

MULTIPLE SCLEROSIS (MS) PREVALENCE IN THIRTEEN NORTHWEST ILLINOIS COUNTIES

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Thanks to everyone who expressed interest or assisted Health Systems Research with this study of MS prevalence in northwest Illinois.

The study would not have been possible without help from the many individuals, organizations, and media who helped. Thanks to everyone who recruited subjects, expressed interest in the study, and most of all to those who completed a participant form. This newsletter summarizes the study and the results.

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THE STUDY: METHODS, ELIGIBILITY REQUIREMENTS AND DATA COLLECTION

Research for this study was focused on seeking answers to these questions:

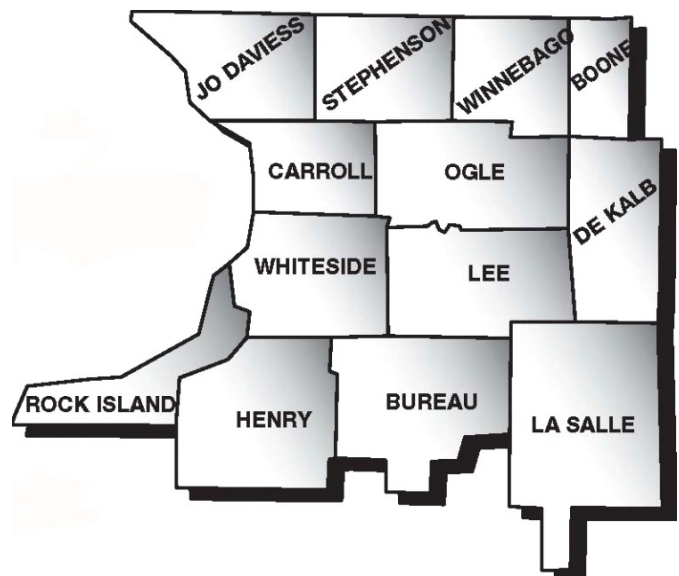
- Is MS prevalence elevated in northwest Illinois?
- Is there variation in MS prevalence across the 13 counties or zip codes within them?
- Do background factors such as ancestry or gender affect the MS prevalence rates?

Health Systems Research used a community-based case-finding methodology for this epidemiologic study to determine the prevalence of multiple sclerosis (MS) in 13 northwest Illinois counties: Boone, Bureau, Carroll, DeKalb, Henry, Jo Daviess, LaSalle, Lee, Ogle, Rock Island, Stephenson, Whiteside, and Winnebago. The region has a total population of about one million persons.

A short participant form was developed including age, zip code, county, ancestry, time since diagnosis, medical tests, relatives with MS, and doctor caring

for their MS. Eligible were persons with MS residing in any of the 13 counties on July 1, 2008.

The participant form was placed online at the College of Medicine's website home page in September 2008 using Survey Monkey for completion and response.



HSR support staff responded to requests for forms by phone or on the HSR "800" number and entered data from responses into SPSS software for statistical analysis. The mailed forms included a postage paid envelope for responding. HSR staff checked responses for duplicates and maintained confidentiality.

HSR staff spoke to MS Support Groups or appeared at professional presentations at DeKalb, Dixon, Freeport, Kewanee, LaSalle/Peru, Ottawa, Rockford, Rock Island, and Stockton.

Media releases, some geographically tailored, were sent out three times in September 2008, December 2008, and March 2009 to 37 daily and weekly newspapers, plus 31 radio and television outlets. In person on-the-air interviews took place at WNTA (Rockford) and WSDR (Sterling) allowing callers to

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interact and ask questions. Numerous other media interviews and reports on the research took place.

The *Rockford Register Star* carried a multi-page feature in the Local & State section on October 7, 2008. Other major articles appeared in the *Bureau County Republican*, *DeKalb Chronicle*, *Dubuque Telegraph Herald*, and *Freeport Journal Standard*.

In January 2009, the National MS Society - Greater Illinois Chapter, sent a mailing urging participation to 1,739 individuals from their database of persons living in the 13 counties. *MS Connection*, the magazine of the Greater Illinois Chapter contained a brief on the research in April 2009. The Prairie Area Library System distributed a letter electronically concerning the study along with a poster for patrons at 385 libraries.

Mailings were also sent to health care providers seeking their cooperation in distributing the participant form and requesting that they place the poster in visible areas and ask patients to take part in the study when newsletters or mailings were sent. Mailings to providers included hospital/health systems, nursing homes, and neurologists. A few physician offices were visited personally.

An additional mailing was sent to more than 500 persons on the HSR "MS List" which includes participants in past studies and individuals interested in MS research who have previously contacted HSR.

Forms were accepted into the study over a ten-month period through May 31, 2009 with 772 received by that time. Just over half, 407 or 52.7% were submitted online while 365 or 47.3% were received through the mail.

The research was supported by a state of Illinois Excellence in Academic Medicine grant from the University of Illinois College of Medicine at Rockford and SwedishAmerican Hospital.

RESULTS: HIGHER MS RATES IN "RURAL COUNTIES," AGRICULTURAL AREAS; COMPTON, WINSLOW, PAW PAW AND ANDOVER HAD HIGHEST RATES OF MS

Overall study area prevalence was 74.7 persons with MS per 100,000 population, less than the 100 per 100,000 level often cited as the U.S. rate. Exceeding 100 were Jo Daviess (135.0), Lee (114.0), Carroll (107.1), and Stephenson (100.9), all non-metropolitan counties. Lowest were Boone (52.6) and Rock Island (40.1) among the 13 study area counties.

MS PREVALENCE BY COUNTY

County	Rate/ 100,000	County	Rate/ 100,000
Boone	52.6	Lee	114.0
Bureau	68.7	Ogle	91.1
Carroll	107.1	Rock Island	40.1
DeKalb	83.7	Stephenson	100.9
Henry	74.6	Whiteside	69.5
Jo Daviess	135.0	Winnebago	71.5
La Salle	87.4	Total	74.7

Of the five highest counties, all are non-metropolitan. At the zip code level, percent employed in farming correlated positively at a statistically significant level, meaning that MS prevalence appears to be associated with the presence of agriculture.

Prevalence was calculated for each zip code in the 13-county area. Compton and neighbor Paw Paw were among the highest rates of MS, along with Winslow and Andover.

MS PREVALENCE HIGHEST ZIP CODES POPULATION OF 500+

Zip Area	Rate/ 100,000	Zip Area	Rate/ 100,000
Compton	855.9	Rock City	262.9
Winslow	435.3	Tampico	242.4
Paw Paw	396.5	Andalusa	238.3
Andover	381.7	Tiskilwa	213.4
Baileyville	328.9	Cortland	213.0

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Small towns may have many related persons, so that some could be prone to elevated levels of MS. Most study participants have been long-term residents of their present community with a median tenure of 30 years. Three-fourths (75.4%) were born in Illinois.

MS PREVALENCE HIGH AMONG WOMEN; AVERAGE PARTICIPANT 42 AT THE TIME OF DIAGNOSIS.

Participants totaled 772 persons self-identified as having MS on July 1, 2008. Each was diagnosed by a health professional.



605 (78.3%) females and 164 (21.2%) males responded. Another 3 (0.4%) did not designate a gender. The female:male ratio was 3.7 for those who answered the gender question. The MS female:male ratio is widely believed to be around 2-3. A 2002 study of MS prevalence and trends observed an increase in MS among women relative to men. With an overall US prevalence of 85 per 100,000 for self-assessed MS, the female:male ratio stood at 2.6. in 1989-1994.

In terms of the age of participants, the median year born was 1956 for a current 2009 age of 53. Median year diagnosed was 1998, so that the “average” participant was 42 at the time of diagnosis.

As for race, 97.2% of participants were white, 1.8% black, and 0.3% American Indian, proportions consistent with MS being a primarily white disease. Hispanic presence was just 0.9%.

Though almost all participants had seen a neurologist, one of ten (10.2%) said that a family doctor is their primary physician for MS care, 81.0% named a neurologist or neurosurgeon, and 5.6% see both a family doctor and neurologist. A handful (2.5%) named another specialty for their care provider.

Asked about tests to verify MS, almost all persons in the study had received an MRI with the great majority

of MRIs being positive. About two-thirds (66.8%) had a cerebrospinal fluid (CSF) test (lumbar puncture or spinal tap). About half (50.6%) were tested for visual evoked potential (VEP) to detect optic neuritis.

GENETICS AND ANCESTRY APPEAR TO PLAY A ROLE IN MULTIPLE SCLEROSIS

Ancestry appears to play a role in the disease. MS is known to be more common in persons of northern European ancestry. MS prevalence increases in the higher latitudes in the United States, though persons of northern European ancestry tend to live in the northern portions of the nation.

Study participants were asked, “To which of the following ancestries do you consider yourself to belong?” Twelve northern European ancestries were listed, same as those reported by the Census. The respondent could mark as many ancestries as they consider themselves to belong or list others.

The leading ancestry by far, marked by 61.0% was German. Following were English (31.3%) and Irish 29.8%, Swedish (14.8%), French (11.8%), Dutch (10.5%), or Scotch-Irish (10.2%). Fewer were Italian (8.5%), Norwegian (8.2%), or Polish (7.1%). Almost all study participants marked at least one northern European ancestry – only 5.7% did not. Northern European ancestry was much greater than predicted by Census data for the entire population of the area.

MS is thought to have a genetic link so that the disease would be expected to be present in some close relatives. Participants were asked whether any close relative (mother, father, sister, brother, son, daughter, first or second cousins) have been diagnosed with MS. Responding positively were 22.2% or greater than one in five study participants. While an exact calculation cannot be made for expected MS in close relatives, this proportion, greater than one in five close relatives with MS is certainly far higher than the overall population prevalence of one-tenth of one percent would appear to yield.



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ENVIRONMENTAL INDICATORS NOT FOUND TO BE ASSOCIATED WITH PRESENCE OF MS

Though environmental causes have been suspected as being associated with MS by some area residents, Health Systems Research could not find evidence of an association.

Four environmental indicators were used to assess the possible influence of community environmental hazards by zip code for the study area, one each for land, air and water contamination, and additionally, the presence of federally designated Superfund sites.



- Indicators used to measure against MS prevalence:
- Leaking underground storage tanks (LUST).
 - Non-compliance violations of the Clear Air Act.
 - Community Water Systems violations.
 - EPA Superfund priority sites.

DISEASE REGISTRIES DESIRABLE

The federal government no longer funds “cluster” studies such as this one because the findings are limited to one geographic area. The National Multiple Sclerosis Society and others are interested in developing state or national patient registries including everyone diagnosed with MS through registration at diagnosis, much like with cancer registries. Accurate research then can be conducted on how many people have MS, their characteristics, residence, and possible risk factors.