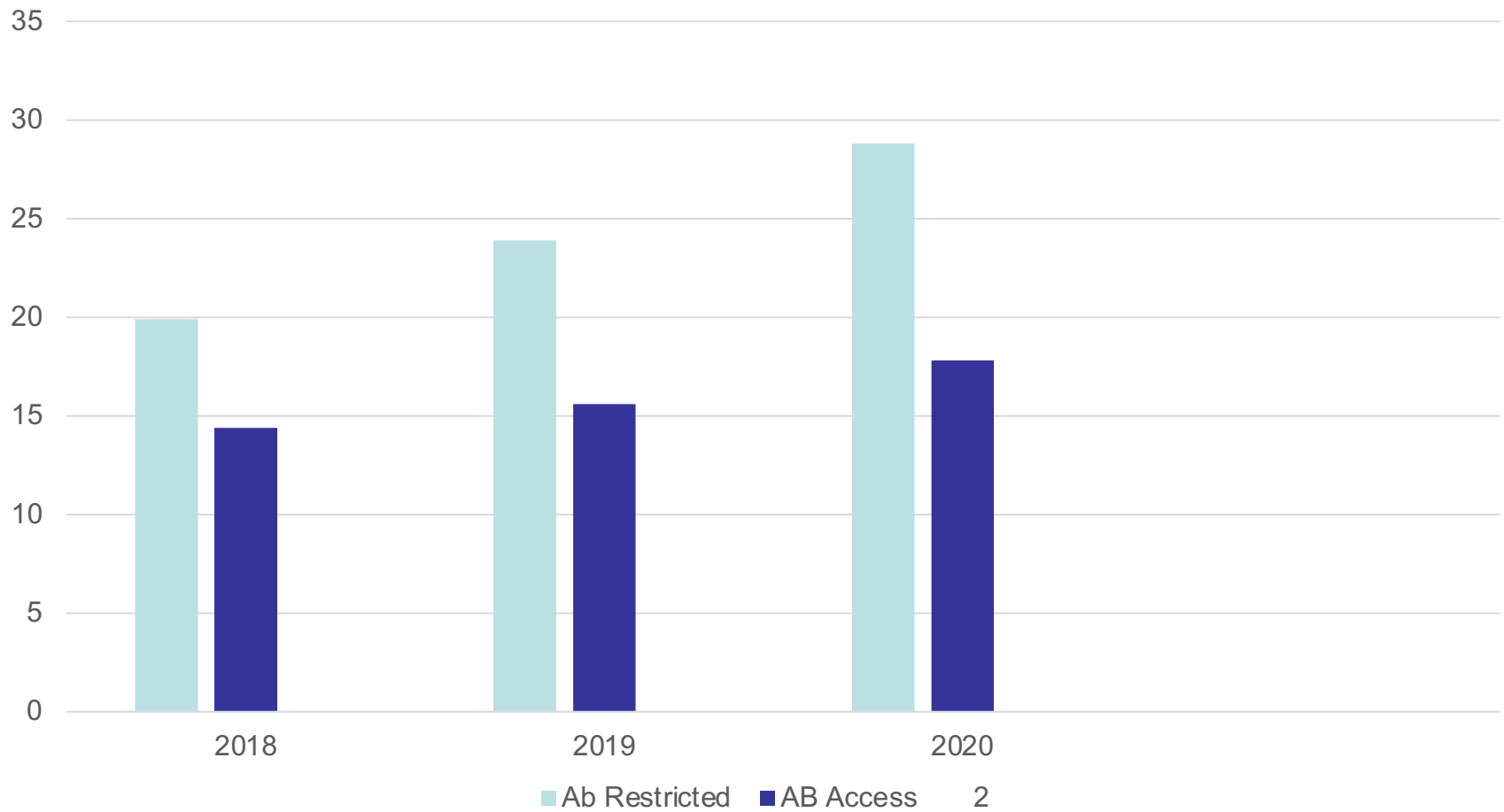
# Abortion rate declining

- With the end of pandemic and other expansion of Medicaid coverage, we can expect an increase demand for Abortions
- But with abortion now banned in many states and severely restricted in others, what are women to do if faced with this terrible Choice?
- Will there be “Wrongful Life” lawsuits against the State ?

# Abortion

- And why do some States ban abortion with no exception for cases of Incest, Rape, Underage (which implies Rape) or in the interest of the Mother's Health?

# Maternal mortality impact by state abortion policy, 2018-2020

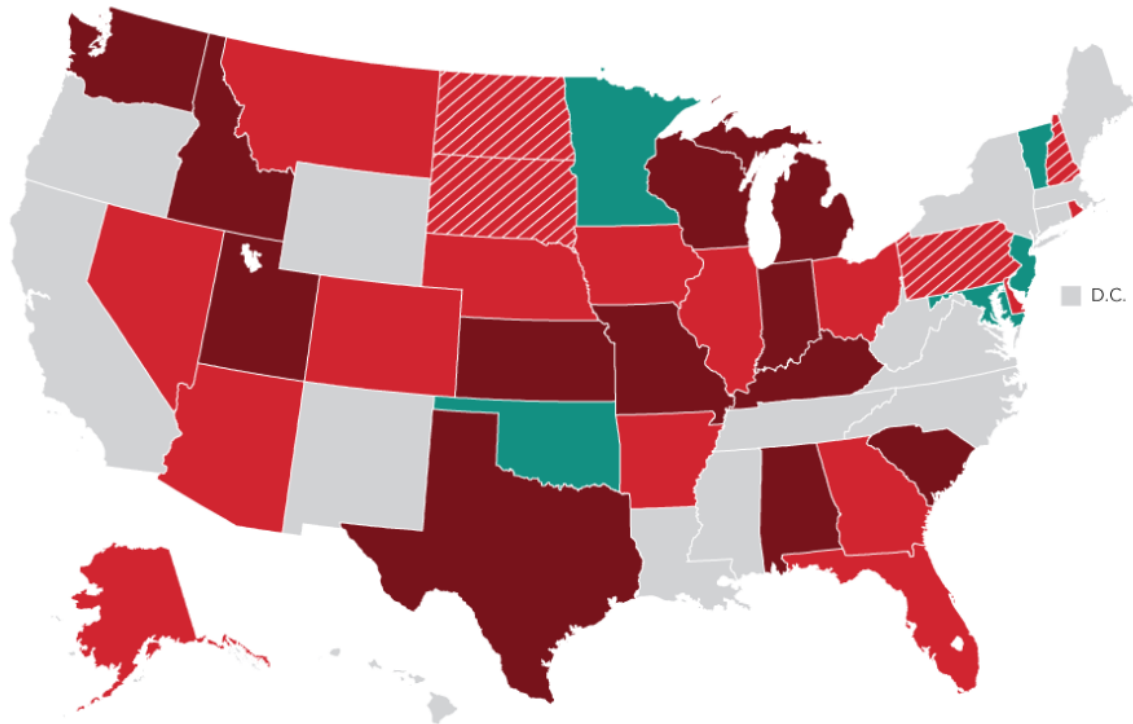


Data: Centers for Disease Control and Prevention, "[National Center for Health Statistics Mortality Data on CDC WONDER](#)," last updated Dec. 22, 2021.

Source: Eugene Declercq et al., *The U.S. Maternal Health Divide: The Limited Maternal Health Services and Worse Outcomes of States Proposing New Abortion Restrictions* (Commonwealth Fund, Dec. 2022). <https://doi.org/10.26099/z7dz-8211>

# Where Pregnant Women Are Forced To Stay On Life Support

In most states, terminally ill pregnant women can be forced to accept life-sustaining treatment, even when the patient has authorized a directive against it. States in dark red here have the most restrictive laws, requiring life support to be continued regardless of the progression of the pregnancy, with no exceptions for pain or physical harm caused by the treatment.



- Automatically invalidates a pregnant woman's advance directive, no exceptions
- Requires life support when it is probable the fetus will develop to the point of "live birth" or viability outside the uterus
- Exceptions may be made for pain or harm caused to the woman by life-sustaining treatment
- Allows women to write their wishes regarding pregnancy into their advance directives and guarantees that their instructions will be followed
- Lacks statutory language regarding the validity of advance directives in the case of pregnancy, or unknown

# International Law regarding Abortions

- UN [Human Rights Committee](#) considers the physical and mental pain a Mother had to endure, including “the distress of seeing her daughter[.]...and knowing she would die very soon.” The committee found that her treatment violated the prohibition on torture, cruel, inhuman, or degrading treatment or punishment in the International Covenant on Civil and Political Rights

# International Law regarding Abortions

- International Covenant on Civil and Political Rights
- has been ratified by 173 countries, including the United States
- The United States will be reviewed by this committee for its compliance with the treaty in Fall of 2023.
- UNHRC required Ireland and Columbia to pay Reparations to Mothers forced to carry to term or travel to other Countries to obtain the care they needed.
  - The Nation June 2023

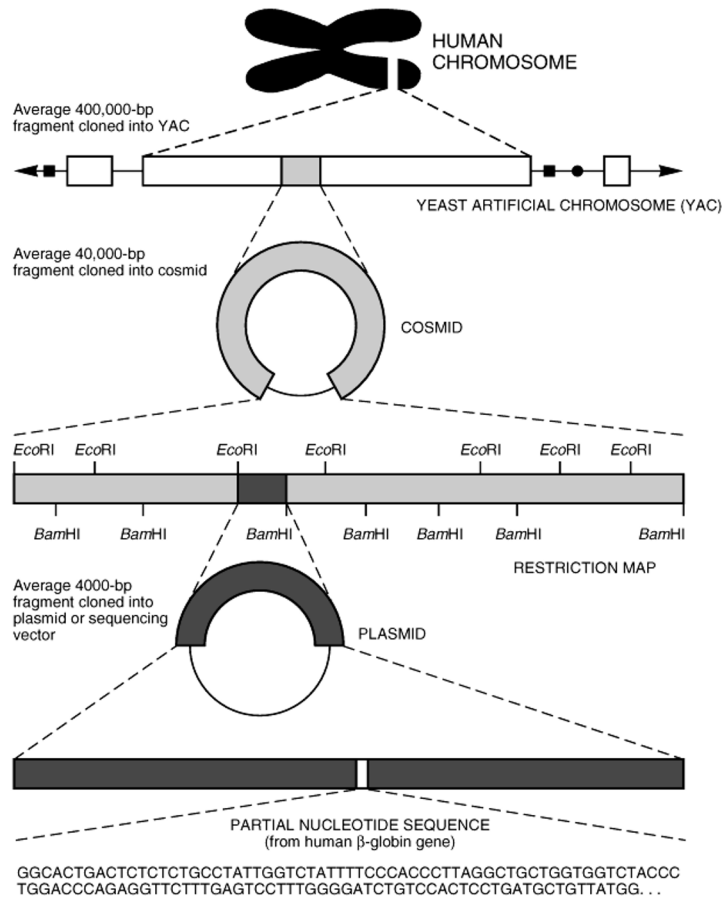


# Cloning Controversies

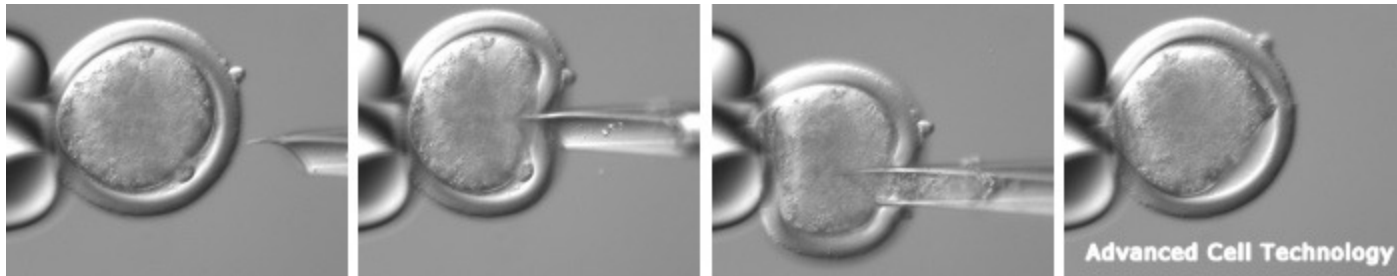
- Gene splicing
- Gene immortality
- Embryonic cell transfer
  - Destroys the embryo
- When does the embryo become a “person” (with rights etc)
- What about embryos which are discarded?
- What about the potential for life saving?

# Cloning Controversies

ORNL-DWG 91M-17367



# Cloning nuclear transfer into an ovum



# Dolly the sheep





# Michigan Law 2008

- State law in 2006 established 10 years/\$10 million fine for scientists who create new embryonic stem cell lines.
- Nov 2008 Michigan Voters approved a Law which overturned the state law, and allows use of embryos discarded after fertility treatments.

# Stem Cell Use

- Embryonic stem cells come from embryos.
- Decision has to be made about the status of embryo:
  - Has potential for full human being.
  - There is fetal loss (not 100% of embryos are able to proceed thru pregnancy to term).
  - What is to become of the embryo if it does not get implanted after IVF?
  - What damage occurs to “societal fabric” when embryos are destroyed?
  - Is this damage balanced by the potential for good?

# Presidential Directive

## March 2009

- Obama Administration restates the Federal Position on Stem Cell Research:
  - May proceed with any cell line (previously was restricted to lines produced before Jan 1 2001).
  - Within “ethical guidelines”
  - NIH will establish guidelines for the ethical use of Embryonic Stem Cells in research.



# Cloning Kidney Tissue



# Henrietta Lacks Case

- HL cell line was cloned from cells taken from cancer from Henrietta Lacks.
- It was discovered that those cells are immortal and they became widely used for cancer research and other purposes
- However, Mrs Lacks never was asked for use of her cells/ tissue.
- Her Family has sued to gain recognition for her contribution to medical science.

# Human Genome

- SCOTUS prohibits patents on naturally occurring human genes, but allows patent protection on synthetically produced Genetic material 2013.
  - Assoc for Molecular Pathology vs Myriad Genetics
  - Myriad had claimed patents on testing for 2 cancer genes, which would have lead to higher price for testing.

# Human Genome

- BUT...
  - Draft Bill in Senate aims to clarify patent eligibility rules, and such rules should not rely on "Judicially created exceptions" like "abstract ideas, Laws of Nature or Natural phenomena"
  - This would invalidate most restrictions on industry and software.
  - Would enable monopolies on discoveries that should be widely available for research and medical use.

# Human Genome

- PXE International. Founded 1995 by the Terry family, which has 2 children with PseudoXanthoma Elasticum.
  - Created research consortium and patient registries.
  - Funds clinical research
  - In order to access the PXE tissue bank, researchers have to agree to list the patient group on any patent filing, ensuring the patients have a voice

# Physician assisted Suicide

- How does it differ from Euthanasia?
- Oregon Death with Dignity Act passed in 1994, survived a recall in 1997 and went into effect 1998.
- In period from 98-2007, 341 pts died under the law.
- In Netherlands, 900 – 1300 pts per year use PAS.
- Washington State passes similar dignity Act Nov 2008. Takes effect March 2009 - 36 pts in 2009, for 2010: 68 docs wrote Rx for 87 pts, 51 of whom took Rx and died. (am Med News, In Brief. May 2011 pg 21)

# Physician Assisted Suicide

- 2001 AG Ashcroft Interpretive rule that PAS is not a legitimate use of medication under the Controlled Substances Act (CSA).
- Appeals all in favor of Oregon Death with dignity act.
- Supreme court case of Gonzales vs Oregon also ruled in favor of States right to regulate medical practice.

# Physician Assisted Suicide

- 1994: Oregon passes the Death with Dignity Act (PAS)
- Washington v Glucksberg 1997. Liberty interest created by the 4<sup>th</sup> amendment does not include a “right to die”. Regulation about PAS is up to the States.
- Gonzalez v Oregon 2006. PAS is up to the state. DEA directive that drugs for PAS violate the Controlled Substances Act exceeded the agency’s authority.



# Physician Assisted Suicide

- Every Medical organization has published policy stating that PAS is never condoned.
- The harm to the status of medical practitioners outweighs the benefit to the patient.
- Patient comfort can and should be obtained in every case, without making death the goal of treatment.

# Physician Assisted Suicide

- Dr Kavorkian pushes issue and 44 states forbid PAS.
- Ohio legislature passes Law forbidding PAS, punishable under criminal law. 2003.
- But Ohio Supreme Court found that PAS is not a crime in 1996.
- After law passed, pt complaints skyrocket as physicians fear prosecution if a pt dies using pain meds they prescribed.
- Ohio passes another law to compell physicians to treat pain ( the fifth Vital Sign).

From: **The Changing Legal Climate for Physician Aid in Dying**

JAMA. 2014;311(19):1961-1962. doi:10.1001/jama.2014.4117

**Table. States Currently Legalizing Aid in Dying for Mentally Competent, Terminally Ill Adults**

State	Year of Legalization	Path of Recognition	Eligibility Criteria	Citation for Statute or Court Decision
Oregon	1994 and 1997	Public referenda	Mentally competent, terminally ill adults	Or Rev Stat §§127.800-127.897
Washington	2008	Public referendum	Mentally competent, terminally ill adults	Rev Code Wash § 70.245
Montana	2009	State supreme court decision	Mentally competent, terminally ill adults	<i>Baxter v State of Montana</i> , 224 P3d 1211 (Mont 2009)
Vermont	2013	Legislation	Mentally competent, terminally ill adults	18 Vt Stat §§5281-5292
New Mexico	2014	State trial court decision (subject to reversal on appeal)	Mentally competent, terminally ill adults	<i>Morris v Brandenburg</i> , No. D-202-CV 2012-02909 (Bernalillo County, NM, January 13, 2014)

**Figure Legend:**

States Currently Legalizing Aid in Dying for Mentally Competent, Terminally Ill Adults

# Palliative Sedation

- Principles:
  - Words matter – Proportional Sedation may be better term
  - Intent Matters – Goal is relief of pain not death
  - Causation Matters
  - Informed Consent must be broadly conceived
    - From Bioethics Network of Ohio Conference 2023

# Artificial Nutrition and Hydration

- Patients and caregivers have the right to withhold or withdraw AN&H
- There are many occasions in which withholding AN&H does not hasten death
- Noisy breathing/ aspiration and incontinence can be consequences of continued AN&H.
- Practice Paper of the Academy of Nutrition and Dietetics: Ethical and Legal Issues of Feeding and Hydration published on the Academy website at: [www.eatright.org/positions](http://www.eatright.org/positions).

# Summary

- You can make your practice according to your beliefs.
- The State has an interest in protecting life.
- Legislators are Idiots.
- Ethics committees are available to help you out in a jam or answer questions!