



ABSTRACT

A North American Registry for Epilepsy and Pregnancy, a unique public/private partnership of health surveillance. *Epilepsia* 1998;39:793-798

Purpose: A North American Registry of Epilepsy and Pregnancy (NAREP), has been established as a surveillance mechanism to identify adverse pregnancy outcomes which may be associated with fetal exposure to antiepileptic drugs (AEDs). As public attitudes become more receptive, and medical management more effective, women with epilepsy (WWE), are choosing to become pregnant in increasingly larger numbers. In the United States alone there are 800,000 to 1.1 million WWE of childbearing age. The offspring of these women have rates of congenital malformations of 1.25 to 11.5%. Although there are several factors that could contribute to the risk: including AEDs, seizures during gestation, and maternal epilepsy, AED are an important variable over which we have some control. Unfortunately there are currently no data that permit physicians to determine the relative safety of specific AEDs. With the introduction of several new AEDs there is even further uncertainty about the potential safety of AEDs in pregnant women.

Methods: We have organized a prospective registry for pregnant WWE, which will systematically monitor pregnancy outcomes. The registry can serve as an early warning system for adverse outcomes associated with specific AED alone or in combination. The registry has required a cooperative effort between the scientific and pharmaceutical communities. The genesis of this effort is described.

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