## A MIXED-METHODS INVESTIGATION OF THE CONTRACEPTIVE NEEDS OF TEENS WITH EPILEPSY

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Epilepsy, a poorly understood and often stigmatized disorder, affects more than one million women and girls in the US, making it the most common neurological disorder in females of reproductive age. The disorder is characterized by the occurrence of unpredictable seizures. There are many different types of seizures and people with epilepsy can experience a range of mental and physical changes during seizures, many of which can increase risks of morbidity and mortality and decrease quality of life.

For many reasons, women and girls with epilepsy must obtain specialized sexual and reproductive health care. This is partly because of the potential for interactions when both epilepsy medications and hormonal contraceptives are taken. If the wrong combination of epilepsy medications and contraceptives is used, the risks of unplanned pregnancy and seizure occurrence increase, though if the right combination is taken both reproductive and seizure control can be improved. Also, though most people with epilepsy who have biological children have safe and normal pregnancies, epilepsy medications taken during pregnancy do increase the risks for fetal malformations.

Prior research shows that many health care providers are unaware of the specialized sexual and reproductive health care needs of women and girls with epilepsy, and that many women with epilepsy face challenges getting the care they need. This study complements prior research and focuses on the sexual and reproductive health care needs of teens with epilepsy. This is a critical area of inquiry because of the potential impacts for both neurological and reproductive health.

We aimed to explore the sexual and reproductive health knowledge and decision making of teens with epilepsy, as well as their current and desired experiences with sexual and reproductive health care. This multi-method study included an online-survey with 114 teens with epilepsy and 12 online focus groups with 26 teens with epilepsy. All survey data was analyzed in SPSS where basic descriptive statistics were generated. All qualitative data was analyzed using framework analysis methods with the support of ATLAS.TI.

Several common themes emerged from the survey and focus group data. First, participants lacked comprehensive information about their specific sexual and reproductive health needs. They reported considerable confusion about the potential for interactions between epilepsy medications and hormonal contraceptives. They were also unclear on how hormonal contraceptives could improve seizure control in some cases. Additionally, participants vastly overestimated the chances of children born to people with epilepsy inheriting epilepsy or being born with birth defects.

These information gaps appeared to have an impact on teens' sexual and reproductive health decisions. A large minority of participants related that they avoid going on hormonal contraception and/or that they aggressively limit the type of contraception they use, decisions not firmly grounded in the existing evidence base showing the safety of contraceptive use in the population. Also, a large majority of participants expressed considerable worry about having children in the future. Participants were particularly concerned about their children inheriting epilepsy or being born with a birth defect caused by their use of epilepsy medications use during pregnancy. Further, participants presumed both outcomes are highly likely though the scientific evidence shows that they are not common. Participants stated they wanted to avoid these outcomes and a small number anticipate avoiding having biological children to prevent them.

Though only a minority of study participants had received sexual and reproductive health information from their health care providers, participants saw these providers as critical and trusted resources for information and health care decision making. The majority of participants expressed a desire for more sexual and reproductive health information and thought that an epilepsy specialist was the most appropriate doctor to provide this information. Participants commonly reported they would want a parent, most likely their mother, to participate in some capacity in health care visits focused on sexual and reproductive health. Participants expressed that they often involve a parent in their epilepsy care and prefer to involve them in any type of health care that might ultimately impact their neurological health.

Though minority experiences, some participants reported poor health outcomes that they contributed to the lacking sexual and reproductive health care they received. These participants reported unplanned pregnancies, increases in seizure occurrence, and missed opportunities to experience many of the benefits of hormonal contraception, such as period regulation and acne improvement.

To help fill information gaps and provide needed sexual and reproductive health decision making support, we created an online resource, www.girlswithnerve.com. We believe the website will help increase the population's knowledge about their sexual and reproductive health options and stimulate teens to discuss their health care needs with appropriate health care providers, increasing the potential for teens to make informed sexual and reproductive health decisions. Findings and the developed resource also have relevance for other teens with chronic health issues that need management during the reproductive years.