

## Greater Illinois Chapter Newsletter

Published for our donors, volunteers, advocates and friends in the Alzheimer community

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www.alzheimers-illinois.org

1 800 272 3900

## Alzheimer's Disease: The Future Comes Into Focus

By William H. Thies, Ph.D.,  
Vice President Medical and Scientific Affairs,  
Alzheimer's Association

Pathways to earlier diagnosis and effective treatment of Alzheimer's disease are coming into focus. While we don't yet know exactly which path will offer the best route, several directions look extremely promising.

**Imaging**—Advances in imaging are revealing the structure and function of the brain in stunning detail.

We can now detect consistent patterns of shrinkage and reduced activity in the brain regions first affected by Alzheimer's. Researchers have also developed new tracer compounds capable of detecting microscopic Alzheimer abnormalities.

**Genetic Profiling and Chemical Markers**—Many scientists also see promise in genetic profiling and in

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## Ogden Spruill Honors Parents With Donation for Alzheimer Education

Dr. Albert W. Spruill lived his life celebrating great passions: his marriage to Floydelia, raising three sons and teaching.

A scholar and voracious reader of great books, he led lively discussions of current events at family meals and expected thoughtful participation from his sons. Ogden, his middle son, admired his father's ability to touch lives on a daily basis.

"Not a day went by that he wasn't teaching us all, his students, colleagues and family," Ogden said. "He challenged us to stretch our minds with quotations, such as 'charity begins at home' and 'you are measured by the least of your deeds,' so we would think how to make the best of ourselves and then make the best of the world."

Now, Ogden also recalls his father's more than 11-year struggle with Alzheimer's, its impact on the family and his father's death in 2004. He wanted to honor his father's legacy as a life-long educator and his mother for being an exceptional caregiver and has made a \$1 million donation to the Alzheimer's Association for Alzheimer education.

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## Chapter-wide Newsletter Debuts

Greetings, this is the inaugural issue of the Greater Illinois Chapter's quarterly newsletter and we hope you will find the news and information here to be informative and engaging.

Articles reflect our dual mission—people and science—plus news about programs, services and activities, including:

- ✓ Research for earlier detection, improved monitoring and better drugs, and on caregiver questions and concerns and the resources we offer through our Helpline.
- ✓ Friends of the Association who are helping us achieve our mission with generous gifts of time and energy.
- ✓ Alzheimer advocacy and highlights of upcoming programs and events on tap throughout our 68-county chapter area.

We already are planning the next issue and welcome your comments on this issue and suggestions for topics you would like us to address. Please send us an e-mail to [gicinfo@alz.org](mailto:gicinfo@alz.org) or call 847.933.2413. Happy New Year.

### **G. Kent Barnheiser**

President and CEO  
Greater Illinois Chapter

### **Alzheimer's Association Vision & Mission**

Our vision is a world without Alzheimer's disease. Our mission is to eliminate Alzheimer's disease and other dementias through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementias through the promotion of brain health.

## Alzheimer's disease

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measuring chemical markers in blood, urine or spinal fluid. None of these techniques has reached the point where we can look at individual test results and say conclusively that a person has very early Alzheimer's or is on the road to developing it. But we are confident we will get there.

We believe the approaches will provide new ways to track disease progression and the impact of treatment, much as we monitor heart health by checking blood pressure and cholesterol levels.

**New Medications**—Progress in earlier detection and monitoring will accelerate drug discovery by giving us better ways to determine whether new therapies can slow or stop the disease. One exciting next-generation class of drugs targets beta-amyloid, a molecule that clumps into hallmark Alzheimer plaques. Several anti-beta-amyloid drugs are undergoing clinical trials with some trials testing the usefulness of tracer compounds developed to detect beta-amyloid.

We'll know in the next five to 10 years whether anti-amyloid drugs represent one path to success. If not, hundreds of additional drugs are in development, and even more will enter the pipeline when we have better ways to gauge their impact. The successful ones are likely to offer the greatest benefit when we can detect the disease in its earliest stages.

The paths to earlier detection, improved monitoring and better drugs intersect, so progress in any of those areas stands a good chance of showing us shortcuts to success in the others. We are moving forward faster than ever before.

## Team CARE Runs Chicago Marathon, Raises \$74,000

We congratulate the 93 Team CARE members who ran the grueling 26.2-mile LaSalle Bank Chicago Marathon on October 9, 2005 and thank them for raising more than \$74,000 for the Association.

Special thanks to committee members Melissa Carlson, Steve Jaycox, Dave Kiefer, Bryan and Jan Selander, Tom Walsh and Bob White for their efforts.

"Team CARE (Conquering Alzheimer's Running Endeavor) was formed in 2002 for marathoners wanting a team structure for training and running and an opportunity to raise awareness of Alzheimer's disease and funds for programs and services," said Selander, a Team CARE founder, seven-time LaSalle Bank Chicago Marathon runner and a member of the chapter's board of directors.

"In the past three years, more than 280 Team CARE members raised more than \$221,000 and donations also came from people wanting to support the runners' efforts and the Association."

Chuck Aron of Chicago did both. "In 2004 I ran the Marathon in honor and memory of my brother-in-law who died at the age of 58 with early-onset Alzheimer's disease," he said.

"I hadn't run a marathon in 25 years, finished in a little more than five hours and raised more than \$11,000."

"I tell everyone their donations not only spur me to train harder but also



*Bryan Selander presents Chuck Aron with the Helmer Selander Award as the top Team CARE fundraiser in 2005.*

help improve the quality of life for people with Alzheimer's and families, like mine, who lost a loved one to this insidious disease. I'm not surprised when they tell me about a personal connection to the disease; after all, one in three of us knows someone with the disease."

## Association Has BBB Wise Giving Alliance Seal

The Alzheimer's Association earned the national Charity Seal of the Better Business Bureau Wise Giving Alliance, the nation's most experienced charity evaluator.

The seal indicates the Association has met the Alliance's *Standards for Charity Accountability* which exceed government requirements, through consistently strong financial practices. Donors are assured that organizations carrying the seal are committed to accountability and ethical practices.

## Memory Walks Draw 7,250 Participants (in all kinds of weather, too)

Greetings, The Greater Illinois Chapter staff and volunteers heartily thank the 7,250 participants in our 10 Memory Walks for their enthusiasm in helping raise awareness of Alzheimer's and funds for programs and services.

In five weekends last September and October we walked hundreds of miles through scenic parks as individuals or as members of more than 378 teams. We shared stories and photos of loved ones in whose memory we walked, met lots of new friends and got to thank sponsors for their support. We also raised more than \$960,000 for programs and services for those with Alzheimer's, family members and caregivers in our chapter area.

Support of Memory Walk has never been greater and we thank all who join us in taking steps toward a world without Alzheimer's.

Sincerely,  
*Lisa Lee*  
Associate Director, Special Events

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## How to Write a Bequest

Outright bequests in wills are popular ways to make gifts to the Alzheimer's Association. Bequests can be included when wills are created or added and updated later by a codicil. Remember to name precisely the organization and people you intend to benefit from the bequest. Avoid generalities, such as an organization's common name, to avoid confusion or possible litigation and ensure your donation reaches its intended beneficiary.

## Cathy Edge Joins National Board of Directors

For Cathy L. Edge, supporting the Alzheimer's Association has meant being a volunteer, board member, advocate and fundraiser for the Greater Illinois Chapter.

She now has added a new dimension to her role as a newly elected member of the Alzheimer's Association national board of directors.

Cathy began her two-year term at the association's national board meeting and retreat in October 2005. She is continuing as a volunteer and board member for the chapter.

"Cathy's work with our chapter in the past six years has been invaluable to our growth and development," said G. Kent Barnheiser, president and CEO of the Greater Illinois Chapter. "We know her commitment to a world without Alzheimer's and her perspective as an Alzheimer caregiver will carry through in her work on our national board of directors."

Cathy's involvement with the chapter began in 1999 when she walked into our Rockford office asking how she could help.

Within days she joined the program committee and the Rockford Leadership Council (community leaders that support dementia programming, care and awareness) and got involved with advocacy, events, awareness activities and fundraising. She joined the chapter board in 2002, chairs the development committee and has chaired the Leadership Council since 2002.



*Cathy L. Edge*

Her involvement on the national level includes chairing the Joint Venture Steering Committee and being vice chair of a national task force on joint fundraising.

Cathy and husband Ken, chairman, president and CEO of AMCORE Financial Inc., live in Rockford, have three children and three grandchildren.

"I am thrilled to be helping further establish the Alzheimer's Association as the leader in Alzheimer research and care here in Illinois and across the country," she said.

"My passion comes from being an Alzheimer caregiver for my father for five years and from being the niece of two aunts and an uncle who had the disease. My passion also comes from being a caregiver for my mother for three years.

"My enthusiasm comes from all we have accomplished and are undertaking on state and national levels to achieve our vision of a world without Alzheimer's disease."

## Caregivers Urged To Be Prepared For Emergencies

Hurricanes, fires, blizzards, tornados, floods ... we urge family members and caregivers to have emergency plans in the event the health and safety of someone with dementia is jeopardized.

We offer these tips in addition to information available from groups such as the American Red Cross and the National Hurricane Center. These tips were developed with input from caregivers and experts who have lived through multiple hurricanes and other emergencies.

If you know a disastrous situation is about to occur:

- ✓ Get yourself and the person with Alzheimer's to a safe place.
- ✓ Alert others (family, friends, medical personnel) you are relocating; give them contact information.
- ✓ Copy the person's medical history, medications and physician information for someone other than the primary caregiver.
- ✓ Purchase extra medications.

Prepare an Alzheimer's-specific "emergency kit" that might include:

- ✓ Easy-on flotation devices
- ✓ Sturdy footwear with Velcro®
- ✓ Incontinence products
- ✓ Something familiar to hug (pillow, toy)
- ✓ Extra medications, eyeglasses
- ✓ Copies of the person's medical history, medications, insurance, Social Security card, power of attorney
- ✓ Contact information for physicians, the Alzheimer's Association, Safe Return®
- ✓ Favorite items or foods
- ✓ Recent photograph of the person

For more tips, call Helpline (800.272.3900) or download our Disaster Preparedness Fact Sheet in English or Spanish at [www.alz.org](http://www.alz.org).

## Help a Phone Call or E-mail Away for Illinoisans Affected by Memory Loss

This past year, the Greater Illinois Chapter has been only a phone call or keystroke away for thousands of people seeking information, support, programs and resources on Alzheimer's, memory loss and brain health.

"Many people using Helpline tell us it's been a first step in gaining some control and confidence in their lives, whether they are starting to understand a recent diagnosis or have been living with the disease for some time," said G. Kent Barnheiser, president and CEO of the Greater Illinois Chapter.

"The questions and concerns range from how to manage daily activities and how to cope with caregiving related to health and jobs, to what to do when you suspect memory loss. Calls and e-mails also are coming from more first-time Helpline users and those whose first language is not English.

"We often are asked what kinds of questions most commonly are raised by Helpline users. While each situation is unique, what keeps us so focused on having quality information and support available 24 hours are the complexity of people's situations and how deeply vested Helpline users are in getting help and learning as much as possible about the disease, treatments and how to cope with its emotional, physical and financial impact. Another aspect is that many Helpline users, especially caregivers, are in touch often to gather specific information to tackle situations as they arise. It's an investment on both sides that none of us takes lightly."

Chapter Helpline user concerns mirror a report about caregivers, "Families Care: Alzheimer's Caregiving in the United States," from the Association in 2004. Highlights include:

**Who Caregivers Care For**—most of the respondents were caring for a parent, parent-in-law, grandparent or spouse.

**Caregiving Duration**—one in four respondents provided constant care (40 or more hours a week); seven in 10 provided care for more than a year; and one-third provided care for five or more years.

**Information Sought**—Respondents sought information on: activities (35%); home safety (34%); challenging behaviors (31%); and choosing a residential facility or home care agency (22%).

**Unmet Needs**—74% of respondents had unmet needs; 55% sacrificed time with family; 49% gave up vacations and activities; and only 44% used paid help to assist with caregiving, though some took part in support groups (11%) and used respite services (9%).

**Personal Health**—18% perceived a link between caregiving and a decline in their own health; 30% got less exercise; and 46% had high levels of emotional stress.

**Caregiving and Jobs**—66% of respondents missed work to provide care; 14% gave up work entirely or chose early retirement; 13% cut back hours or took a less demanding job.

"All this, plus knowing one in three Americans knows someone with Alzheimer's, is exactly why everyone in Illinois should have our 24-hour Helpline number and Web address on their refrigerators and in their wallets."

**24-Hour Helpline**  
**800.272.3900 (TDD: 866.403.3073)**  
[www.alzheimers-illinois.org](http://www.alzheimers-illinois.org)

## New Association Office Opens in Carterville



Carterville community leaders met with Greater Illinois Chapter staff and board members on November 9, 2005 to cut the ribbon in front of our new office. Pictured are (from left): Mike Williams; Dr. Robert Mees; Tami Frank, chapter program manager for the Carterville office; James Dearing, senior program manager; Candace Watt, chapter board and Leadership Council member; Richard Habiger; Bob Browning; Derek Hood; Gary Willis; Bob Campbell and Tracy Glenn. From this office we provide information, programming, resources and support for 26 counties in southern Illinois. The office is at 402 E. Plaza Drive. The phone number is 618.985.1095.

## File State Taxes, Support Alzheimer Research

Illinois taxpayers can donate \$1 or more for Alzheimer research when filing state income tax forms. Donations are tax-deductible and either will be deducted from a refund or added to the amount due.

## Know Your Charity

If you don't see this brand mark, your donation is not going to the Alzheimer's Association.



The Alzheimer's Association is the world leader in Alzheimer research and support, and the first and largest voluntary health organization dedicated to finding the cause, treatments, prevention methods and an eventual cure for Alzheimer's disease.

## Advocates Speak Up For More Than Half a Million Illinoisans Impacted by Alzheimer's

We invite you to be an Alzheimer Advocate and speak up in support of quality care and good quality of life for the more than half million Illinoisans impacted by Alzheimer's today.

As an Alzheimer Advocate with the chapter, you are in the Illinois Chapter Network, the leading Alzheimer's advocate group in Illinois that includes volunteers from the other Alzheimer's Association chapters serving Illinois counties.

Here's more on Alzheimer Advocate activities:

**Advocates help us forward our public policy priorities** (see next column) to improve quality of life for Illinoisans impacted by Alzheimer's.

**Advocates make calls or write to legislators** on these priority areas.

**Advocates attend Advocate Day (March 15-tentative)** during the spring Legislative Session to learn more about our policy issues and to meet with legislators and aides.

**Advocates consider being "Lead Advocates"** to cultivate relationships with state representatives to heighten awareness of the impact of Alzheimer's in Illinois and the need for quality care for people with dementia. Our goal is a Lead Advocate in every legislative district in our 68-county chapter area by July 1.

**Advocates stay on top of policy and legislative issues** through alerts and updates from the chapter.

## Alzheimer's Association Illinois Public Policy Priorities

### Home, Community Care Options.

Expand eligibility, availability and accessibility for services that allow for consumer choice.

### Effective Training For Dementia Care Staff.

Promote ongoing, effective and appropriate education for staff that make decisions or provide services that impact the quality of life of people with dementia, including owners, managers and direct care staff.

### Quality Care in All Settings.

Monitor and evaluate the impact of long-term care regulations, consumer standards, reimbursement and other compliance activities impacting lives of people with dementia and families, throughout the continuum of care.

**Medicaid.** Protect the quality of life and care of the most frail citizens of Illinois with dementia, who depend on Medicaid support, through a flexible system that provides care in the most effective setting of choice. Ensure these funds follow recipients throughout the continuum of care.

## Checklist: Recent Successful Advocacy Activities in Illinois

- ✓ **Created**—Special Care Unit regulations for intermediate, skilled nursing facilities
- ✓ **Passed**—Establish Illinois Legislative Alzheimer's Disease Task Force
- ✓ **Restored**—Funding for Alzheimer Disease Centers in Illinois
- ✓ **Passed**—Older Adults Services Act that promotes a person-centered long-term care system and offers community-based and home options for people with Alzheimer's
- ✓ **Designated**—November proclaimed Alzheimer's Disease Month in Illinois

## Ogden Spruill *Continued from Page 1*

Ogden's donation is funding the Greater Illinois Chapter Professional Training Institute for education and training for health professionals and the chapter's expanding outreach activities in the Chicago area and throughout the chapter's 68-county service area.

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*"This commitment is to honor my father's body of work and my mother's commitment to her family, and to make sure education is available for health professionals and families like mine living with this disease today and those who will face it tomorrow."*

*- Ogden Spruill*

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have opportunities to better understand this disease, be aware of risk factors and know how many other medical situations that afflict them can contribute to Alzheimer's. It's an honor to have that chance and also carry through my father's beliefs."

Ogden's vision crystallized when he attended the chapter's first Summer Institute on Aging, *"Exceptional Alzheimer Care and Services: Giving Hope and Help to Persons Affected by the Disease in the Early, Middle and Late Stages."*

"Ogden's vision dovetails with the chapter's vision of expanded outreach activities to increase awareness and services in multicultural communities," said Melanie Chavin, vice president of program services for the Greater Illinois Chapter.

The four-day program, hosted by the Professional Training Institute and Loyola University's Schools of Law, Social Work, and Nursing, focused on Alzheimer's and related dementias for professionals, including social workers, nurses, counselors, geriatric care managers, case managers and attorneys, and for University graduate and law students.

"African-American and Hispanic/Latino communities already are priorities for the chapter and we're thrilled Ogden's gift will help us to expand even more as well as introduce programming to other underserved, multi-ethnic communities."

The Professional Training Institute offers cutting-edge, interactive educational opportunities for new and seasoned professionals working with people affected by Alzheimer's to gain essential skills and expertise about the latest and most state-of-the-art Alzheimer care practices.

"Every day I recall the Summer Institute on Aging and feel so proud to know my father's name is associated with it," Ogden said with a smile. "I also wonder where he is teaching today and then realize that with this donation in his name, I can extend his reach to educate people and touch their lives on a daily basis, so he'll be teaching for years to come."

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"I want the Professional Training Institute to be the prime source of Alzheimer education here in Illinois and hope all chapters to use it as model," Ogden said. "With this donation, I can carry on my father's belief that, every day, you should go out with the purpose of changing life for the better. I see networks being created for people to connect and learn as much as possible. Education is so important, especially in underserved populations and especially for caregivers and others in the family. I want other families to

## What Happens in the Brain of Someone with Alzheimer's?

Visit "Inside the Brain: An Interactive Tour," an exciting new feature on the Association's Web site ([www.alz.org](http://www.alz.org)). Navigate through 16 illustrated screens that explain how the brain works and how Alzheimer's disease affects it.

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### About The Newsletter ...

You received this newsletter when you indicated an interest in Alzheimer's, dementia and/or brain health, attended a chapter program or event, contacted us through Helpline or our Web site or made a donation.

To unsubscribe to this newsletter or to subscribe

to our chapter e-newsletter, send an e-mail to [gicinfo@alz.org](mailto:gicinfo@alz.org) or call Lorraine at 847.933.2413.

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## Mark Your Calendars for Programs, Conferences, Events

### Public Education Programming

#### Maintain Your Brain®: How to Live a Brain-Healthy

**Lifestyle** – for everyone interested in brain health. Feb. 1—New Lenox • Feb. 7—Carbondale • Feb. 27—Eureka • March 21—Evanston • March 22—Chicago • April 18—Rochester • April 25—Evanston • May 25—Danville

**Alzheimer's: Beginning to Cope** – an overview of dementias for family and friends of people with dementias. Feb. 21—Bloomington • Feb. 23—Chicago • March 21—Athens • March 23—Charleston • April 10—Coal City • April 27—Taylorville

**Partnering With Your Doctor** – a workshop to develop skills for interacting with health professionals for people with memory loss and caregivers. March 16—Joliet • March 23—Mattoon • March 30—Norridge • April 4—Rantoul • April 19—Lake Zurich • May 9—Chatham • May 23—Carterville • June 7—DeKalb • June 14—Crete



*More than 600 family caregivers attending our Family Conference in November saw Julie Meisner-Eagle's award-winning documentary, "Alzheimer's: My Mom, Our Journey," and heard Julie and her brothers, Mark and Craig, talk about their Mom, Gloria Jean, and how they coped with the impact of this disease. They are pictured here with Wendy Miller, the Family Conference founder.*

**Making Sense of Memory Loss** – a five-part series for families of people in the early stages of memory loss on caregiving, communicating, adjusting to changes and relationships. Wednesdays, March 15 – April 12, in Elk Grove Village.

### Conferences for Family Caregivers

February 23 – Carterville - "A Journey Through the Mind: Taking Care," 3rd annual conference for family caregivers, professionals and clergy  
April 25 – Joliet - "Focus Forward: Pathways Through Alzheimer's," annual conference for family caregivers, professionals, clergy and friends  
April 29 – Chicago - "Memory Loss: Putting the Pieces Together," educational event for family and friends of people with memory loss  
May 25 – Springfield - "Synchronizing Science and Support," 11th annual conference for caregivers and health professionals  
November 11 – Rosemont - "Alzheimer's Association Family Conference: Support for Families Living with Memory Loss," 4th annual conference for family and friends of people with Alzheimer's and other dementias

### Special Events

February 9—Chicago - "First Look for Charity." Guests at the gala 2006 Chicago Auto Show preview party can support the Association and 18 other benefiting charities with a portion of the ticket price  
April 6—Chicago - "Wine & Roses: Savoring Memories," an evening of fine wine-tasting, hors d'oeuvres, live and silent auctions  
April 21—Bloomington - "Remember When...Memphis in May," 5th annual gala with dinner by award-winning BBQ masters from Memphis, musical entertainment, raffle, silent auction and the "Person of the Year" award  
April 22—Rockford - "Unforgettable Art," enjoy hors d'oeuvres while 50 artists create masterpieces to auction later in the evening  
April 23—Joliet - "Champagne Brunch" - details available after February 20  
April 28—Springfield - "A Night to Remember," 9th annual gala with dinner, musical entertainment, raffle, auction and wine tasting  
April 30—Kankakee - "Champagne Brunch" - details available after February 20

**Note to health professionals in all care settings:** Visit our Professional Training Institute Web pages for program listings to help you expand and sharpen dementia care skills...form more cohesive and more highly motivated teams...and bring enthusiasm and imagination to your work.

**For details and to register, visit [www.alzheimers-illinois.org](http://www.alzheimers-illinois.org) or call your local office.**

## How to Contact the Greater Illinois Chapter

We're as close as your phone or computer for information, support and access to community resources

**24-Hour Helpline 800.272.3900**  
(TDD: 866.403.3073)  
We offer translation in 140  
languages and dialects

**Chapter Web site [www.alzheimers-illinois.org](http://www.alzheimers-illinois.org)**  
The link to Helpline e-mail is in the  
upper right-hand corner of our home  
page.

**National Web site [www.alz.org](http://www.alz.org)**

We are a proud member of



### Chapter Offices

**309.827.9508** **Bloomington/Normal**  
2027 S. Main, Ste 3, Bloomington, IL 61704

**618.985.1095** **Carterville**  
402 E Plaza Dr, Ste 4, Carterville, IL 62918

**312.377.6633** **Chicago**  
225 N Michigan Ave, 17th FL, Chicago, IL 60601

**815.744.0804** **Joliet**  
300 Caterpillar Dr, Box 3506, Joliet, IL 60434

**815.936.0464** **Kankakee**  
401 N Wall St, Ste LL08, Kankakee, IL 60901

**815.484.1300** **Rockford**  
4777 E State St, Rockford, IL 61108

**847.933.2413** **Skokie**  
4709 Golf Rd, Ste 1015, Skokie, IL 60076

**217.726.5184** **Springfield**  
6 Drawbridge Rd, Ste 4, Springfield, IL 62704

RETURN SERVICE REQUESTED

www.alzheimers-illinois.org  
800 272 3900

We are fighting on your behalf 24/7  
to give everyone a reason to hope.

Greater Illinois Chapter  
4709 Golf Road, Suite 1015  
Skokie, IL 60076