



# Mission: Control. How Can We Increase Highly Effective Contraception Use in Women With Epilepsy?

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## Prevalence of Highly Effective Contraception Use by Women With Epilepsy

Herzog AG, Mandle HB, MacEachern DB. *Neurology*. 2019; pii: 10.1212/WNL.0000000000007581. doi:10.1212/WNL.0000000000007581. [Epub ahead of print]. PMID: 31101739.

**Objective:** To determine (1) the proportion of women with epilepsy (WWE) at risk of unintended pregnancy who use highly effective contraception, (2) demographic predictors, and (3) folic acid (FA) use. **Methods:** These cross-sectional data come from 311 US WWE, 18 to 47 years, who participated in the Epilepsy Birth Control Registry (EBCR) web-based survey in 2017. They provided demographic, epilepsy, antiepileptic drug (AED), contraceptive, and FA data. We report frequencies of highly effective contraception use and use logistic regression to determine demographic predictors. We report the proportion who take FA. **Results:** A total of 186 (59.8%) of the 311 WWE were at risk of unintended pregnancy. A total of 131 (70.4%) used a highly effective contraceptive category; 55 (29.6%) did not. An additional 13 (7.0%) used a combination of generally effective hormonal contraception with an enzyme-inducing AED, which poses increased risk of unintended pregnancy. Overall, 68 (36.6%) of the 186 WWE at risk did not use highly effective contraception. Increasing income ( $P = .004$ ) and having insurance ( $P = .048$ ) were predictors of highly effective contraception. A total of 50.0% took FA supplement. There was no significant difference in relation to the use or lack of use of highly effective contraception. **Conclusion:** A total of 36.6% of WWE in the EBCR did not use highly effective contraception and 50.0% did not take FA in 2017 despite the important negative consequences of unintended pregnancy on pregnancy outcomes. There is a need for more readily available information and counseling on safe and effective contraception and FA use for this community.

## Commentary

Women with epilepsy (WWE) are encouraged to plan their pregnancies in order to minimize avoidable risk of teratogenic antiepileptic drug (AED) exposure and to optimize seizure management. Achieving this goal requires that women are adequately informed and empowered to manage their epilepsy and their family planning. In the United States, half of all pregnancies are unintended.<sup>1</sup> The risk of unplanned pregnancy in WWE can be increased due to a lack of awareness of the interaction between hormonal contraceptives and hepatic enzyme-inducing antiepileptic drugs (EIAED).<sup>2</sup> Therefore, epilepsy quality metrics state that all WWE of childbearing potential should receive regular counseling from their neurologist on issues related to reproductive health.<sup>3</sup> Women who are sexually active and do not want to become pregnant should be recommended to use an effective form of contraception.

Despite a growing body of evidence and increased focus on issues related to pregnancy in WWE over the last decade, improvement in clinical practice performance has been slow to follow. In 2000, the rate of unintended pregnancy among WWE was reported at 56%.<sup>4</sup> In 2014 and 2018 assessments,

that rate was found to still be 50% to 65%.<sup>2,5</sup> A retrospective chart review study in 2016 found that neurologists documented counseling on pregnancy and contraception for only 1 in 3 WWE, the same rate that was reported in 2000 and 2005.<sup>4,6,7</sup> Problematic interactions between AEDs and oral birth control pills with increased rates of contraceptive failure were already reported in the 1970s, yet a survey of WWE in 2009 found that 65% were unaware of this issue.<sup>8,9</sup> In order to improve the gap in quality of care and increase the odds that WWE will achieve planned pregnancy, it is critical that we improve our understanding of contraceptive practices and barriers to optimal care in this population.

The study of Herzog et al provides an important benchmark of current contraceptive practices among WWE. The Epilepsy Birth Control Registry (EBCR) was an online survey of WWE aged 18 to 44 who were primarily referred via Facebook (36%) or through the Epilepsy Foundation of America (34%), with 5% referred by a neurologist. The analysis was based on 186 women who self-identified as heterosexually active, not currently pregnant or attempting pregnancy, but capable of becoming pregnant. The survey was completed in 2017 and




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was a follow-up to a similar assessment made from 2010 to 2014.<sup>2</sup> Only 10 women were on no AED therapy, 17% were on an EIAED, and 7% were taking valproate. Only 4 women reported using no method of contraception. Highly effective contraceptive methods were defined as those with an expected <10% per year failure: systemic hormonal therapies, intrauterine device, tubal ligation, and partner vasectomy. Among the survey respondents, 70% were using a highly effective form of contraception. However, 7% were using a hormonal contraceptive in conjunction with an EIAED. Thus, in total, 36.6% were not using a highly effective contraceptive method and were at risk of unintended pregnancy. Predictors of highly effective contraception use included older age, having insurance, and higher income. Only 20% of the women surveyed with no insurance were using effective contraception. Only half of the women were taking folic acid supplement, and this rate did not differ between those taking versus not taking highly effective contraception. These numbers show little improvement from the prior EBCR survey of 2010 to 2014, in which 45% of respondents were found to be at increased risk of unintended pregnancy.<sup>2</sup> Specifically, in that report, 30% were not using highly effective contraception and 14.5% were taking both hormonal contraceptive with an EIAED. Survey participants were primarily white (89%), highly educated (92% with education level of some college or greater), and highly insured (97%). Income levels were similar to those of the general US population. These demographics are important as race, education, and income are known to influence contraceptive use patterns and risk of unintended pregnancy in the general population, suggesting that a similar assessment done in a cross-sectional population sample of WWE could show even lower rates of highly effective contraceptive use.<sup>1</sup>

There is a demonstrable need for continued improvement in pregnancy planning for WWE. There is some evidence for effective strategies to achieve this goal. Ongoing education of health-care providers in primary care, gynecology, and neurology is needed. Neurologist should not expect to defer these conversations to other providers, as many WWE report that they expect to receive information about contraception in the epilepsy clinic.<sup>2</sup> Counseling by the neurologist about contraception in general and a specific recommendation for a highly effective contraceptive have been shown to significantly increase the utilization of same contraceptive in WWE.<sup>7</sup> Educating women on the effectiveness of specific forms of contraception is critical, so they can make informed choices. Methods that do not require active compliance, such as an intrauterine device, are preferable. We can learn from the experience of our dermatology colleagues with isotretinoin, a medication for severe cystic acne with a high teratogenic potential. Despite increasingly strict regulations for isotretinoin use in women of childbearing potential including required monthly pregnancy testing, mandated patient education with an online test of knowledge, and an agreement to use contraception or to be abstinent, the rate of exposed pregnancies did not improve.<sup>10,11</sup>

Two main barriers were identified: the first was women's lack of understanding of the relative effectiveness of different contraceptive methods with many using less reliable methods such as condoms. The second was failure of the chosen contraceptive method due to noncompliance, including missed doses of oral birth control pills. Ultimately, contraceptive choice for each individual should reflect her unique preferences and goals. However, we can encourage WWE who do not desire pregnancy to use methods that are highly effective and ideally do not require active compliance such as the intrauterine device. As neurologists, we have the necessary tools to help our patients with epilepsy plan their pregnancy. Let's not let another decade pass before we can say that this mission is accomplished.

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