

# The AHCA and anencephaly

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In anencephaly, lower brain structures are present. Credit: CDC

Last week I read with incredulity section 215 of the American Health Care Act, the part that states that it "does not include coverage for abortions (other than any abortion necessary to save the life of the mother or any abortion with respect to a pregnancy that is the result of an act of rape or incest)."

How would such a draconian measure, should it become law, affect the field of prenatal diagnosis? For surely in some medical circumstances for some individuals, terminating a pregnancy after learning of a devastating fetal malformation is an appropriate, if tragic, choice – even if the woman's life is not threatened nor is she a victim of rape or incest. (Here is a [map](#) of states that do and do not cover elective abortion under the Affordable Care Act.)

To me, what is threatening is the use of the religious beliefs of some to control the bodies of others. And I suspect that very few of the happy white men celebrating in the Rose Garden last Thursday after their "victory" over women's bodies are experts in prenatal diagnosis.

## **A rare neural tube defect**

The first scenario that popped into my mind last week: a [prenatal diagnosis](#) of [anencephaly](#), a severe type of [neural tube defect](#). NTDs are parts of several syndromes and have genetic and environmental underpinnings. They are not caused by an unhealthy lifestyle, not believing in a certain deity, or belonging to a particular political party – they just happen.

Anencephaly affects only 1206 pregnancies a year in the US.

Development derails at day 28 of embryonic development, when tissue running along the back should fold into a tube, then the front swell and form the brain while the tail part specializes into the spinal cord. If this neural tube doesn't close up on schedule, gaps remain, like a broken zipper. Lower gaps result in spina bifida; the highest gaps, [anencephaly](#).

A fetus with anencephaly develops, but without the forebrain and the cerebrum, the higher brain centers. That means no perception of pain, no consciousness. Lower brain centers, which control vital functions such as breathing, persist, but a good portion of the brain, skull, and scalp are missing. The fetus looks like the Zika kids born with microcephaly, only much worse.

The media tend to use unscientific language, as does the AHCA section 215. For example, "[Mother decides to carry baby without brain to term to donate organs](#)" describes a fetus as a baby, the baby as brainless, and a [pregnant woman](#) without children as a mother. But semantics are the least of the problems.

Parents of anencephalic offspring occasionally make [headlines](#) when they decide to carry to term and then harvest and donate the organs of their infant. That's a very brave and generous choice – emphasis on choice.

I couldn't stand to be a newborn organ incubator. Yet the AHCA would condemn every woman carrying a fetus known to have anencephaly, or any of more than 1000 other anomalies, to endure the pregnancy to its tragic and inevitable end, unless she could afford to end it sooner than does nature.

It's difficult to find even Google Scholar articles free from religious undertones or outright judgment, but the results of one study from Brazil provide [actual data](#). It reviews 180 cases: 77 (43%) ended as spontaneous

abortions or stillbirths, 50 (28%) of the pregnant women dropped out of care once learning the diagnosis, and of 53 (29%) that were delivered, 33 were alive, and of those, 27 lived fewer than 5 minutes. Development had ceased among those that made it to delivery at 31 to 32 weeks.

Another study reports that 40% of those born alive survive for longer than a day, and of these, 5% make it a week. Googling anencephaly brings up images of the very few who survive longer – they're difficult to look at.

## Seeking prenatal care

How might the AHCA play out for a woman carrying a fetus doomed by anencephaly and unable to afford prenatal care or an abortion?

Imagine an unplanned pregnancy. A woman, let's call her June, doesn't know that taking folic acid supplements, starting before conception, can [lower the risk](#) of a neural tube defect. (

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