

The Research Priorities at the CDC Epilepsy Program

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Institute of Medicine Report 2012

— Epilepsy Across the Spectrum

- ❑ In 2012, the CDC and our partners supported the IOM report
 - identified progress in epilepsy made over the past decade and highlighted remaining gaps
- ❑ IOM report set priorities for recommendations and suggested strategies for action on epilepsy in public health, health care, and human services, and guided our program's activities

Epilepsy Surveillance

- ❑ IOM report recommendation 2: Continue and expand collaborative epilepsy surveillance and data collection efforts
 - Nationally representative samples
 - National Health Interview Survey (NHIS)
 - School Health Profile
 - Statewide representative samples
 - Sudden Death in the Young Registry (for SUDEP)
 - Other specific populations
 - Rare epilepsy in NY

Epilepsy Prevention

- ❑ IOM report recommendation 3: Develop and evaluate prevention efforts for epilepsy and its consequences
 - Support CDC and commercial labs to develop a better and easy-to-use methodology to effectively detect neurocysticercosis infection in high-risk populations in the field
 - Work with CDC National Injury Center, CDC Division of Heart Disease and Stroke Prevention, Michigan Public Health Institute, and other academic institutions
 - Epilepsy-related causes of death, accident and injury, suicide, SUDEP, and heart comorbidity
 - Work with National Association of Medical Examiner and Coroner (NAME), American Epilepsy Society, Epilepsy Foundation SUDEP Institute and North America SUDEP Registry
 - Improve the awareness of epilepsy related death and strive for consistent death investigation

Epilepsy Self-management

□ Epilepsy self-management programs

- To advance the science of epilepsy self-management by conducting research in collaboration with network and community stakeholders, and broadly disseminating the findings
- CDC leads “Managing Epilepsy Well Network” (MEW network) through the CDC's Prevention Research Centers to develop evidence for the efficacy/validation of epilepsy self-management programs



8 collaborating sites and 6 major programs

<http://web1.sph.emory.edu/ManagingEpilepsyWell/>

Public Health Programs with Epilepsy Foundation

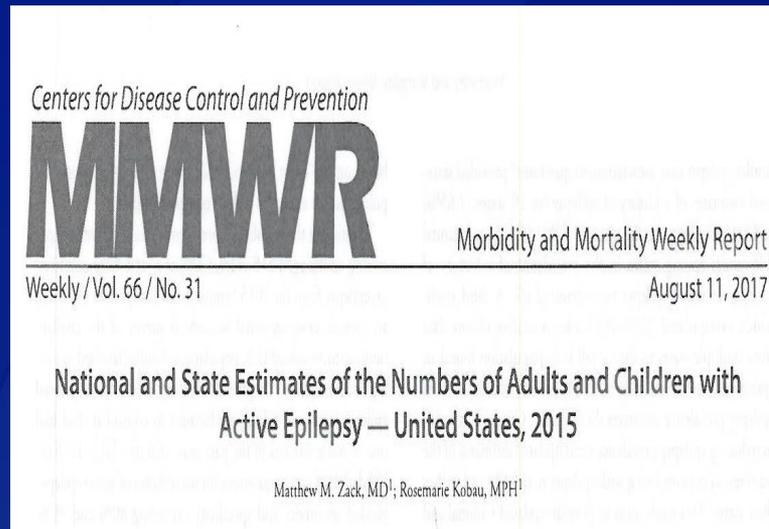
- ❑ Using National Health Interview Survey data, our recent report estimated that about 1.2% of population or 3.4 million persons in the U.S. had epilepsy (*CDC Morbidity and Mortality Weekly Report, August 11, 2017*)
- ❑ Promoting epilepsy as a public health issue and work with one of our key partners—Epilepsy Foundation of America to implement public health programs
 - Improve provider education
 - Increase public awareness/reduce stigma
 - Promote evidence-based self-management programs

In Summary

- ❑ Epilepsy is a spectrum of disorders. (IOM report, 2012) No progress has been made in preventing new-onset epilepsy (JAMA neurology, 2015), and about 30% of all patients with epilepsy are drug-resistant epilepsy (IOM report, 2012)
- ❑ CDC epilepsy program's research projects focus on:
 - Epilepsy surveillance;
 - Epilepsy prevention (primary, secondary and tertiary)
 - Epilepsy self-management
- ❑ Other important public health programs with U.S. Epilepsy Foundation

MMWR, August 2017

- The first State estimates of the numbers of adults and children with active epilepsy



Morbidity and Mortality Weekly Report

TABLE 2. Estimated numbers of active epilepsy cases, by state and age group — United States, 2015

Geographic area	Age group (yrs)		
	All ages	<18 ^a	≥18 ^b
	No. (95% CI) ¹	No. (95% CI)	No. (95% CI)
United States	3,439,600 (3,009,100–3,870,100)	471,900 (392,600–551,200)	2,967,700 (2,544,500–3,390,800)
Alabama	54,100 (46,400–61,900)	7,500 (5,900–9,200)	46,600 (39,000–54,200)
Alaska	7,200 (6,100–8,300)	1,100 (800–1,400)	6,100 (5,000–7,200)
Arizona	77,000 (66,400–87,500)	11,200 (8,900–13,600)	65,700 (55,400–76,000)
Arkansas	32,800 (28,000–37,600)	4,900 (3,700–6,100)	28,000 (23,300–32,600)
California	427,700 (372,600–482,900)	59,800 (49,000–70,600)	367,900 (313,800–422,000)
Colorado	56,800 (48,300–65,300)	7,800 (6,000–9,600)	49,000 (40,700–57,300)
Connecticut	35,900 (30,400–41,400)	4,500 (3,400–5,700)	31,400 (26,000–36,800)
Delaware	9,700 (8,200–11,100)	1,300 (900–1,600)	8,400 (7,000–9,900)
District of Columbia	7,500 (6,300–8,800)	800 (600–1,100)	6,700 (5,500–7,900)
Florida	223,900 (194,100–253,800)	27,300 (21,900–32,800)	196,600 (167,200–225,900)
Georgia	110,200 (94,900–125,500)	16,700 (13,200–20,100)	93,500 (78,600–108,500)
Hawaii	14,000 (11,900–16,100)	2,000 (1,500–2,400)	12,000 (10,000–14,100)
Idaho	16,800 (14,200–19,300)	2,600 (2,000–3,200)	14,200 (11,700–16,600)
Illinois	136,600 (117,900–155,400)	18,600 (14,900–22,400)	118,000 (99,700–136,400)
Indiana	69,500 (59,600–79,400)	10,600 (8,300–13,000)	58,900 (49,200–68,500)
Iowa	31,400 (26,800–36,100)	4,400 (3,400–5,400)	27,000 (22,500–31,600)
Kansas	29,900 (25,500–34,300)	4,400 (3,400–5,400)	25,500 (21,200–29,900)
Kentucky	49,500 (42,000–57,000)	6,800 (4,900–8,700)	42,700 (35,500–50,000)
Louisiana	54,900 (46,600–63,200)	7,900 (6,200–9,700)	47,000 (38,900–55,100)
Maine	14,100 (11,900–16,300)	1,700 (1,200–2,200)	12,400 (10,300–14,600)
Maryland	59,900 (50,700–69,100)	7,900 (6,200–9,700)	52,000 (42,900–61,000)
Massachusetts	71,600 (60,900–82,300)	8,400 (6,500–10,300)	63,200 (52,600–73,700)
Michigan	108,900 (92,200–124,500)	13,600 (10,900–16,400)	95,300 (79,900–110,600)

The estimated number of persons with active epilepsy, after accounting for income and age differences by states, ranged from 5,900 in Wyoming to 427,700 in California

MMWR, April 19, 2018

- ❑ The first national estimates of specialist visits, medication use, and seizure control status among people with active epilepsy

CDC Funded Cornell Project

---Rare Epilepsy in New York city: Epidemiology and health outcomes

- ❑ Lack of diagnostic codes for the rare epilepsies make it nearly impossible to identify affected individuals
- ❑ Sophisticated natural language processing system using machine learning algorithms can be trained effectively to classify text documents, including physicians' clinical notes
- ❑ 1 million clinical notes have been collected from five medical centers in New York City to establish a population-based cohort
 - Incidence, prevalence, comorbidities, and mortality
 - Easy-to-disseminate set of “regular expression” to identify rare epilepsies in large multi-institutional studies

Epilepsy by the Numbers

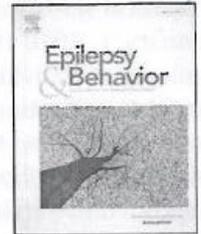


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journal homepage: www.elsevier.com/locate/yebeh



Epilepsy by the Numbers – from the US Centers for Disease Control and Prevention

People with epilepsy are diagnosed most often with unspecified epilepsy, followed by focal epilepsy, generalized convulsive epilepsy, and generalized nonconvulsive epilepsy—US MarketScan data, 2010–2015☆

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- ❑ We are looking forward to collaborating with our partners to improve epilepsy awareness, seizure control, and quality of life among people with epilepsy

Further Information

Reference our website at:

www.cdc.gov/epilepsy

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