

Great Lakes Regional
Stroke Network



The Burden of Stroke in the Great Lakes States



Everybody teaches, everybody learns

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Table of Contents

Executive Summary	4
Introduction	5
What Is Stroke?	6
Why Is Stroke Important?	7
The Stroke Continuum of Care	8
Demographic Characteristics	9-10
Stroke Risk Factors	11-13
Survivor Stories: Stroke Risk Factors	14-16
Recognition of Stroke Symptoms and Anticipated Response to Stroke Symptoms	17-19
Survivor Stories: Stroke Warning Signs	20-21
Pre-transport Stroke Deaths	22
Survivor Story: Pre-hospital Transport	23
Acute Care	24
Stroke Mortality Rates by County and Location of Primary Stroke Centers	25-27
Survivor Story: Acute Care	28
Hospital Discharge Data	29-30
Survivor Story: Rehabilitation	31
Prevalence of Stroke	32
Stroke Mortality Rate	33
Stroke Mortality Rate by Age Group	34
Survivor Stories: Young Survivors	35-36
Stroke Mortality Rate by Gender and Race	37
Summary	38
References	39
Appendices:	
Appendix A-Glossary of Terms	40
Appendix B-Data Sources	41-43
Appendix C-Great Lakes Regional Stroke Network Participants	44

Executive Summary

Stroke is a leading cause of adult disability and the third leading cause of death among men and women in the states of Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin, accounting for over 25,000 deaths or 5.7 percent of all deaths that occurred in the total population in the Great Lakes region in 2002. According to estimates from the Behavioral Risk Factor Surveillance System survey and other state administered surveys, more than 880,000 persons are living with the aftermath of a stroke in the Great Lakes region.

In the Great Lakes region:

- The estimated prevalence of stroke ranges from 2.0 percent (Wisconsin) to 3.9 percent (Michigan);
- The age-adjusted stroke mortality rate per 100,000 ranged from 51.3 (Minnesota) to 60.1 (Indiana) in 2002, with five of the six states having a higher rate than the U.S. age-adjusted rate of 56.2 per 100,000, far exceeding the Healthy People 2010 Objective of no more than 48 per 100,000 population;
- Black men have the highest age-adjusted stroke mortality rates, ranging from 74.6 (Wisconsin) to 89.9 (Ohio) per 100,000 in 2002;
- According to the 2003 Behavioral Risk Factor Surveillance System survey and other state administered surveys, sudden severe headache and sudden vision trouble are the least recognized symptoms of stroke among adults ages 18 and older;
- Among all stroke related deaths in 1999, 45.4 percent (Illinois) to 62.1 percent (Minnesota) occurred before transport to an emergency room;
- There are 49 Joint Commission on Accreditation of Healthcare Organizations (JCAHO) certified primary stroke centers, hospitals fully equipped to meet the specialized needs of stroke patients as of December 2005; and
- More than 122,000 stroke patients were discharged from hospitals in the region with total hospital charges over \$2.3 billion.

Stroke is primarily a disease of lifestyle, and is largely preventable through risk factor awareness and modification. Risk factors for stroke that can be modified or treated include: high blood pressure, heart disease, atrial fibrillation, smoking, diabetes, obesity, and elevated blood cholesterol. Three of the six Great Lakes states have a higher percentage of adults who have high blood pressure, a poor diet, and are physically inactive than the U.S. median. Four of the six states have a higher percentage of adults who have diabetes, high cholesterol, and smoke than the U.S. median. Five of the six states have a higher percentage of adults who are obese than the U.S. median.

States in the Great Lakes region have various and sometimes dissimilar data related to stroke. Specifically, data for stroke prevalence, recognition of and anticipated response to stroke symptoms, and hospital discharge data are from different years or are unavailable for some states. Data on incidence and quality and costs of medical care are lacking. It is especially challenging to find reliable data on American Indian/Alaskan Native, Asian, Hawaiian/Pacific Islander, and Hispanic populations. These limitations make it difficult to compare states within the Great Lakes region and the region with other regions in the United States. Better coordination and timely data analysis is needed to improve efforts to reduce the burden of stroke in the Great Lakes region.

Introduction

The mission of the Great Lakes Regional Stroke Network (the Network) is to optimize collaboration and coordination among the Great Lakes regional states to reduce the burden of stroke and disparities. The Network works through a state advisory board, steering committee, work groups, and individual state stroke task forces/committees to share experiences and resources across six states to implement a common public health plan for stroke. The Network includes state health department heart disease and stroke prevention staff and state stroke task force/committee members in Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. The Illinois Department of Public Health receives funds from the Centers for Disease Control and Prevention to serve as the administrative and fiscal agent for the Network. The Illinois Department of Public Health contracts with the University of Illinois at Chicago Department of Neurology and Rehabilitation's Center for Stroke Research to provide scientific and administrative support for the Network's activities.



The Burden of Stroke in the Great Lakes report is the first attempt to assess the burden of stroke in the Great Lakes region. It is a critical source of information for the Network states and their partners in stroke prevention and treatment. The report presents data on stroke for each Network state including: prevalence, age-adjusted mortality rate, distribution of risk factors, recognition of and response to stroke symptoms, pre-transport deaths, and hospital discharges. In addition, the experiences of stroke survivors from each Great Lake state are shared throughout the report and reveal the true impact of stroke. The data presented will guide the Network's recommendations for public education and quality improvement interventions that address stroke.

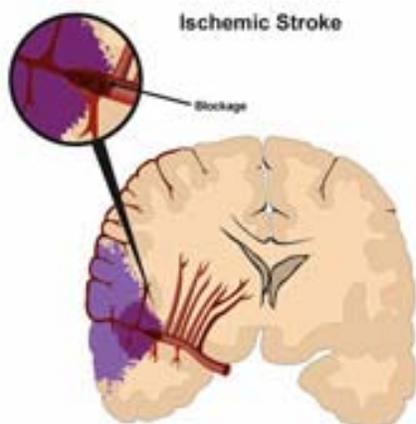
What Is Stroke?

A stroke occurs when the blood supply to part of the brain is suddenly interrupted or when a blood vessel in the brain bursts, spilling blood into the spaces surrounding brain cells. Brain cells die when they no longer receive oxygen and nutrients from the blood or there is sudden bleeding into or around the brain. The symptoms of stroke include:

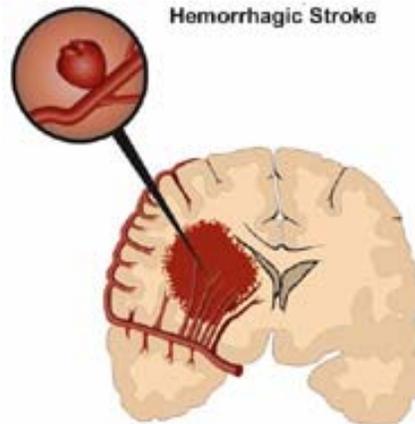
- Sudden numbness or weakness, especially on one side of the body;
- Sudden confusion or trouble speaking or understanding;
- Sudden trouble seeing in one or both eyes;
- Sudden trouble walking, dizziness, or loss of balance or coordination; and
- Sudden severe headache with no known cause.

A person may experience one or several of these warning signs. It is important to call 911 immediately if someone experiences these warning signs.

There are two forms of stroke: **ischemic** - blockage of a blood vessel supplying the brain and **hemorrhagic** - bleeding into or around the brain.^{1, 2}



Ischemic Stroke (Blockage)- caused when there is a blockage in the blood vessels to the brain.



Hemorrhagic Stroke (Bleeding)- caused by burst or leaking blood vessels in the brain.

Transient Ischemic Attacks-Transient ischemic attacks or TIAs are temporary interruptions to the blood supply to an area of the brain. During a TIA, a person experiences a sudden onset of stroke symptoms. A TIA can last up to 24 hours, but most last only a few minutes and cause no permanent damage or disability. Sometimes called "mini-strokes," TIAs must be taken seriously because they are usually a precursor to full strokes.³

Why Is Stroke Important?

Stroke impacts everyone. It is the third leading cause of death in the United States and a leading cause of serious, long-term disability. About 700,000 Americans suffer strokes each year and nearly every three minutes, someone dies of a stroke.⁴ Americans will incur about \$57 billion in stroke-related medical costs in 2005.⁴ As the U.S. population continues to age, the prevalence of stroke is expected to increase, meaning more persons will require hospitalization and rehabilitation services for stroke.

The Great Lakes region is significantly affected by stroke. Stroke is the third leading cause of death and a leading cause of disability in the Great Lakes region. According to estimates from the Behavioral Risk Factor Surveillance System survey and other state administered surveys, more than 880,000 persons are living with the aftermath of a stroke in Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. The exact amount of stroke-related medical costs for the Great Lakes region is unknown. However, with more than 880,000 persons estimated to have suffered a stroke in the region, the economic cost for these individuals and their families is likely substantial. This includes both direct costs (cost of physicians and other medical professionals, hospital and nursing home services, surgical and diagnostic procedures, medications, rehabilitation, and home health care) and indirect costs (lost productivity from disability and premature death).⁵

Stroke is treatable and can be prevented. Not smoking and controlling high blood pressure are examples of steps that can be taken to reduce a person's risk of stroke. Therapies exist for stroke, but must be given soon after the onset of stroke symptoms in order to reduce the likelihood of permanent damage.

The physical, emotional, and financial effects of stroke can be reduced by increasing the public's knowledge of the warning signs and risk factors for stroke as well as the importance of calling 911. Evaluating emergency care, hospital care, and rehabilitation needs of stroke patients can help reduce the negative impact of stroke as well. Learning why some communities suffer disproportionately from stroke is also critical for alleviating the devastating consequences of stroke.

The Stroke Continuum of Care



The stroke continuum of care refers to the range of factors involved in delivering treatment and care for stroke patients. From managing risk factors, recognizing warning signs, and emergency medical services to hospital care and rehabilitation, the stroke continuum of care describes the breadth of stroke care. Rather than simply describing successive steps in stroke care, the continuum is a fluid model, showing that aspects of stroke care are equally important and not exclusive. For example, a person can receive stroke rehabilitation as well as simultaneously manage risk factors for stroke such as high blood pressure. In fact, because stroke patients are at greater risk for another stroke, a stroke survivor may experience points of the continuum more than once.

The Burden of Stroke in the Great Lakes States presents data for each step in the stroke continuum of care. In this report, the prevalence of both modifiable and non-modifiable risk factors for stroke are highlighted. Data on the knowledge of stroke warning signs and anticipated response to stroke symptoms are presented as well. The report includes pre-transport stroke death data that underscores the importance of timely response to stroke symptoms. Data on the number of Joint Commission on Accreditation of Healthcare Organizations (JCAHO) certified primary stroke centers in each state that are equipped to provide acute care for stroke patients are also shared. In addition, hospital discharge data details the number of patients diagnosed with stroke and the total hospital charges for these patients. Finally, prevalence and mortality data for stroke are presented and illuminate the scope of the burden of stroke in the Great Lakes states.



Demographic Characteristics

Anyone can have a stroke, but adults ages 65 and older are more likely to have a stroke. Stroke is more common in men than women. However, overall, more women than men die of stroke. In the U.S., blacks have higher stroke incidence, severity, and mortality than whites.

Table 1 highlights selected demographic characteristics for each Great Lakes state and the United States. The percentage of the total population is presented in parentheses below the estimated number for age, race, and poverty level. Though the Network states vary in population size, each has a significant portion of older, minority, and lower-income residents who are at greater risk of having a stroke. The number of persons age 65 and older in the Great Lakes states will increase to 7.7 million in 2025.⁶ The number of minorities in the Great Lakes states are expected to increase by 90,000 for American Indians, 972,000 for Asians, 1.5 million for blacks, and 1.9 million for Hispanics/Latinos from 1995 to 2025.⁶ As the population continues to age, the burden of stroke is expected to increase. This will have a significant impact on the Great Lakes region as more persons will require health care services. If recent trends continue, disparities may widen, increasing the need for stroke surveillance, prevention, and quality improvement initiatives.⁷

Risk Factors

Recognition of Warning Signs

Pre-hospital Transport

Acute Care

Rehabilitation

Table 1: Selected Demographic Characteristics, 2003

	Illinois	Indiana	Michigan	Minnesota	Ohio	Wisconsin	United States
Population	12,328,721	6,017,445	9,825,840	4,919,584	11,137,722	5,316,215	282,909,885
Persons 65 and over	1,411,495 (11.4%)	713,375 (11.9%)	1,177,082 (12.0%)	563,090 (11.4%)	1,425,707 (12.8%)	662,878 (12.5%)	33,896,172 (12.0%)
White	9,183,037 (74.5%)	5,246,252 (87.2%)	7,888,358 (80.3%)	4,361,106 (88.6%)	9,455,522 (84.9%)	4,692,709 (88.3%)	215,451,392 (76.1%)
Black or African American	1,815,231 (14.7%)	475,654 (7.9%)	1,362,762 (13.9%)	185,355 (3.8%)	1,275,620 (11.5%)	303,396 (5.7%)	34,313,529 (12.1%)
American Indian and Alaska Native	28,813 (0.2%)	19,386 (0.3%)	51,144 (0.5%)	44,044 (0.9%)	26,407 (0.2%)	30,906 (0.6%)	2,173,384 (0.8%)
Asian	484,768 (3.9%)	72,745 (1.2%)	215,470 (2.2%)	170,112 (3.5%)	151,595 (1.4%)	97,025 (1.8%)	11,743,093 (4.1%)
Native Hawaiian and Other Pacific Islander	3,874 (0.0%)	517 (0.0%)	1,184 (0.0%)	1,015 (0.0%)	1,358 (0.0%)	1,402 (0.0%)	404,619 (0.1%)
Hispanic or Latino (of any race)	1,694,185 (13.7%)	237,800 (4.0%)	341,722 (3.5%)	155,015 (3.2%)	227,059 (2.0%)	211,352 (4.0%)	39,194,837 (13.8%)
Median household income (dollars)	47,977	42,067	44,407	50,100	41,350	44,084	43,564
Per capita income (dollars)	24,694	21,063	23,167	25,579	21,643	22,178	23,110
Individuals below poverty level	1,389,329 (11.3%)	633,395 (10.6%)	1,118,345 (11.4%)	383,076 (7.8%)	1,342,982 (12.1%)	553,787 (10.5%)	35,846,289 (12.7%)
Percent of population not covered by health insurance during 2003	14.4%	13.9%	10.9%	8.7%	12.1%	10.9%	15.6%

Sources: U.S. Census Bureau, 2003 American Community Survey.
U.S. Census Bureau, Current Population Survey, 2004 Annual Social and Economic Supplement.



Stroke Risk Factors

Risk factors are behaviors or conditions that influence susceptibility to a specific health problem. Risk factors for stroke that can be modified or treated include: high blood pressure, heart disease, smoking, diabetes, obesity, atrial fibrillation, and elevated blood cholesterol. Non-modifiable stroke risk factors include: age, sex, race/ethnicity, family history, and prior stroke. Geographic location, socioeconomic factors, excessive alcohol intake, and certain kinds of drug abuse are other, less well-documented stroke risk factors.⁸

High Blood Pressure

High blood pressure, defined by systolic pressure of 140 mm Hg or more and/or diastolic pressure of 90 mmHg or more, affects an estimated 50 million people in the United States.⁹ High blood pressure increases the risk of heart disease and stroke. About 66 percent of people experiencing a first stroke have blood pressure above 160/95 mm Hg.⁹ In the Great Lakes region, the percentage of adults with high blood pressure ranges from 22.2 percent (Minnesota) to 27.0 percent (Indiana) (see chart 1 on page 13). Indiana, Michigan, and Ohio have a higher percentage of adults with high blood pressure than the U.S. median (24.8 percent).

Diabetes

Diabetes is a disease in which the body does not produce or properly use insulin, a hormone needed to convert food into energy needed for daily life.¹⁰ About 18 million people have diabetes in the U.S. and about 65 percent of deaths among people with diabetes are due to heart disease and stroke.¹¹ The risk for stroke is two to four times higher among people with diabetes.¹¹ In the Great Lakes region, the percentage of adults with diabetes ranges from 5.5 percent (Minnesota) to 8.9 percent (Ohio) (see chart 1 on page 13). Illinois, Indiana, Michigan, and Ohio have a higher percentage of adults with diabetes than the U.S. median (7.2 percent).

High Cholesterol

High blood cholesterol is a major modifiable risk factor for stroke. An estimated 106.9 million American adults have total blood cholesterol levels of 200 milligrams per deciliter (mg/dL) or higher, which is above desirable levels.¹² Of these, 37.7 million people have levels of 240 mg/dL or higher, which is considered high risk.¹² In the Great Lakes region, the percentage of adults with high cholesterol ranges from 30.8 percent (Minnesota) to 38.2 percent (Michigan) (see chart 1 on page 13). Illinois, Indiana, Michigan, and Ohio have a higher percentage of adults with high cholesterol than the U.S. median (33.1 percent).



Obesity

Being overweight or obese increases the risk of many diseases and health conditions, including stroke. Thirty percent of U.S. adults 20 years of age and older—over 60 million people—are obese (Body Mass Index of 30 or higher).¹³ In the Great Lakes region, the percentage of obese adults ranges from 20.9 percent (Wisconsin) to 26.0 percent (Indiana) (see chart 1 on page 13). Illinois, Indiana, Michigan, Minnesota, and Ohio have a higher percentage of obese adults than the U.S. median (22.7 percent).

Smoking

In the U.S., an estimated 46 million adults smoke cigarettes.¹⁴ Cigarette smoking is a major risk factor for stroke. The risk of stroke decreases steadily after smoking cessation.¹⁴ In the Great Lakes region, the percentage of adults who smoke ranges from 21.1 percent (Minnesota) to 26.1 percent (Indiana, Michigan) (see chart 1 on page 13). Illinois, Indiana, Michigan, and Ohio have a higher percentage of adults who smoke than the U.S. median (22.0 percent).

Physical Inactivity

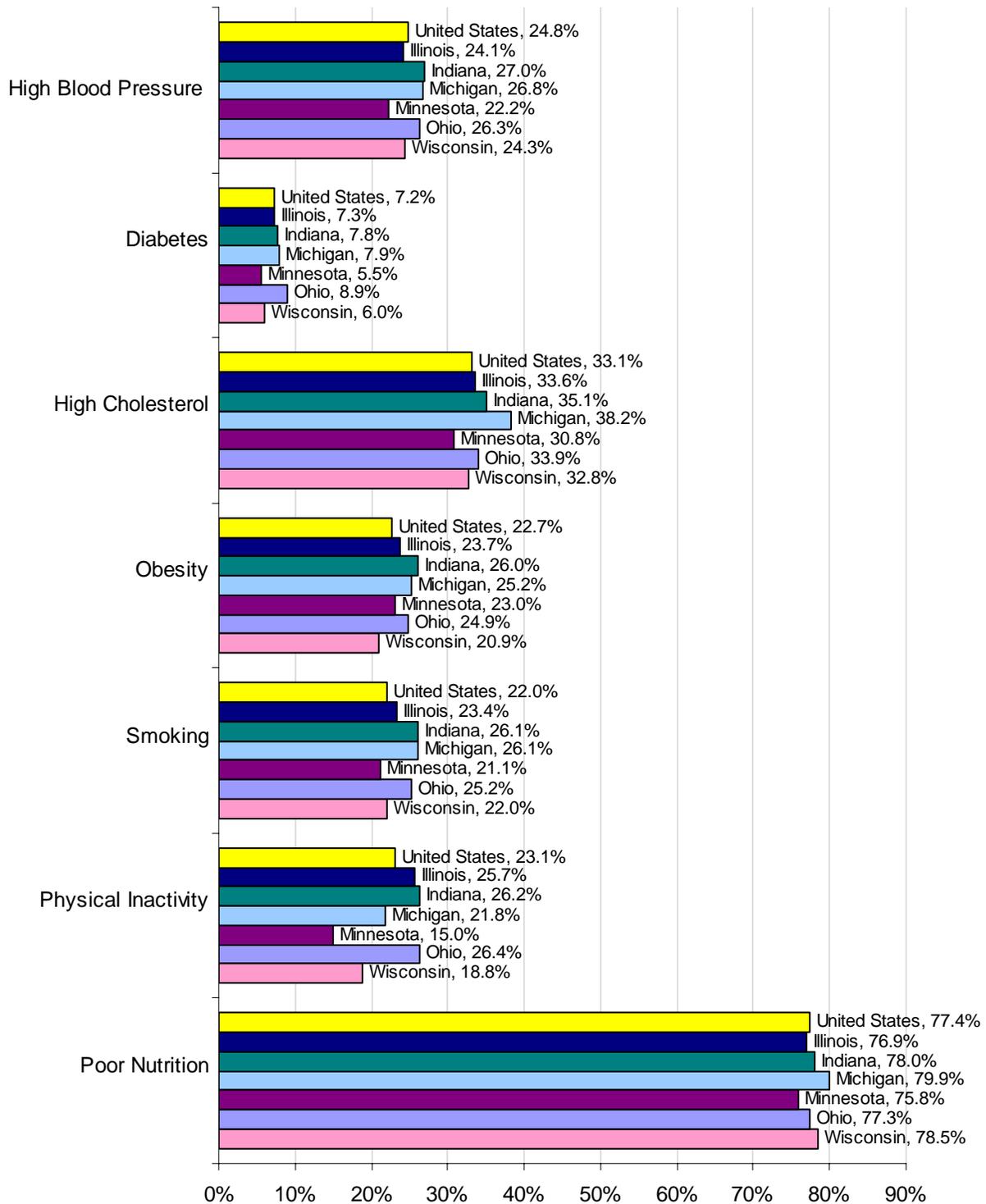
Regular physical activity reduces risk for heart attack, colon cancer, diabetes, and high blood pressure and may reduce the risk for stroke.¹⁵ Despite the proven benefits of physical activity, more than 50 percent of U.S. adults do not get enough physical activity to provide health benefits; 26 percent are not active at all in their leisure time.¹⁵ In the Great Lakes region, the percentage of adults who report getting no physical activity in the past 30 days ranges from 15.0 percent (Minnesota) to 26.4 percent (Ohio) (see chart 1 on page 13). Illinois, Indiana, and Ohio have a higher percentage of adults reporting no physical activity in the past 30 days than the U.S. median (23.1 percent).

Poor Nutrition

Good nutrition can help lower risk for many chronic diseases including stroke. However, a large gap remains between recommended dietary patterns and what Americans actually eat. For example, in 2003, only about one-fourth of U.S. adults ate the recommended five or more servings of fruits and vegetables each day.¹⁶ In the Great Lakes region, the percentage of adults who eat less than the recommended five servings of fruits and vegetables per day ranges from 75.8 percent (Minnesota) to 79.9 percent (Michigan) (see chart 1 on page 13). Indiana, Michigan, and Wisconsin have a higher percentage of adults who eat less than the recommended five servings than the U.S. median (77.4 percent).



Chart 1: Prevalence of Stroke Risk Factors, 2003



Source: Behavioral Risk Factor Surveillance System, 2003

Survivor Story: Stroke Risk Factors

Joyce Beatty, 50, suffered a stroke in June 2000, and in her unique position as an Ohio legislator and career woman, the Columbus resident is out to show she won't take her full recovery for granted.

Beatty experienced her stroke at work. "The first thing I noticed was I had no control of my throat muscles. I thought I was strangling or choking." Beatty says her first response was to get some water. However, before she could react, her left side "seemed to go numb."



Joyce Beatty
Ohio

Following her stroke, she was almost immediately placed into emergency medical service care, and rushed to a team of doctors who quickly diagnosed that she had experienced some type of stroke.

Beatty never thought she would be the type of person who experiences a stroke. But in retrospect, she realized she was a prime candidate despite her active lifestyle.

Beatty's maternal and paternal grandparents both died of complications caused by strokes which were followed by heart attacks. She realizes she has the **genetic predisposition** for heart disease and stroke, and was on medical treatment for **high blood pressure** prior to her stroke.

Beatty was, and continues to be, "extremely active," exercising on a regular basis and sticking to a healthy diet. In addition, she does not smoke, and drinks alcoholic beverages responsibly. "It makes me tend to think that I'm the healthy all-American person," Beatty says. "I think that's why my story is so important, because a lot of people thought that way." Beatty says the outpouring of cards and other messages of support she received following her stroke all expressed some variation of the message, "We were so surprised to hear this."

For whatever reason, it's still difficult for the public at large to learn to say, "stroke," even when symptoms clearly point to that likelihood, Beatty says.

"It's important for me as a public figure to let people know it's OK," she says. "Each day is a wonderful new day for me, but I never lose sight of the past. I count my blessings and work hard to do all of the things that I should have done before," including an even greater commitment to positive lifestyle practices to prevent another stroke, Beatty says.

Great Lakes Regional Stroke Network thanks the American Heart Association for sharing Ms. Beatty's story.

Survivor Story: Stroke Risk Factors

I knew I was having a stroke. I just didn't want to believe it. It was my 19th wedding anniversary and I woke up feeling different. The left side of my body felt like it had fallen asleep, but not completely. I was still able to move it, but it felt like I didn't have total control over my movements. Because I am **diabetic**, I thought my sugar was low. But when orange juice and sugar didn't make me feel better, I knew.

When I got to the emergency department at the closest hospital, I told the triage nurse that I thought I was having a stroke. She didn't believe me. For six hours they kept asking me to squeeze their fingers and wiggle my toes. It was not until I was moved into an ER observation bed and saw a neurologist that I was taken seriously. By the time my stroke completed, I lost my ability to walk, stand or sit. My speech immediately began to slur and my vision went double. I was told my stroke occurred in the cerebellum of the brain – the area that handles coordination, balance and voluntary movements.

Then the rehabilitation started. I did inpatient rehabilitation with physical therapy, occupational therapy, speech therapy, and case management. After physical therapy each day, I would return to my room and cry. I was not sure that I would ever walk again, so I worked really hard. I learned how to dress myself, how to bathe myself with assistance, and the therapists got me ready for the real work that was going to begin in outpatient therapy which lasted over 11 weeks. I was able to return to work, but was challenged in that I could only do one task at a time and my job required multi-tasking. I decided to retire.

I have often said, "I wouldn't wish this experience on my worst enemy, but I wouldn't trade it either." I have learned there is so much more to life than work-home-work-home. If I am able to help one person learn the warning signs of a stroke or get them to want to make a change in their life to try to avoid a stroke, or even get someone to join me in the fight against stroke, everything I have been through would be worth it.



**Mickey Clancy and her husband, Tom
Illinois**

Survivor Story: Stroke Risk Factors

Pierre Delorme was leading a bit of a wild lifestyle in July 2001. At age 52, this Haitian immigrant had been partying after work and his schedule was not regular. In fact, he'd not taken his insulin for his **diabetes** in four days. By Thursday he was in bad physical shape while standing at his welding machine at an automotive company. He was shaking and kept dropping things. His boss walked over and shut off his machine. Delorme was sent to the office and had a full-blown stroke shortly after.



**Pierre Delorme
Michigan**

It was two months later when he regained consciousness in Harper Hospital in Detroit. He was in a wheelchair and could not talk or stand. His right side was completely immobile. He was later sent home and told to stop drinking and stop **smoking**. He started physical therapy with the Rehab Institute of Michigan and attributes the staff, led by Anita Rodger-Craig, with turning his life around.

After years of therapy he's taken the long road toward learning to talk and walk again and has lost a lot of weight. "Stroke is a mind thing. You just have to 'get it'," said Delorme about his success with recovery.

For the past few years he's also attended the Stroke Connection Retreat hosted by the American Stroke Association staff in Michigan. The camp is designed for stroke survivors and their families as a safe environment to experience camping and networking with other survivors. Delorme has enjoyed the weekend retreat and become close to others who are in therapy with him.

Delorme wishes he could re-do the events of July 2001 and wishes he'd given up his bad habits in time to prevent his stroke. **African-Americans** are at higher risk for stroke and he hopes his story will convince others to take their medications on schedule, eat right, stop smoking, and modify their risk factors.

Great Lakes Regional Stroke Network thanks the American Heart Association for sharing Mr. Delorme's story.



Stroke Warning Signs

The warning signs of a stroke include:

- Sudden numbness or weakness, especially on one side of the body;
- Sudden confusion or trouble speaking or understanding;
- Sudden trouble seeing in one or both eyes;
- Sudden trouble walking, dizziness, or loss of balance or coordination; and
- Sudden severe headache with no known cause.

It is especially important to call 911 when stroke symptoms occur. Therapies exist for stroke, but must be administered soon after the onset of stroke symptoms. Stroke outcomes can be improved by timely care, so it is important for the general public as well as EMS professionals to recognize the major stroke symptoms. Unfortunately, public recognition of stroke symptoms is low. Of 61,019 adults participating in the 2001 Behavioral Risk Factor Surveillance System (BRFSS), only 17.2 percent of respondents—fewer than one in five—correctly classified all stroke symptoms and indicated that they would call 911 if they thought someone was having a stroke.¹⁷

While not all of the Great Lakes states administered the optional BRFSS survey modules for recognition of and response to stroke symptoms, results from Illinois, Minnesota, Ohio, and Wisconsin are presented on page 18. Michigan used a different methodology to ascertain the results to questions about recognition of and response to stroke symptoms. Data for Michigan are presented on page 19.

Table 2 shows the number and percentage of respondents ages 18 and older in each Great Lakes state who recognize the symptoms of stroke. Severe sudden headache and sudden vision trouble are the least recognized symptoms of stroke. Table 3 shows the number and percentage of respondents ages 18 and older in each Great Lakes state who would respond to stroke symptoms by taking the person to the hospital, calling a doctor, calling 911, calling spouse/family, or doing something else. Overall, 85.8 to 89.1 percent of survey participants responded they would call 911. Additional public education activities about stroke signs and symptoms in the Great Lakes region would increase knowledge of all stroke symptoms and of the importance of calling 911.



Table 2: Recognition of Stroke Symptoms

	Illinois	Minnesota	Ohio	Wisconsin
Severe Headache	282 (52.0%)	2,558 (64.7%)	2,122 (57.2%)	1,114 (59.1%)
Severe Dizziness/Imbalance/Trouble Walking	451 (84.5%)	3,465 (89.8%)	3,072 (83.6%)	1,651 (87.5%)
Sudden Vision Trouble	345 (66.2%)	2,951 (76.3%)	2,431 (66.4%)	1,273 (67.5%)
Sudden Numbness/Weakness	487 (91.2%)	3,676 (94.9%)	3,431 (94.1%)	1,789 (94.8%)
Sudden Confusion/Trouble Speaking	469 (86.8%)	3,547 (91.1%)	3,217 (86.9%)	1,673 (88.7%)

Sources: Illinois Point-In-Time Survey (based on BRFSS methodology), 2005.
 Minnesota, Ohio—Behavioral Risk Factor Surveillance System, 2003.
 Wisconsin Family Health Survey, 2003.

Indiana did not administer the optional BRFSS survey module for recognition of stroke symptoms.

Michigan used a different methodology to ascertain the results to the questions about recognition of stroke symptoms. The data for Michigan are presented on page 19.

Table 3: Anticipated Response to Stroke Symptoms

	Illinois	Minnesota	Ohio
Take to Hospital	38 (7.0%)	137 (3.8%)	181 (5.2%)
Call Doctor	3 (1.2%)	33 (0.8%)	22 (0.6%)
Call 911	453 (85.8%)	3,395 (88.1%)	3,229 (89.1%)
Call Spouse/Family	3 (0.2%)	13 (0.2%)	19 (0.6%)
Do Something Else	28 (5.7%)	235 (6.1%)	149 (4.1%)
Don't Know/Not Sure	2 (0.1%)	41 (0.9%)	12 (0.5%)

Sources: Illinois Point-In-Time Survey based on BRFSS methodology, 2005.
 Minnesota, Ohio—Behavioral Risk Factor Surveillance System, 2003.

Those who refused to answer the question were excluded from the denominator.

Indiana and Wisconsin did not administer the optional BRFSS survey module for anticipated response to stroke symptoms.

Michigan used a different methodology to ascertain the results to the questions about anticipated response to stroke symptoms. The data for Michigan are presented on page 19.



The question on recognition of stroke symptoms was first included in Michigan’s Behavioral Risk Factor Survey in 1999. Stroke questions were not part of the CDC BRFSS at that time. The question used was derived from a published project in the Cincinnati area and was repeated in 2004 for comparison.¹⁸ Table 4 presents the percentage of responses to the question “From anything you may have heard or read, what do you think are the three most important signs or symptoms of stroke?” Sudden vision trouble, numbness/weakness, and confusion/trouble speaking were the most identified symptoms.

The question on anticipated response to health situations was added to Michigan’s BRFSS in 2004 to get more specific information about responses to stroke symptoms. Table 5 presents the number and percentage of responses to the statement “I’m going to describe several health related situations. For each one, please tell me what you would be most likely to do first after you evaluated the person’s condition.” Most respondents stated they would call 911 if a person experienced trouble speaking. For numbness and trouble seeing, most respondents stated they would take the person to an emergency room.

Table 4: Recognition of Stroke Symptoms, Michigan

Severe Headache	10.2%
Severe Dizziness/Imbalance/Trouble Walking	15.2%
Sudden Vision Trouble	23.3%
Sudden Numbness/Weakness	65.6%
Sudden Confusion/Trouble Speaking	46.5%

Source: Preliminary data from Michigan BRFSS, 2004.

Table 5: Anticipated Response to Health Situations, Michigan

Response to Health Situation	Trouble Speaking	Numbness	Trouble seeing
911	2,586 (51.0%)	2,067 (42.0%)	1,005 (20.4%)
Go to ER	1,284 (27.2%)	2,093 (45.0%)	2,446 (51.9%)
Call physician	491 (11.7%)	408 (8.3%)	827 (17.1%)
Other	436 (9.1%)	227 (4.7%)	493 (10.3%)

Source: Preliminary data from Michigan BRFSS, 2004.

Survivor Story: Stroke Warning Signs

Stevie K. Nelson, 35, was at his two week annual military reserve training when he started getting **headaches**. His symptoms persisted for several weeks. Stevie continued going to work despite bumping into a wall and having trouble driving. Since he was only 35, he thought he had a bad case of the flu.



**Stevie K. Nelson
Minnesota**

A co-worker looked at Stevie and knew something was wrong. This persistent co-worker contacted the paramedics over Stevie's protests. When EMS arrived, they rushed him to the hospital and it was there that he learned he had a hemorrhagic stroke. "Stroke is for older people in my world," said Stevie. He could not believe that he had a stroke at age 35.

After many days in the hospital, more days in a long term acute care facility, weeks at rehabilitation facility and months at an independent living facility, Stevie was able to go home. It was six months after his stroke.

Stevie is still surprised that he had a stroke. He did not smoke. He watched his sodium intake. No family members had ever had a stroke. Stevie had regular check ups in the military. He did not have high blood pressure and was not overweight or diabetic. He had heard his family members talk about people that, "had a crooked mouth," but he never thought it would be him.

"I didn't know what my purpose in life was until after I had a stroke," reported Stevie. He leads stroke support groups in the Minneapolis area. He visits stroke survivors in the hospital to answer their questions and be a friend. He has become a stroke advocate at his church, and tries to bring awareness to people about stroke every where he goes.

Survivor Story: Stroke Warning Signs

Connie Ritchie was reading to her second grade class, when she began to **feel dizzy**. Thinking it was a bout of flu going around school, she asked for someone to drive her home.

As soon as she walked in the door, she got much worse. She had a **'stabbing' headache** that was 'unreal.' She had not had problems with headaches before, so she called 911.

Connie had been a runner for 15 years. She did not have high blood pressure, diabetes or high cholesterol. But she did have a grandmother and a cousin who died of a stroke.

When EMS arrived, they transported Connie to a small rural hospital. Despite undergoing a CT scan, she was not diagnosed as having a stroke and was going to be sent home. While in the hospital she became very nauseated. Scared and upset, she was told "If you would calm down, your symptoms would go away." But she knew something was wrong.

Connie was transferred to another hospital the next day, and the staff there determined she had had a brainstem stroke. Eventually, she was transferred to a third hospital so that she could undergo inpatient rehabilitation for four weeks. An additional three and a half months of outpatient therapy followed.

Since her stroke seven years ago, Connie has been very active in stroke education. She is a volunteer for the American Heart Association, American Stroke Association. She was named the National Stroke Advocate of the Year and she completed a half marathon in Kona, Hawaii as part of Train to End Stroke.



**Connie Ritchie
Indiana**



Pre-transport Stroke Deaths

Responding quickly to stroke warning signs is essential for reducing stroke-related deaths and disability. Table 6 presents the number of stroke deaths and the percentages of stroke decedents who died before transport to an emergency department in 1999. Pre-transport deaths occurred at a residence, in a nursing home, or in an extended-care facility before transport to a hospital or emergency room. Data are presented for the Great Lakes states and the U.S. The percentage of stroke-related deaths that occurred pre-transport range from 45.4 percent (Illinois) to 62.1 percent (Minnesota) and Indiana, Michigan, Minnesota, Ohio, and Wisconsin had a higher percentage than the U.S. percentage of 47.6 percent.

The greatest percentage of pre-transport deaths occurred among persons aged 85 years and older (40.1%) followed by those aged 75-84 (34.3%), those aged 65-74 years (14.4%), and those aged 65 years and younger (11.2%). The high percentage (63.9%) of stroke-related deaths that occurred pre-transport among adults aged 85 years and older might be partly due to do-not-resuscitate orders in nursing homes and long-term care facilities, especially for older persons disabled by previous strokes. However, approximately 25 percent of stroke-related deaths among persons younger than 65 occurred pre-transport, as DOA or in the ED, suggesting that persons in this age group might dismiss stroke as a problem of the elderly and therefore delay their response to symptoms.

Table 6: Number and Place of Stroke-Related Deaths[†], by State[§], 1999

State	Number	Place of Death				
		Pre-transport	DOA [¶]	ED*	In Hospital	Data Missing
Illinois	7,487	45.4%	2.2%	4.0%	48.4%	0.0%
Indiana	4,128	52.3%	0.1%	3.2%	44.3%	0.0%
Michigan	5,951	50.6%	0.3%	3.7%	45.3%	0.1%
Minnesota	2,972	62.1%	0.1%	1.6%	35.5%	0.8%
Ohio	7,199	54.4%	0.5%	3.4%	40.6%	1.1%
Wisconsin	3,841	60.7%	0.1%	1.9%	37.2%	0.0%
United States	167,366	47.6%	0.5%	3.3%	48.0%	0.5%

[†] *International Classification of Disease. Tenth Revision (ICD-10) codes 60-69.*

[§] Percentages for place of death are based on state of occurrence.

[¶] Dead on or before arrival at a hospital.

*Emergency department.

Source: CDC, 2002, *State-Specific Mortality from Stroke and Distribution of Place of Death---United States 1999.*

Survivor Story: Pre-hospital Transport

Dave Cooper, 40, knew there was something wrong when he woke up. His wife's grandfather had passed away from a stroke the week before; now he was having the same symptoms.

His wife **immediately called 911**. EMS transported him to the closest hospital, where Dave learned he had had a brainstem stroke. His vital signs had crashed so low, they did not think he would survive.

Because of his wife's quick reaction and his physician's knowledge, Dave was given tPA (tissue plasminogen activator), an acute interventional drug for stroke that must be given within three hours of ischemic stroke symptoms. The tPA limited the damage of his stroke, but there was a long road of recovery ahead.

Dave was moved to a larger hospital in Milwaukee. He had lost all motor function. He was on a respirator and was tube fed. Uncertainty prevailed during the first six weeks for his wife and five children.

Gradually, Dave began to regain motion. He spent three weeks in rehabilitation, and made progress. He learned to walk with a walker, but continued to have problems swallowing. For about a month, he had to communicate by blinking, eventually he was able to point to a letter board. Even after a year he had very limited speech, which was difficult for him as Pastor of St. Paul's Lutheran Church in Slinger, Wisconsin.

It has been six years since Pastor Dave's stroke. He describes his recovery as "like running a marathon for years." His biggest challenge was learning patience because he could not do all the things that he had done prior to his stroke.

When he was in the hospital, he asked his doctors if he would be able to play basketball with his children. He was told that would not be possible. This concerned him, because he had played ball with his older children and felt like the younger ones would miss out.

Luckily, Pastor Dave can now shoot hoops with his children. He can even play his guitar and continues to notice small improvements, "little pieces of healing" still taking place.

Prior to his stroke, Pastor Dave was treated for mild hypertension and had a grandmother who died of a stroke at a young age.

Pastor Dave has been recommended to serve on the Wisconsin Occupational Therapy Board and has testified in front of the Wisconsin Legislature about his stroke experience.



**Pastor David R. Cooper
Wisconsin**



Acute Care

The state maps in this section (Figures 1-6) detail stroke mortality for adults 35 years and older by county. The counties shaded the darker color have a higher stroke mortality rate. The yellow diamond shapes indicate the location of Joint Commission on Accreditation of Healthcare Organizations (JCAHO) certified primary stroke centers in the state.

Primary stroke centers are hospitals that are able to provide care that meets the specialized needs of stroke patients. Primary stroke centers must have acute stroke teams, stroke units, written care protocols, and an integrated emergency response system as well as have CT scans available 24 hours every day and rapid laboratory testing.

In most cases, primary stroke centers are not located where the need is the greatest or where the stroke mortality rate is highest. Typically, primary stroke centers are in hospitals with more resources to meet primary stroke center certification requirements. It is important to note that a hospital does not have to be a JCAHO certified primary stroke center to adequately serve stroke patients. There are hospitals in the Great Lakes states capable of treating stroke patients to recommended guidelines that are not JCAHO certified primary stroke centers.

As of December 2005 there are 49 primary stroke centers in the Great Lakes states. The number of primary stroke centers in each state ranges from four (Wisconsin) to 13 (Ohio). More hospitals are expected to become JCAHO certified in the Great Lakes region. In addition, comprehensive stroke centers, hospitals with the resources to diagnose and treat complex types of stroke or patients who require more complex care are likely to emerge soon.

Risk Factors

Recognition of Warning Signs

Pre-hospital Transport

Acute Care

Rehabilitation

Stroke Death Rates, 1991-1998 Adults Ages 35 Years and Older, by County and Location of Primary Stroke Centers, December 2005

Figure 1: Illinois

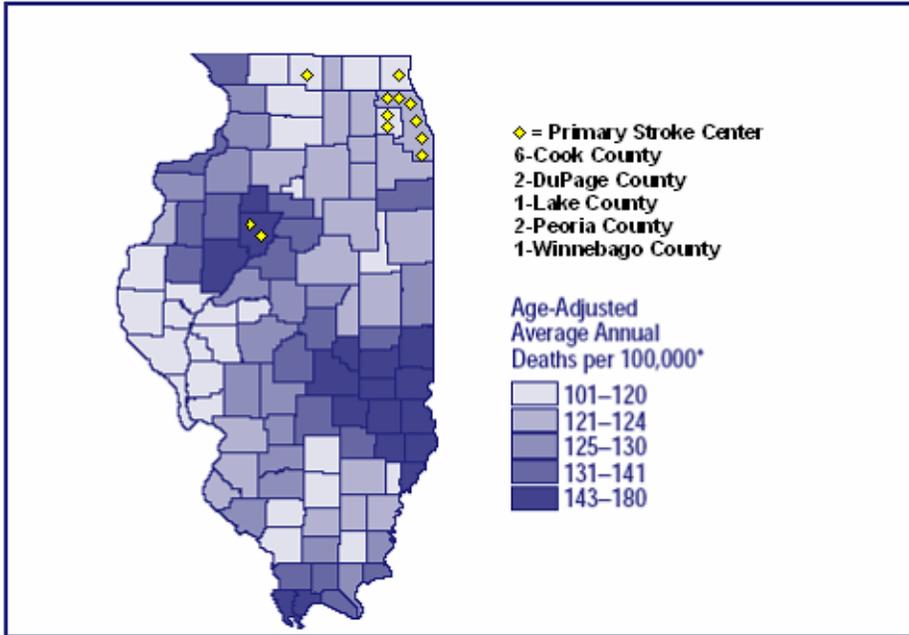
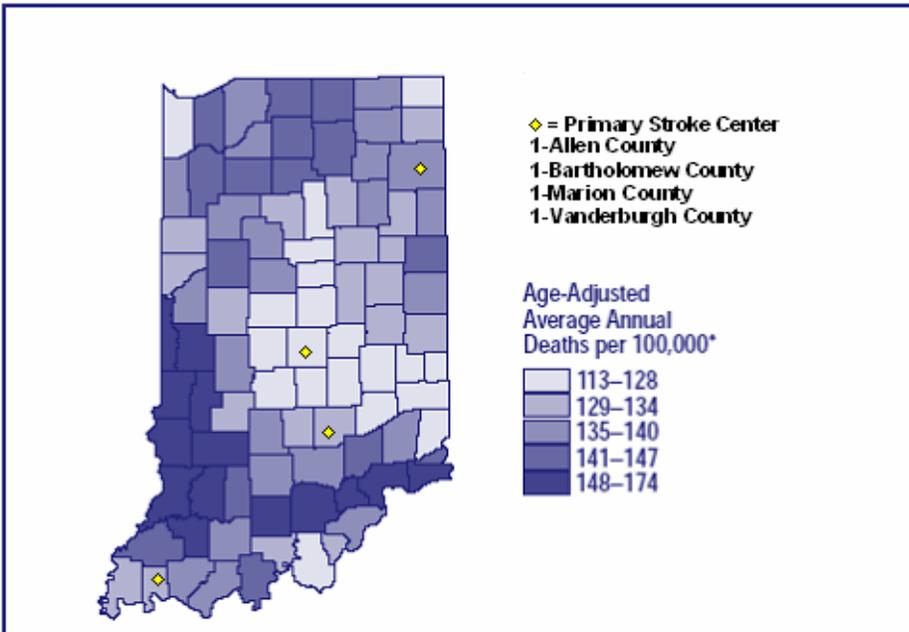


Figure 2: Indiana



Sources: CDC Atlas of Stroke Mortality, 2003.
Joint Commission on Accreditation of Healthcare Organizations, 2005.

Stroke Death Rates, 1991-1998 Adults Ages 35 Years and Older, by County and Location of Primary Stroke Centers, December 2005

Figure 3: Michigan

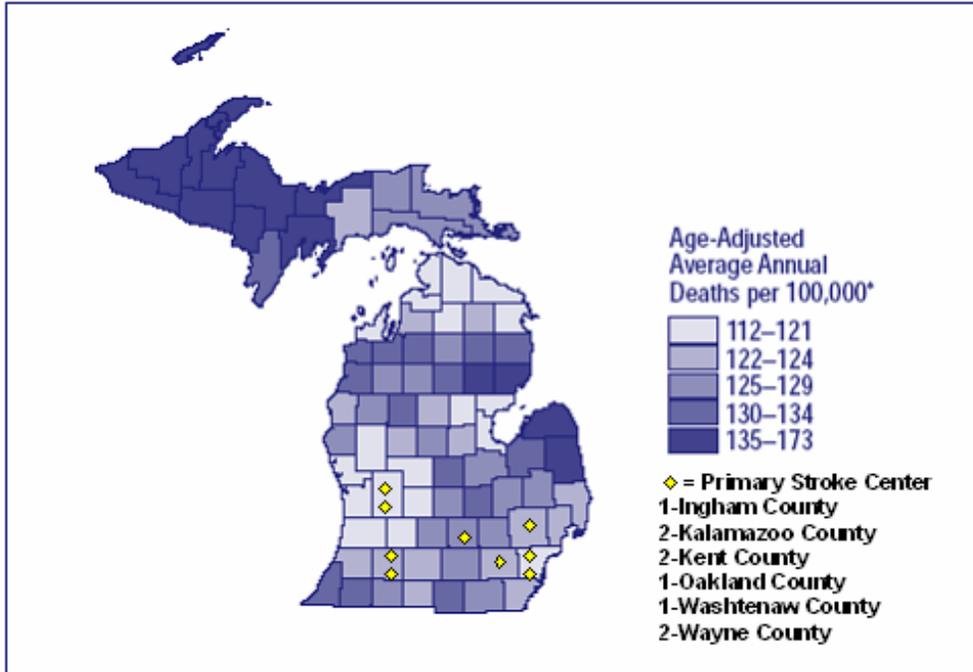
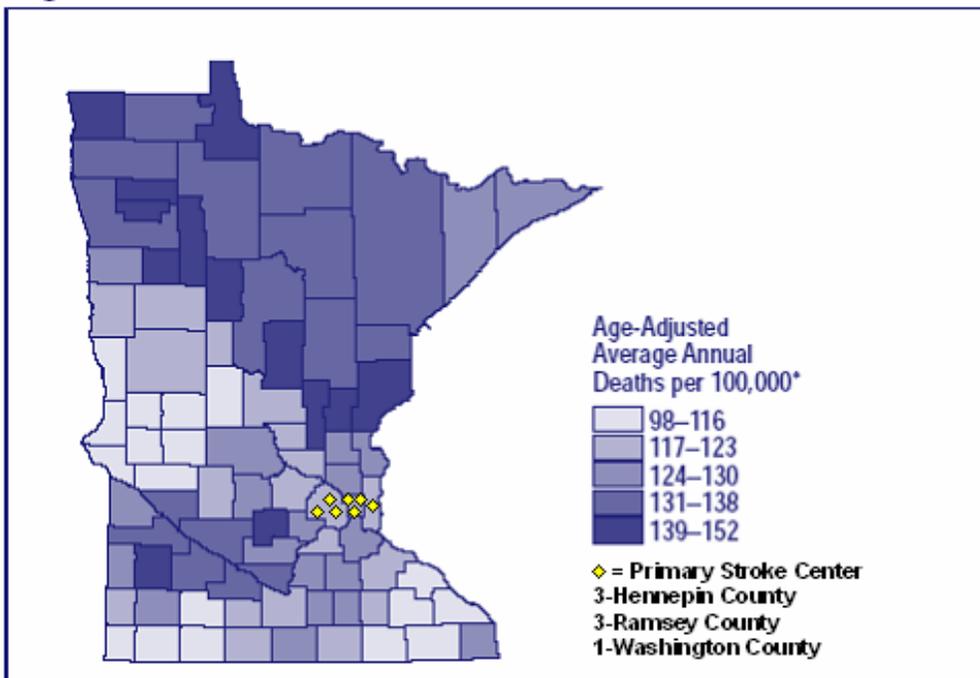


Figure 4: Minnesota



Sources: CDC Atlas of Stroke Mortality, 2003.
Joint Commission on Accreditation of Healthcare Organizations, 2005.



Stroke Death Rates, 1991-1998 Adults Ages 35 Years and Older, by County and Location of Primary Stroke Centers, December 2005

Figure 5: Ohio

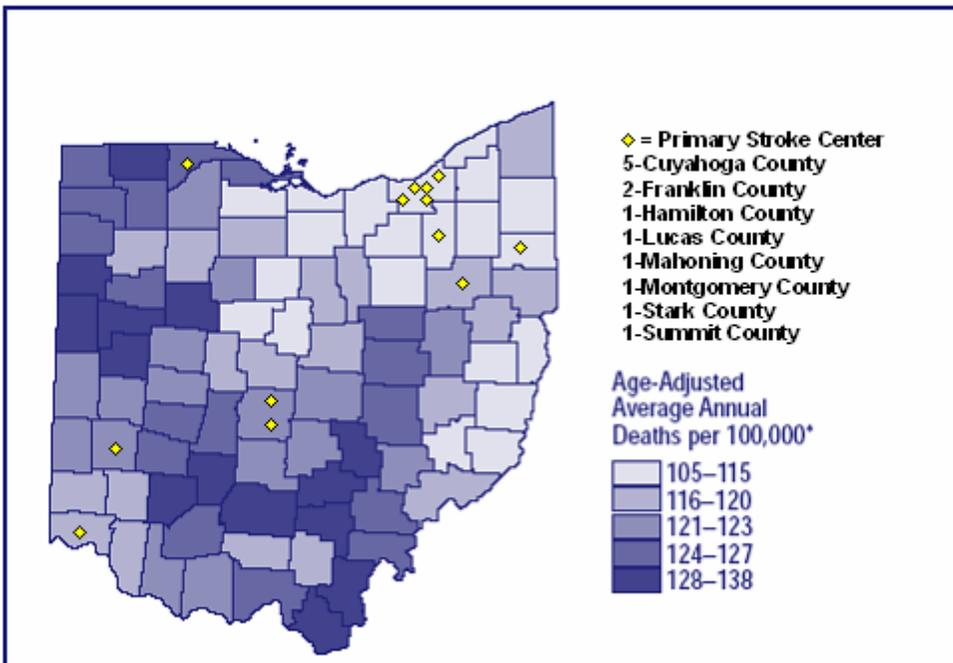
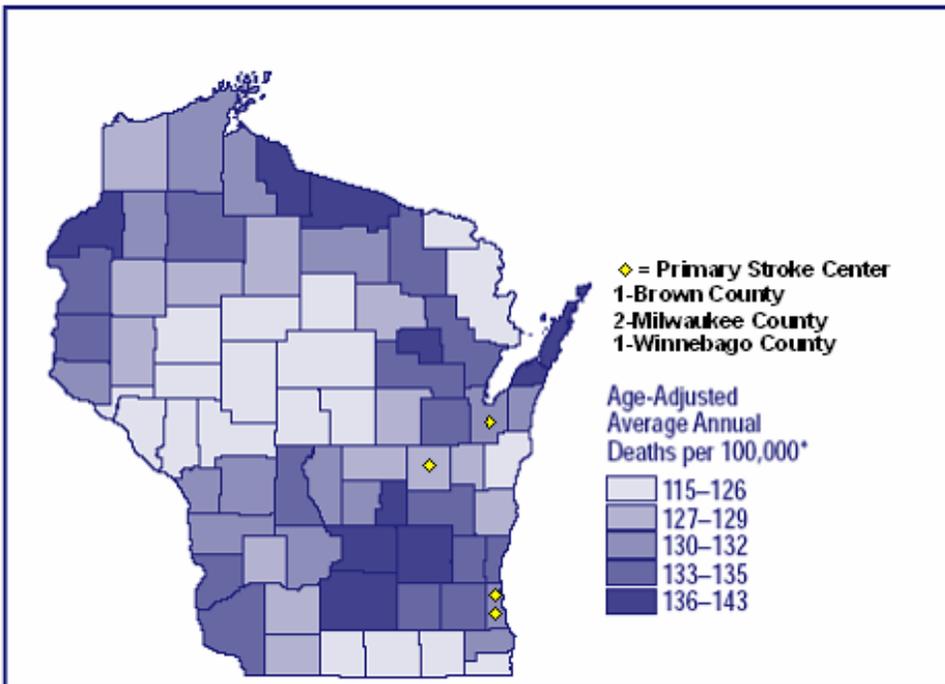


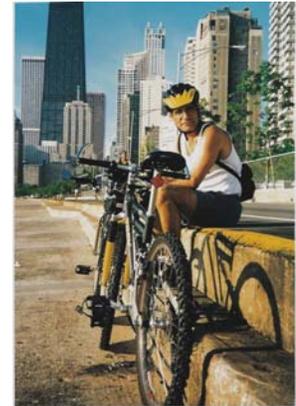
Figure 6: Wisconsin



Sources: CDC Atlas of Stroke Mortality, 2003.
 Joint Commission on Accreditation of Healthcare Organizations, 2005.

Survivor Story: Acute Care

“I want to live ‘til my last breath,” a healthy Javier Martinez joked to his lawyer in 2001 while creating a living will with his wife, Bertha, in their Lemont, Illinois home. The couple, then married 30 years, was looking forward to retiring together, visiting family in their native Mexico, and then traveling the world. Javier, an avid cyclist, runner, and former semi-professional soccer player, was in top physical condition and could have never anticipated the health crisis that lay ahead.



**Javier Martinez
Illinois**

One year later, it would be these very words – “I want to live” – that would give Bertha the strength to fight for her husband’s life as he battled double pneumonia, coma, seizures – and eventually several strokes. In March of 2002, after running 10 miles the night before, an otherwise-healthy Javier came home from work early complaining of flu-like symptoms. By that Monday, Javier’s immune system had crashed and doctors informed his wife that he wouldn’t live to the next morning.

“I remembered what he said – ‘I want to live’ – and knew he would want to fight for his life,” said Bertha, who refused to believe the doctors’ prognosis and advocated that he be **airlifted to another hospital**.

Though Javier survived, his condition worsened before it got better. After spending four months in a coma, he suffered two strokes that compromised his vision, speech and use of the right side of his body. The strokes triggered a series of seizures, which caused further damage. Though doctors constantly doubted his survival, Bertha never questioned that her husband would live. After more than seven months in the hospital, Javier went home for the first time in October of 2002.

Bertha, who had just launched her own human resources consulting firm, gave up her career to be her husband’s full-time caregiver. Under her constant care, Javier recovered enough to visit his hometown of Uruapán, Michoacán, Mexico in 2004, where old friends dubbed him *milagros*, or miracles.

Today, Javier, 61, continues to recover from the effects of his illnesses. Though his speech is still slurred, Javier walks short distances with the help of a cane, enjoys riding a stationary bike and weekly horseback riding lessons. He’s also active in the lives of their two daughters and three grandchildren.

Great Lakes Regional Stroke Network thanks the American Heart Association for sharing Mr. Martinez’s story.



Hospital Discharge Data

Administrative claims data from hospitals are a source of information about the patterns of care, the public health burden, and the cost associated with disease and injury. Table 7 presents hospital discharge data from inpatient hospital admissions for stroke from each state's hospital association. Data presented are for hospital discharges with a principal diagnosis of stroke (ICD-9 codes 430-438). The patient discharge status codes and definitions listed are used by hospitals to bill for patient services. Data from 2002 are presented for Wisconsin and 2003 data are given for Illinois, Indiana, Minnesota, and Ohio. Michigan was unable to share its hospital discharge data, but expects an analysis of state hospital discharge data to be available Spring 2006.

Table 7 presents the total number of hospital inpatients with a principal diagnosis of stroke and the number and percentage of those patients by discharge status for each Great Lakes state. The total charges for stroke patients are also listed for each state. More than 122,000 stroke patients were discharged from hospitals in the Great Lakes region. The total hospital charges for those patients were over \$2.3 billion. The true cost of care is unknown but is much greater than \$2.3 billion, as most stroke patients require additional care after they leave the hospital. In each state, more than half of all stroke inpatients were discharged to a private home. A significant percentage of stroke patients (16.8 to 21.0 percent) were discharged to a skilled nursing facility for continued care. In addition, a large number were discharged to a rehabilitation facility (6,994 total) or to their home under the care of a home health service (7,970).

Table 7: Hospital Discharges* by State

	Illinois	Indiana**	Minnesota***	Ohio	Wisconsin	
Total charges for stroke event discharges	\$899,623,574	\$295,675,562	\$221,700,084	\$717,694,665	\$233,187,125	
Total number of stroke events†	39,476	19,012	10,513	38,502	14,888	
Patient Status						
Code	Patient Discharge Status					
01	Discharged to home care or self care (routine discharge)	21,240 (53.8%)	12,209 (64.2%)	5,533 (52.6%)	20,178 (52.4%)	8,007 (53.8%)
03	Discharged/transferred to a skilled nursing facility (SNF) with Medicare certification	6,764 (17.1%)	3,197 (16.8%)	2,210 (21.0%)	7,287 (18.9%)	2,599 (17.5%)
04	Discharged/transferred to an intermediate care facility	866 (2.2%)	—	104 (1.0%)	838 (2.2%)	284 (1.9%)
05	Discharged/transferred to another type of institution for inpatient care	1,652 (4.2%)	769 (4.0%)	173 (1.7%)	1,293 (3.4%)	881 (5.9%)
06	Discharged/transferred to home under care of organized home health service	2,695 (6.8%)	945 (5.0%)	592 (5.6%)	3,097 (8.0%)	641 (4.3%)
07	Left against medical advice or discontinued care	232 (0.6%)	40 (0.2%)	20 (0.2%)	150 (0.4%)	37 (0.2%)
20	Expired	2,312 (5.9%)	1,232 (6.5%)	716 (6.8%)	2,087 (5.4%)	1,071 (7.2%)
50	Discharged/transferred to Hospice-home	105 (0.3%)	—	24 (0.2%)	397 (1.0%)	39 (0.3%)
51	Discharged/transferred to Hospice-medical facility	348 (0.9%)	—	60 (0.6%)	454 (1.2%)	108 (0.7%)
61	Discharged/transferred to swing beds in this facility	194 (0.5%)	—	94 (0.9%)	25 (0.1%)	115 (0.8%)
62	Discharged/transferred to another rehabilitation facility	2,742 (6.9%)	—	810 (7.7%)	2,383 (6.2%)	1,059 (7.1%)
All other patient status types not listed	326 (0.8%)	620 (3.3%)	167 (1.6%)	313 (0.8%)	47 (0.3%)	

Sources: Illinois, Indiana, Minnesota, and Ohio-State Hospital Discharge Data, 2003. Wisconsin-State Hospital Discharge Data, 2002.

Michigan data analysis will be available Spring 2006.

*Number and percent of state resident hospital discharges by discharge status for hospital discharges with a principal diagnosis of cerebrovascular disease (stroke). Cerebrovascular disease (stroke) was defined as ICD-9 codes 430-438.

**Indiana State Department of Health collapses its hospital discharge data into eight categories. For this report, Indiana State Department of Health has attempted to map its categories to the patient discharge status listed.

***Minnesota data are based upon claims shared by 119 out of 134 acute care hospitals in Minnesota. Mayo Clinic and some of its affiliated hospitals do not participate in the Minnesota Hospital Discharge Database.

†Patients discharged/transferred to a short term general hospital have been excluded to avoid double-counting stroke events. However, these patients are included in the total charges for stroke event discharges.

Survivor Story: Rehabilitation

"Our stroke changed our lives completely," reports Walter Elsnau. His wife, Anita, had a clot that broke loose and blocked the blood flow to a large area in her brain, leaving her severely aphasic and paralyzed on her right side.

The prognosis at the time (October 1989) was that she would never talk again and would never walk again without help. At the time she wanted to die but soon, stubborn determination kicked in and she began her long, hard road back.

For months she focused on just making simple syllable sounds, then gradually made one-syllable words. After three years she was able to start driving again. In 1996, she went to the University of Michigan for six weeks of **intensive speech therapy**.

"The most challenging thing for me was re-acquiring patience after having worked with computers for the last 7 years of my working career," says Walter, "It was very scary when Anita came home from the hospital and I had to take care of her without the aid of the nursing staff. Eventually, as is usually the case, we fell into the routine of our "new" life and learned to do what we can and not be concerned about what we can't do."

After 16 years, Anita speaks well enough to get along with a high degree of independence. The couple has coordinated an **aphasia support group** at one of the local hospitals. Anita also remains a very good bridge player.



**Anita and Walt Elsnau
Ohio**

Prevalence of Stroke

Prevalence of stroke refers to the number of people in the population at a particular time who have had a stroke. For example, it is estimated that 95,800 individuals in Indiana were living with the effects of a stroke in 2002.

Table 8 shows the estimated number of non-institutionalized adults ages 18 and older who have had a stroke in each Great Lakes state and the U.S. (Michigan data are estimates for adults age 35 and older). More than 880,000 persons are estimated to have had a first or recurrent stroke in the Great Lakes region. Over 5 million adults in the United States are estimated to have had a stroke. The percentages in Table 8 are estimates of the total number of all individuals in the state and U.S. who have had a stroke, at any time in the past, divided by the number of persons in the population at the time the information was collected. Prevalence estimates for the six states range from 2.0 percent (Wisconsin) to 3.9 percent (Michigan) of the adult population. The estimated percent of adults in the U.S. who have had a stroke is 2.4.

Table 8: Estimated Prevalence of Stroke

	Estimated Number	Percentage
Illinois	211,000	2.3%
Indiana	95,800	2.1%
Michigan*	197,000	3.9%
Minnesota	98,000	2.7%
Ohio	198,300	2.3%
Wisconsin	81,000	2.0%
United States	5,070,000	2.4%

Sources: Illinois Point-In-Time Survey, 2005.

Indiana-Behavioral Risk Factor Surveillance System, 2002.

Michigan Behavioral Risk Factor Survey, 2002.

Minnesota and Ohio- Behavioral Risk Factor Surveillance System, 2003.

Wisconsin Family Health Survey, 2003.

United States-National Center for Health Statistics, 2003.

*Estimated number and percentage for adults age 35 and older.

Stroke Mortality Rate

Mortality specifies the number of deaths in a population within a prescribed time. Mortality rates may be expressed as crude death rates (total deaths in relation to total population during a year) or as death rates specific for diseases or other attributes such as age or race.¹⁹ Stroke mortality refers to the number of deaths from stroke in a population within a certain time period.

Age is a major factor affecting the risk of death for stroke. Populations differ in age composition and a population with a higher percentage of older residents will likely have a higher crude death rate for all deaths as well as for stroke than a younger population. Age adjustment takes these age differences in the population into account. Adjusted rates allow for comparisons of mortality across states.

Table 9 presents the age-adjusted stroke mortality rate and number of stroke deaths for each Great Lakes state and the U.S. for 2002. The age-adjusted stroke mortality rate per 100,000 for the Great Lakes states ranges from 51.3 per 100,000 (Minnesota) to 60.1 per 100,000 (Indiana). Illinois, Indiana, Michigan, Ohio, and Wisconsin have a higher age-adjusted stroke mortality rate than the U.S. rate of 56.2 per 100,000. Stroke deaths account for over 25,000 deaths or 5.7 percent of all deaths that occurred in the total population in the Great Lakes region in 2002.²⁰

Table 9: Stroke Mortality Rate* (per 100,000) by State, 2002

	Stroke Mortality Rate	Number of Stroke Deaths
Illinois	57.2	7,183
Indiana	60.1	3,717
Michigan	58.1	5,814
Minnesota	51.3	2,706
Ohio	59.4	7,252
Wisconsin	57.7	3,479
United States	56.2	162,672

Source: National Center for Health Statistics, 2002

*Age-adjusted to U.S. 2000 standard population.

Stroke Mortality Rate by Age Group

The risk of having a stroke increases with age. In fact, a person's risk of having a stroke more than doubles each decade after age 55. Table 10 shows the 2002 stroke mortality rate per 100,000 by age for each Great Lakes state and the U.S. As expected, the stroke mortality rate increases with age for each state. Despite the fact that older adults typically die from stroke, a significant portion of stroke deaths occur in adults age 64 and younger. These untimely deaths are costly to decedents' families and to the Great Lakes states in terms of years of potential life lost.

Table 10: Stroke Mortality Rate (per 100,000) by Age, 2002

	25-34	35-44	45-54	55-64	65-74	75-84	85+
Illinois	1.5	5.4	15.9	34.9	125.7	441.0	1,465.0
Indiana	1.8	4.7	14.7	40.8	125.4	445.9	1,568.4
Michigan	2.0	6.5	16.0	37.4	113.8	430.5	1,528.0
Minnesota	—	2.9	9.6	23.2	98.3	413.2	1,427.6
Ohio	2.2	4.8	13.9	37.3	125.9	455.8	1,520.8
Wisconsin	1.5	6.2	11.3	34.5	111.9	445.7	1,545.0
United States	1.4	5.4	15.1	37.2	120.3	431.0	1,445.9

Sources: Illinois Department of Public Health, Vital Statistics, 2002.
 Indiana State Department of Health, Vital Statistics, 2002.
 Michigan Department of Community Health, Vital Statistics, 2002.
 Minnesota Department of Health, Vital Statistics, 2002.
 Ohio Department of Health, Vital Statistics, 2002.
 Wisconsin Department of Health and Family Services, Vital Statistics, 2002.
 National Center for Health Statistics, 2002.

—Insufficient data

Survivor Story: Young Survivors

“I didn’t know that kids could have strokes,” reported Cindi Hamblin. She learned firsthand when her **five-day-old daughter, Zoe, had a stroke.**

Zoe was at home when she started acting very agitated, unusual for this normally happy baby. She was taken to the hospital and after many tests, was diagnosed as having a blood clot over one-third of her brain and a brain hemorrhage. She had a five percent survival rate if she made it out of the coma and then was expected to be in a vegetative state because so much of her brain had been damaged.

Zoe proved them all wrong. After three and a half weeks in the hospital, Zoe returned home. She is now 14 months old and full of smiles. She still attends physical and occupational therapy and recently started speech therapy. Zoe has overcome tremendous obstacles including blindness (she now can see with the assistance of glasses) and right side paralysis.

Doctors still do not know what caused Zoe’s stroke. It may have been from a hereditary blood clotting disorder which her mother and big sister, Brooke, have called Anti-thrombin 3 Deficiency. However, Zoe's brain is recovering from her stroke and she is doing very well.



**Zoe Hamblin with her big sister, Brooke
Ohio**

Survivor Story: Young Survivors

"We used to joke, 'oh, she's going to be a lefty,'" said Grayslake resident Judy Bergman of her then-four-month-old daughter, Noelle, when she began reaching for objects with her left hand. After a smooth pregnancy and birth, Bergman and her husband, Rich, were excited to welcome their second child in February 2003. But as the months progressed and Noelle never used her right hand, her parents started to worry and consulted their pediatrician, who referred them to a physical therapist and finally a neurologist. The conclusion was startling: **before she was even born, Noelle had suffered a stroke that affected the right side of her body.**



**Judy and Noelle Bergman
Illinois**

"I was in shock," said Bergman, "I didn't realize a child could have a stroke."

Even though stroke is considered an older person's disease, the statistics indicate otherwise. According to the Children's Hemiplegia and Stroke Association, childhood stroke occurs in about six of 100,000 children, and claims the lives of about 12 percent of those affected. Pediatric stroke occurs most frequently in children less than one year of age, and 25 percent of strokes happen in infancy, right around childbirth.

Noelle was officially diagnosed at eight months, and her physicians assembled a team of physical, occupational and speech therapists to begin early intervention. Today, two-and-a-half-year-old Noelle receives therapy four times a week and is progressing well. "Noelle has movement of her right arm, but still not her fingers. She'll open her right hand with her left hand and will try to use it," Bergman said, "it's encouraging."

While steady, Noelle's progress is not enough for her mom. Bergman has committed to raising funds for pediatric stroke research through the Train to End Stroke program with the American Stroke Association, a division of the American Heart Association. While she claims she is not a runner, Bergman has committed to complete a half-marathon in Phoenix in January 2006 and has been training with a local Train to End Stroke team every weekend. She hopes to raise \$3,600 to fund stroke research and raise awareness.

"So many kids are not being diagnosed until later. Early detection and intervention are key," Bergman said. "I'm hoping to increase awareness of childhood stroke so parents can recognize the symptoms early and work with their doctors."

Great Lakes Regional Stroke Network thanks the American Heart Association for sharing the Bergman Family's story.

Stroke Mortality Rate by Gender and Race

Table 11 shows the 2002 age-adjusted stroke mortality rate per 100,000 for each Great Lakes state and the U.S. by gender and race. Stroke mortality rates are higher for men than women for each state and across race categories. Black men and black women have higher stroke mortality rates than white men and white women in the Great Lakes states. Overall, black men have the highest stroke mortality rates ranging from 74.6 per 100,00 (Wisconsin) to 89.9 per 100,00 (Ohio). Data on other race and ethnic groups are not available because of unreliable population estimates.

Racial disparities in stroke mortality in the Great Lakes states reflect the national trend in stroke mortality. Black mortality has been highest across all stroke types in all but the oldest age categories (75 years +).²¹ Variations among the Great Lakes states might reflect differences in lifestyle and stroke risk factors as well as socioeconomic status.²² In an analysis of the 2003 BRFSS survey, 48.7 percent of black respondents reported having two or more risk factors for stroke.²³

Table 11: Stroke Mortality Rate* (per 100,000) by Gender and Race, 2002

	Men	Women	Black Men	Black Women	White Men	White Women
Illinois	57.9	55.8	—	—	55.8	54.0
Indiana	57.7	59.2	83.5	74.6	56.4	58.4
Michigan	59.4	55.2	80.3	65.9	57.1	53.5
Minnesota	53.3	49.2	87.9	92.8	52.4	48.1
Ohio	61.1	56.4	89.9	62.0	58.6	55.9
Wisconsin	60.7	54.1	74.6	75.3	60.0	53.3
United States	56.5	55.2	81.7	71.8	54.2	53.4

Sources: Illinois Department of Public Health, Vital Statistics, 2002.
 Indiana State Department of Health, Vital Statistics, 2002.
 Michigan Department of Community Health, Vital Statistics, 2002.
 Minnesota Department of Health, Vital Statistics, 2002.
 Ohio Department of Health, Vital Statistics, 2002.
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 National Center for Health Statistics, 2002.

*Age-adjusted to U.S. 2000 standard population.

— Illinois stroke mortality data for race/ethnicity are grouped as “white” and “non-white” and therefore data for black men and black women are not available.

Summary

The Great Lakes region is significantly impacted by stroke. Stroke remains a leading cause of death and a leading cause of disability in the region. Much work is needed to reduce the burden of stroke in Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin.



Disparities in stroke mortality between race groups in the Great Lakes states are particularly disturbing. In addition, the prevalence of stroke risk factors in each state are unacceptably high. Interventions that address these disparities and risk factors are critical and much needed.

States in the Great Lakes region have various and sometimes dissimilar data related to stroke. Specifically, data for stroke prevalence, recognition of and anticipated response to stroke symptoms, and hospital discharge data are from different years or are missing for some states. These limitations make it difficult to compare states within the Great Lakes region, and the region with other areas in the United States. Better coordination and timely data analysis for stroke are needed and must include data on minority populations, incidence, and quality and costs of medical care.

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Appendix A: Glossary of Terms

Age-Adjusted Mortality Rate

The expected number of deaths that would occur if a population had the same age distribution as a standard population, expressed in terms of deaths per 1,000 or 100,000 persons.

Cause of Death

For the purpose of national mortality statistics, every death is attributed to one underlying condition, based on the information reported on the death certificate and utilizing the international rules for selecting the underlying cause of death from the reported conditions.

Demographics

Characteristic data, such as size, growth, density, distribution, and vital statistics, that are used to study human populations.

Incidence

A measure of the disease or injury in the population, generally the number of new cases occurring during a specified time period.

Morbidity

A measure of disease incidence or prevalence in a given population, location, or other grouping of interest.

Mortality

Expresses the number of deaths in a population within a prescribed time. Mortality rates may be expressed as crude death rates (total deaths in relation to total population during a year) or as death rates specific for diseases and sometimes for age, sex, or other attributes (e.g., the number of deaths from cancer in white males in relation to the white male population during a given year).

Prevalence

A measure of the burden of disease or injury in a population, generally the number of cases of a disease or injury at a particular point in time or during a specified time period. Prevalence is affected by both the incidence and the duration of disease in a population.

Quality of Care

The degree to which health services for individuals increase the likelihood of desired health outcomes and are consistent with established professional standards and judgments of value to the consumer. Quality also may be seen as the degree to which actions taken or not taken maximize the probability of beneficial health outcomes and minimize risk and other undesired outcomes, given the existing state of medical science and art.

Rehabilitation

An intervention strategy that seeks to return individuals to the maximum level of functioning possible.

Risk Factor

A behavior or condition that, on the basis of scientific evidence or theory, is thought to influence susceptibility to a specific health problem.

Years of Potential Life Lost (YPLL)

A measure of the impact of disease or injury in a population that calculates years of life lost before a specific age (often age 65 or age 75). This approach places additional value on deaths that occur at earlier ages.

(Source: Turnock BJ. Public Health: What It Is and How It Works. Maryland. Aspen Publishers. 2001.)

Appendix B: Data Sources

1) The American Community Survey (ACS) collects information from U.S. households similar to what was collected on the Census 2000 long form, such as income, commute time to work, home value, veteran status, and other important data. The ACS collects and produces population and housing information every year instead of every ten years. About three million households are surveyed each year. (Source: U.S. Census Bureau, American Community Survey, <http://www.census.gov/>)

2) The Current Population Survey, a monthly household survey of a sample of 60,000 households conducted by the Bureau of the Census for the Bureau of Labor Statistics, provides a comprehensive body of information on the employment and unemployment experience of the U.S. population, classified by age, sex, race, and a variety of other characteristics including health insurance status. Data are collected by personal and telephone interviews. Basic labor force data are gathered monthly; data on special topics are gathered in periodic supplements. (Source: <http://www.bls.gov/cps/home.htm>)

3) The Behavioral Risk Factor Surveillance System (BRFSS) is a collaborative project of the Centers for Disease Control and Prevention (CDC) and U.S. States and territories. The BRFSS is an ongoing data collection program designed to measure behavioral risk factors in the adult population (18 years of age or older) living in households. Data are collected from a random sample of adults (one per household) through a telephone survey. There are sets of questions on specific topics such as cardiovascular disease that states can opt to use on their BRFSS questionnaires, so every state may not collect the same information each year. The BRFSS provides the best estimate of stroke prevalence and the prevalence of risk factors for stroke. However, it has its limitations: 1) the BRFSS only measures prevalence, not incidence, 2) it only surveys the non-institutionalized population (nursing homes are omitted), 3) only people capable of participating in a telephone survey are able to participate (i.e. those with a disability preventing them would not be included), 4) it relies on self-reported information; and 5) it only includes adults age 18 and older, so it most likely is an underestimation of the people who have had a stroke. (Source: CDC, Behavioral Risk Factor Surveillance System survey, <http://www.cdc.gov/brfss/index.htm>)

4) The purpose of the Illinois Department of Public Health 2005 Point-In-Time Survey is to provide information about cardiovascular health knowledge and behavior, and, particularly about the prevalence of cardiovascular risk factors, for Illinois residents. A total of 500, 10 minute telephone interviews of household residents in Illinois was conducted. The study used questions from the Cardiovascular and Stroke modules developed by the Centers for Disease Control and Prevention (CDC). All procedures were developed according to the guidelines promulgated by the CDC for the Behavioral Risk Factor Surveillance Survey (BRFSS), which articulate calling rules as well as procedures for protecting the confidentiality of data.

5) The annual Michigan surveys follow the overall CDC telephone survey protocol for the BRFSS. The 2002 and 2004 Michigan Behavioral Risk Factor Survey (BRFS) data were collected quarterly by the Institute for Public Policy and Social Research at Michigan State University. (Source: http://www.michigan.gov/mdch/0,1607,7-132-2944_5327-12702--,00.html)

6) The Wisconsin Family Health Survey is a telephone survey of Wisconsin households, designed to provide estimates of health care coverage, various health problems, and use of health care services among people across the state. In 2003, the final sample consisted of 2,437 households, representing a total of 6,398 Wisconsin household residents. (Source: <http://dhfs.wisconsin.gov/stats/familyhealthsurvey.htm>)

7) Data on stroke mortality were provided by each state health department and the National Center for Health Statistics on causes of death come from a database of death certificates, collected and maintained by each state health department's vital statistics unit. The International Classification of Disease (ICD) code indicates the underlying cause of death. ICD-9 codes 430-438 were used for death certificates prior to 1999 to classify stroke. From 1999 on, death certificates are coded with ICD-10 codes 60-69. (Source: <http://www.cdc.gov/nchs/>)

8) The 1991-1998 stroke death rate (for adults 35 years and older) county maps presented in this report are from the CDC's *Atlas of Stroke Mortality*. For each map, the spatially smoothed, age-adjusted county death rates within each state were ranked from highest to lowest and then categorized into quintiles. The legend that accompanies each map indicates the range of county rates. A graded color scheme differentiates each quintile, with the darkest color representing counties with the highest rates and the lightest color representing counties with the lowest rates. Because the range of stroke death rates varies substantially by state, the quintile cutpoints are different for each state map. Consequently, the range of values represented by a given quintile varies from map to map. (Source: *Atlas of Stroke Mortality: Racial, Ethnic and Geographic Disparities in the United States*, CDC, <http://www.cdc.gov/cvh/maps/strokeatlas/index.htm>)

9) The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) evaluates and accredits health care organizations and programs in the United States. An independent, not-for-profit organization, JCAHO also awards Disease-Specific Care (DSC) Certification to health plans, disease management service companies, hospitals and other care delivery settings that provide disease management and chronic care services. JCAHO's certification program for DSC provides a comprehensive evaluation of disease or condition-specific services including primary stroke care. The number and location of Primary Stroke Centers in the Great Lakes states were obtained from the JCAHO website in September 2005. (Source: Joint Commission on the Accreditation of Healthcare Organizations, <http://www.jcaho.org>)

10) Data on pre-transport stroke deaths in this report are from the CDC's *Morbidity and Mortality Weekly Report*. The report presents national and state-specific death rates for stroke in 1999, which indicate state-by-state variations in both stroke-related death rates and the percentages of stroke decedents who die before transport to an emergency department. (Source: State-Specific Mortality from Stroke and Distribution of Place of Death—United States, 1999, CDC, MMWR, May 24, 2002/51 (20); 429-433.)

11) Hospital discharge data are from inpatient hospital admissions from each Great Lakes state's hospital association. Data presented are for hospital discharges with a principal diagnosis of stroke (ICD-9 codes 430-438). Data limitations include a lack of a defined denominator and the same person may be counted more than once in the event of two or more hospital separations during the year.

Appendix C: Great Lakes Regional Stroke Network Participants

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