

House Bill No. 1478

There are a myriad of reasons that an individual seeks out contraception, including preventing unwanted pregnancy, treating a medical condition such as endometriosis or polycystic ovarian syndrome, preventing pregnancy when on a medication that could be harmful to a developing fetus, and due to a medical condition, that would make pregnancy dangerous.

In my scope as a genetic counselor who practices in reproductive medicine, I have had the privilege of working directly with individuals and families as they navigate reproductive planning and decision-making. I recall one couple who had recently found out they were both carriers of the same recessive genetic condition, meaning each of their future pregnancies had a 25% chance of being affected. For the sake of privacy, I will not name the condition, but it is a disease with onset of symptoms in childhood. Symptoms can be serious and life-threatening, and this condition is associated with an overall shorter life-expectancy. In addition to significant health concerns, treatment for this condition can cost hundreds of thousands of dollars, placing an additional financial burden on families.

The couple I was working with had a prior pregnancy scare and were incredibly anxious about passing on this genetic condition. They felt immense guilt for not being careful and for their status as carriers of a genetic disease (which they have no control over) Thankfully this couple was able to access birth control which gave them peace of mind and time to discuss various reproductive options with their medical team before pursuing pregnancy when it was right for them. All North Dakota residents deserve the right to make decisions about if or when to pursue creating a family, and they deserve an open discussion about family building options.

I have also worked with individuals who have a genetic condition in which pregnancy can be very dangerous to the health of the pregnant person. One example is a connective tissue disorder called Marfan Syndrome, which has a prevalence of about 1 in 5,000 individuals (~156 North Dakotans). Individuals with Marfan Syndrome are at an increased risk of aortic root dilation and dissection, the leading cause of early mortality in affected individuals. Pregnancy can be incredibly taxing on the cardiovascular system and can lead to further weakening and dilation of the aortic root in individuals with Marfan Syndrome. Prior studies have documented increased infant and maternal mortality rates, as well as an increased need for emergency cardiac surgery for pregnant patients with Marfan syndrome. Individuals with Marfan syndrome should carefully consider pregnancy and the associated risks, as well as have a monitoring plan in place with high-risk pregnancy providers and Cardiologists. When or if an individual with Marfan syndrome pursues pregnancy should be their choice, and they deserve access to reliable ways to prevent pregnancy.

Protecting access to contraception protects North Dakotans. I have highlighted situations that I encounter on a regular basis but there are countless others. I am happy to answer any further questions and can be reached at ejohnson7107@gmail.com. Thank you for your time and consideration.

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