

# Success Story: South Carolina Blazes a Trail for Epilepsy Surveillance



## Epilepsy: A Public Health Problem



Epilepsy is a brain disorder that causes repeated seizures and affects up to 3.4 million people in the United States.<sup>1</sup> Uncontrolled seizures can interfere with life and lead to early death.<sup>2</sup>

Enhanced data collection on epilepsy began at the national level in 2010,<sup>3</sup> but little or no data have been collected at the state level. This data gap has left state and local public health leaders without information on their population's needs for epilepsy services and programs.

## Data Collection Critical to Public Health Efforts

With funding from the Centers for Disease Control and Prevention (CDC), the Medical University of South Carolina (MUSC) has collected data and conducted studies to help increase knowledge about epilepsy and how it affects people living in South Carolina. These efforts included setting up the South Carolina Epilepsy Surveillance System (SCESS), the country's first and only state-based epilepsy surveillance system.

The SCESS monitors incidence, prevalence, and unmet needs for people with epilepsy in South Carolina. Data come from inpatient, emergency, and hospital encounters, including information from outpatient surgical offices, physician offices, nursing homes, and specialized clinics and institutions. Health care providers are required to submit the data to the SC Office of Research and Statistics.

**SCESS worked with several partners across the state to gain access to health-related data,<sup>4</sup> including:**

- SC Department of Health and Environmental Control
- SC Budget and Control Board Office of Research and Statistics
- Epilepsy Association of South Carolina
- Medical Association of South Carolina
- SC Hospital Association
- SC Chapter of the American Neurological Association

## South Carolina Conducts Innovative Research

**In addition to collecting data through the SCESS, MUSC conducted innovative research projects from 2001 to 2015 on the following topics:**

- Epilepsy prevalence, incidence, and locations where people with epilepsy receive care.
- The prevalence and effect of comorbid conditions.
- The influence that income and social factors, health care access, attitudes, and beliefs have on health outcomes among people with epilepsy.

The first project was the South Carolina Epidemiological Studies of Epilepsy & Seizure Disorders, which established the SCESS in 2002.<sup>5</sup> Other key activities included initial studies on prevalence and incidence and validation of the SCESS case definitions and data sources.<sup>5</sup>

From 2004 to 2007, the South Carolina Health Outcome Project on Epilepsy (SC HOPE) developed surveys and conducted phone interviews with 370 adults and young people aged 11 to 17 who had received treatment for epilepsy in the past 5 years. One goal was to learn more about their experiences living with epilepsy. The SC HOPE team used multiple strategies to reach people with epilepsy, including mail-outs and phone calls to patients identified from hospital discharge records, emergency department records, and some health plans.

MUSC found that targeted recruitment of patients in clinics worked better than community wide strategies, such as inserting information about the study in local water bills or publishing articles about the study in regional newspapers and local newsletters.<sup>6</sup>

The MUSC team continued to analyze data and publish findings between 2007 and 2011. Later, from 2011 to 2015, MUSC conducted a study called Risk Factors of Epilepsy Outcomes: Comorbidities in Population with Epilepsy.<sup>7</sup> This project assessed the



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