Dear Friends,

I am pleased to share with you the results of our 2014 State of Illinois Alzheimer’s Disease Survey.

In this second year of the survey, we increased participation by 58 percent to a total of 1161 respondents from 61 Illinois counties. The input of more than a thousand concerned Illinois citizens is extremely valuable. The results will guide the Alzheimer’s Association and others when making recommendations to Illinois legislators and state agencies regarding Illinois’ response to the growing health crisis of Alzheimer’s disease.

With the number of people who have Alzheimer’s in Illinois rising from current levels of 210,000 to 260,000 by the year 2050, Illinois needs to have a strong, coordinated response to the needs of individuals with dementia.

For me, these were the most important stories to emerge from this survey:

1. For two years now, fewer than half of the survey respondents were familiar with programs and services offered by the state of Illinois for individuals with Alzheimer’s and their families. In 2013, just over 47 percent of respondents felt they were somewhat or very familiar with the state programs; this year that number dropped to 43 percent. Clearly, education about state services is needed.

2. A high percentage of respondents do not utilize state services (67.57 percent this year compared to 67.19 percent in the first survey). For those who do utilize state programs, the top three this year are specially designated care units for dementia in nursing homes, followed by adult day services and homemaker services. Prescription drug assistance made the top three last year, but dropped to sixth place in this year’s survey.

3. Survey respondents overwhelmingly believe that the state of Illinois is not doing enough to address Alzheimer’s and related dementias. Fewer than five percent of respondents in both years of the survey think Illinois is doing enough to address Alzheimer’s.

4. Respondents ranked two Illinois programs as the most valuable services: In-Home Programs (nursing /medical care/personal care/companion services) were rated most valuable, followed by Adult Day Center programs for those individuals in the middle and later stages of Alzheimer’s.

5. Nearly 86 percent of respondents felt that the state of Illinois should spend more money funding programs that provide Alzheimer’s care, while fewer than eight percent felt the amount of Illinois spending is just right. Fewer than one percent thought they should spend less.

We were pleased to see that the percentage of people who felt they could get good information about Alzheimer’s from their doctor rose from last year just a bit (18 percent to 21.3 percent). The Association is working diligently to help physicians become equipped with information to share with patients. Of course, the Association itself remains a strong source of information about the disease and caregiving. We are the first stop for help and hope for individuals recently diagnosed, for those who are living with Alzheimer’s, and for their families and caregivers.

Thank you to everyone who took the time to respond to the survey. Many thanks to our official survey partners for their help in disseminating the survey. A complete list of their names can be found on the back page of this report. We look forward to working with you to make Illinois a dementia capable state.

Sincerely,

Erna E. Colborn
President and CEO
Alzheimer’s Association, Greater Illinois Chapter

For a complete set of 2014 Alzheimer’s Disease State Plan Survey Resources, visit our website at www.alz.org/illinois and click on the link entitled “Advocate” to find SURVEY information, including:

- A pdf copy of the 2013 and 2014 survey reports
- The complete data set from both years
- Press release reflecting highlights from the 2014 survey
Section 1

Profile of 2014 Survey Participants

1161 RESPONDENTS

61 Counties Represented

Age of Respondents

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNDER 30</td>
<td>4.33%</td>
</tr>
<tr>
<td>30-39</td>
<td>7.89%</td>
</tr>
<tr>
<td>40-49</td>
<td>14.55%</td>
</tr>
<tr>
<td>50-59</td>
<td>33.78%</td>
</tr>
<tr>
<td>60-69</td>
<td>26.89%</td>
</tr>
<tr>
<td>70+</td>
<td>12.5%</td>
</tr>
</tbody>
</table>

Communities

<table>
<thead>
<tr>
<th>Community Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban/City</td>
<td>28.84%</td>
</tr>
<tr>
<td>Suburban</td>
<td>53.12%</td>
</tr>
<tr>
<td>Small Town</td>
<td>10.80%</td>
</tr>
<tr>
<td>Rural/Farm Area</td>
<td>7.24%</td>
</tr>
</tbody>
</table>

Race/Ethnicity

- 7.02% Chose not to identify
- 1.23% Asian
- 5.91% Black or African American
- 2.12% Hispanic or Latino
- 1.67% Two or more races
- 81.94% White
- 0% American Indian or Alaskan Native
- 0.11% Native Hawaiian or Pacific Islander

Sexual Orientation

- Heterosexual: 85.4%
- LGBT: 1.9%
- Prefer not to answer: 12.7%

Experience with Alzheimer’s Disease or a Related Dementia*

- I have Alzheimer’s disease (AD) or a related dementia: 0.56%
- My spouse/partner has AD or a related dementia: 15.89%
- My grandparent has AD or a related dementia: 10.56%
- My parent has AD or a related dementia: 55.11%
- My sibling has AD or a related dementia: 3.33%
- My aunt, uncle or cousin has AD or a related dementia: 10.11%
- A close friend has Alzheimer’s or a related dementia: 9.89%
- I do not have personal experience with AD or a related dementia: 4.89%
- I am a professional employed in the field of AD care, support or research: 16.67%

*Respondents could choose more than one category.
Section 2

**Illinois Alzheimer’s Policy Implications**

1. How familiar are you with services and programs provided by or supported by the State of Illinois that address the needs of individuals with Alzheimer’s disease or a related dementia?

2. What programs or services supported by funding from the State of Illinois that improve quality of life for those with Alzheimer’s disease and related dementias have you used? (Choose all that apply.)

3. Thinking about current policies and programs of the State of Illinois to address Alzheimer’s, would you say that they are.................to address Alzheimer’s and related dementias in Illinois? (Fill in the blank.)

4. When thinking about Illinois policies to help people with Alzheimer’s and their care partners, which policy is most important? (Choose just one.)
The State of Illinois should spend.................MONEY looking for effective ways to treat and cure Alzheimer's. (Fill in the blank.)

<table>
<thead>
<tr>
<th>Significantly more</th>
<th>Somewhat more</th>
<th>About the same</th>
<th>This is not a state responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>50.6%</td>
<td>26%</td>
<td>7.7%</td>
<td>14.2%</td>
</tr>
</tbody>
</table>

The State of Illinois should spend.................MONEY funding programs that provide Alzheimer's or related dementia care services to anyone in need. (Fill in the blank.)

<table>
<thead>
<tr>
<th>Significantly more</th>
<th>Somewhat more</th>
<th>About the same</th>
<th>This is not a state responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>52.7%</td>
<td>33.1%</td>
<td>7.6%</td>
<td>6.3%</td>
</tr>
</tbody>
</table>

Should the State of Illinois provide tax credits for the purchase of long-term care insurance?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>86.1%</td>
<td>13.9%</td>
</tr>
</tbody>
</table>

Should the State of Illinois restrict driving for anyone with a diagnosis of Alzheimer's disease?

<table>
<thead>
<tr>
<th>For anyone with a formal diagnosis</th>
<th>Let their doctor determine when it is time to stop driving</th>
<th>Let their family determine when it is time to stop driving</th>
</tr>
</thead>
<tbody>
<tr>
<td>29.8%</td>
<td>50.9%</td>
<td>18.7%</td>
</tr>
</tbody>
</table>

Thinking about services available for individuals with Alzheimer's disease that may or may not be supported by the State of Illinois, which do or would you VALUE the most—even if it isn't currently available? (Please rank all possible answers.)

<table>
<thead>
<tr>
<th>Adult day center for individuals in middle/later stages of Alzheimer's</th>
<th>Nursing homes with specialized care units</th>
<th>Respite care programs</th>
<th>More housing options (other than nursing homes)</th>
<th>In-home programs (nursing/medical care/personal care/companion services)</th>
<th>Prescription drug programs</th>
<th>Transportation programs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Ranking</td>
<td>Average Ranking</td>
<td>Average Ranking</td>
<td>Average Ranking</td>
<td>Average Ranking</td>
<td>Average Ranking</td>
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<table>
<thead>
<tr>
<th>Service</th>
<th>Average Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult day centers</td>
<td>4.8</td>
</tr>
<tr>
<td>Respite care programs</td>
<td>4.3</td>
</tr>
<tr>
<td>In-home programs (nursing/medical care)</td>
<td>5.8</td>
</tr>
<tr>
<td>In-home personal services (bathing, toileting, eating, cooking, etc.)</td>
<td>5.2</td>
</tr>
<tr>
<td>In-home companion services</td>
<td>5.5</td>
</tr>
<tr>
<td>Home-delivered meals</td>
<td>3.6</td>
</tr>
<tr>
<td>Prescription drug assistance</td>
<td>3.4</td>
</tr>
<tr>
<td>Home energy assistance</td>
<td>2.4</td>
</tr>
</tbody>
</table>

If the State of Illinois were to improve care for people in NURSING HOMES, what would be the best first step to achieve that?

- **22.3%** More training for staff in quality care techniques
- **11%** Improve enforcement of regulations and oversight of nursing homes by qualified state surveyors
- **25.6%** More staff required in nursing homes to care for people
- **15.2%** Residents with dementia can only be accepted if staff have a minimum number of hours of training in dementia care
- **8.6%** Improve partnerships between nursing home and family around care of resident
- **5.8%** Improve/publish the list of available nursing homes serving people with Alzheimer’s and other dementias
- **11.5%** Expand availability of nursing home ombudsmen with specialized knowledge of Alzheimer’s care

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ARE YOU CARING FOR SOMEONE WITH ALZHEIMER’S DISEASE? CALL 800.272.3900

The Alzheimer’s Association is here to help you and those you care about through care consultation, education, support and more. Call us 24 hours a day, seven days a week at 800.272.3900 or visit alz.org/illinois.
Section 3
Alzheimer’s Awareness and Access

When it comes to getting information about Alzheimer’s disease, which of the following do YOU trust the most? (Choose one)

- The Alzheimer’s Association: 58.7%
- My doctor: 21.3%
- Leading scientists and researchers: 14.6%
- Online sources like WebMD: 3.9%
- My county health department: 1%
- The State of Illinois: .1%
- My Media: .3%
- The Area Agency on Aging: 7.4%
- My senior center: 16.5%
- My doctor or my doctor's staff: 24.6%

How did you learn about community services that are available in your area? (Choose all that apply)

- The Alzheimer’s Association: 43.1%
- Alzheimer’s Support Group: 16.5%
- Word of mouth/family and friends: 8.1%
- My religious organization: 35.1%
- Online searches: 34%
- My senior center: 7.4%
- The Area Agency on Aging: 16.5%
- My doctor or my doctor’s staff: 24.6%
- My county’s health department: 2.4%
- My employer: HR/EAP: 4.7%

How difficult was it for you or a loved one to get a diagnosis from a local doctor?

- Very difficult – there were few doctors to choose from: 9.9%
- Somewhat difficult: 21.3%
- Somewhat easy: 30.7%
- Very easy – there were lots of doctors to choose from: 10.2%
- This question does not apply to me: 25%
- Impossible – had to travel to another city: 2.8%

When you or a loved one was given the diagnosis, was helpful information about care planning, community resources or referrals to the Alzheimer’s Association or other organizations provided?

- No, no information was shared: 39.9%
- Information about the Alzheimer’s Association was shared: 18.1%
- Information about community resources was shared: 15.2%
- Referrals were made directly to the Alzheimer’s Association: 3.9%
- Referrals were made directly to other community organizations: 28%
- This question does not apply to me: 2.9%

How would you rate the availability of services for people with Alzheimer’s or a related dementia in your area?

- We can’t find any services locally: 4.8%
- There are a few services, but they are very expensive: 25%
- There are a few services that are affordable: 17.7%
- There are adequate services but they are too expensive: 12.9%
- We have lots of options at all price ranges: 5.6%
- We don’t know what the services in our area are like: 5.2%
- There are adequate services and they seem affordable: 29%
Thank you to our survey distribution partners for their assistance in reaching diverse audiences throughout our state and helping us to obtain greater participation in the survey:

- Alzheimer’s Association, Central Illinois Chapter
- Alzheimer’s Association, St. Louis Chapter (serving parts of Illinois)
- Alzheimer’s Association, Greater Iowa Chapter (serving parts of Illinois)
- AARP Illinois
- AgeOptions
- Coalition of Limited English Speaking Elderly (CLESE)
- Egyptian Area Agency on Aging
- Illinois Cognitive Resources Network
- Illinois Public Health Association
- Northwestern University Feinberg School of Medicine – Cognitive Neurology and Alzheimer’s Disease Center
- Rush University Medical Center - Rush Alzheimer’s Disease Center and Rush Health and Aging
- Southern Illinois Center for Independent Living
- Southern Illinois University School of Medicine - Center for Alzheimer’s Disease and Related Disorders
- Western Illinois Area Agency on Aging

our mission
To eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision
Our vision is a world without Alzheimer’s disease®