THE RESULTS ARE IN: IAPG COMPLETES STATEWIDE NEEDS ASSESSMENT

In the fall of 2010, the Idaho Alzheimer’s Planning Group (IAPG) was formed to bring attention to the rising challenge of Alzheimer's disease and related dementias (ADRD) and the need for a state plan to deal with it. Part of the IAPG's mission, endorsed this past spring by the state legislature, was to determine the "state of play" throughout Idaho by talking to stakeholders – those people who are directly or indirectly impacted by the disease. Do family members and caregivers feel they and their loved ones are getting the right services and enough of them? Are service providers able to do their jobs the best way possible? Are there obvious problems that

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IAPG Activities:
Friday, September 21
National Alzheimer’s Action Day. Wear purple and show your support for the fight against Alzheimer’s.

Saturday, October 6
10:00 a.m.
2012 Walk to End Alzheimer’s – Treasure Valley
Julius M. Kleiner Memorial Park, Meridian, Idaho

Friday, October 19 - 2:00 p.m.
IAPG presentation at the Fifth Annual Thomas Geriatric Symposium, Idaho State University, Pocatello, Idaho

Fall (date TBD)
IAPG update presented to the Idaho Legislature’s Health Care Task Force
need solutions? The IAPG started asking questions – lots of them.

Founding IAPG member Dr. Sarah Toevs, a professor in Boise State University’s Department of Community and Environmental Health, led the research effort. Well versed in a variety of data gathering techniques, Dr. Toevs directed a team of student researchers and community volunteers; they devised a multi-pronged approach consisting of written surveys, telephone interviews and focus groups. It was up to other IAPG members to make sure voices were heard from all over the Gem State, and those voices were heard loud and clear [see “Voices Heard” on this page].

Now, almost a year later, the last of the focus groups have been held, the surveys have all been tabulated and the responses have been analyzed. The results are in.

“We learned a lot from Idahoans who are impacted by Alzheimer’s and other dementias,” Dr. Toevs explained. “One of the consistent themes is that our residents want to manage on their own for as long as possible. Caregivers and family members aren’t looking for a hand out, but could use some support as they navigate the stressful, and often unpredictable, course of the disease.”

Respondents from every area of Idaho ranked the need for more information and training a top priority. Many reported that their physicians seemed reluctant to give them a diagnosis of dementia, and even if the diagnosis was made, their doctors couldn’t adequately answer the obvious question, “What do we...
do next?” Learning about the scope and trajectory of the disease as well as how best to care for family members with dementia were important concerns for a large majority of the respondents.

“Clearly, the responses we heard point toward improving the way we inform and educate Idahoans about what they can expect regarding Alzheimer’s,” said Mike Berlin, IAPG founder and local gerontologist.

“Determining a central source for credible information – one that physicians can feel comfortable referring their patients to, and caregivers can reliably go to – should be one of the first priorities to come out of a state plan.”

People with Alzheimer’s, their family members and caregivers weren’t the only groups to give input for the IAPG Needs Assessment. Administrators of assisted living and skilled nursing facilities – where many later-stage dementia patients spend their lives – also voiced their concerns. Many issues surfaced, including the need for more staff training in the area of geriatric and dementia care; the lack of specialists in rural areas, such as geriatricians who understand the varied needs of the elderly; patient safety concerns; inconsistent regulations, and reimbursement rates that don’t distinguish between an average older person and one with dementia.

Berlin, who conducted many of the focus groups across the state, was struck by the level of compassion the administrators felt for both their clientele and their employees.

“It wasn’t all about money,” Berlin explained. “These professionals really want...”

**Seven Hallmarks of the Idaho State Plan**

1. It will increase awareness about ADRD and its impact on patients, families, communities and the state.

2. It will be based on input from people self-identified as concerned about ADRD, and people representing all regions within the state.

3. It will contain recommendations based on the needs of people suffering from ADRD; their family members; their caregivers, and professionals working to assure a safe environment for people with ADRD.

4. It will emphasize public-private ventures when possible and will not allow conflicts of interests among plan participants.
what’s best for their residents, patients and workers. Caring for individuals with dementia is hard work, both physically and emotionally; they see a need for better training as well as higher compensation for those who are on the front lines dealing with the disease.”

**What’s Next?**

The IAPG Needs Assessment clearly identifies a number of service and program areas that need improvement, and those challenges will form the spine of the state plan. When completed, the plan will follow guidelines set forth by the IAPG steering committee [see “Hallmarks” pg. 3] and offer proposed solutions to the problems. Berlin takes it a step further.

“IAPG members have put in countless volunteer hours, so the last thing we want to see is a state plan gathering dust on a shelf,” he said. “Instead, we’re going to put the right people together who can come up with initiatives that will solve or at least rectify some of the problems Idahoans have identified. We’ve got plenty of expertise and brain power to do that.”

One such initiative is already in the works. The IAPG will be forming a work group to determine the best way to disseminate the right information to health care professionals, the patients and their families who are facing Alzheimer’s. Members of the group will include representatives from AARP and the Alzheimer’s Association, who already provide information about the disease, as well as experts from the Idaho Commission on Aging (ICOA) and Idaho’s Department of Health and Welfare, who can provide effective conduits to those in need.

**Hallmarks - continued**

5. It will build upon best practices of existing services and systems.

6. It will include cost-effective recommendations.

7. It will include specific goals and measurable objectives.
“Idahoans, like so many others across the country, are hungry for reliable information that can help them deal with Alzheimer’s disease,” said Cathy McDougall, Associate State Director, AARP Idaho. “Caregivers and family members also want to learn what they can do to avoid memory issues themselves. We can help get the word out but it will take a united effort to do it effectively.” [See following article for a more in-depth interview with Ms. McDougall].

As stipulated in Senate Concurrent Resolution 112, the IAPG plans to report on its progress to the Health Care Task Force and the Idaho State Legislature later this year and during the 2013 legislative session. Those interested in reading the entire Needs Assessment report can view it at http://hs.boisestate.edu/CSA/IAPG.

Q&A with Cathy McDougall of AARP

One of the IAPG’s most ardent supporters is AARP. Cathy McDougall, associate state director of outreach for AARP Idaho, is an IAPG member. She was instrumental in securing a grant of $10,000 from the national organization to help the IAPG in its research efforts. The funds have been used for traveling and other expenses related to putting on focus groups throughout the state. Recently she talked about her role at AARP and how it intersects with the interests of IAPG.

IAPG: What brought you to AARP Idaho?

McDougall: I became interested in gerontology when my grandparents moved from sunny California to

How to Maintain a Healthy Brain

Even though there’s no foolproof way to avoid memory loss (yet!), researchers now believe you can take steps to keep your brain functioning at its best, no matter how old you are. Here’s what the experts suggest:

1. Consume foods high in antioxidants, like berries, beans, fruits, nuts and vegetables.
2. Avoid junk food – especially snacks and meals loaded with sugar and refined carbohydrates.
3. Exercise daily – even 30 minutes of walking will help.
4. Manage and reduce your stress.
5. Get enough sleep.
6. Stay social – maintain a network of at least five people.
7. Give your brain a workout through brain games (e.g. Sudoku, crossword puzzles), learning a new skill or language, or doing something old in a new way, like writing with your opposite hand.
snowy Idaho because they needed extra care that only family can provide. My grandparents as elders and my parents as caregivers made a lasting impression on me. I watched my grandparents age, deal with decline and eventually pass on. I watched my parents cope with “sandwich generation” caregiving. These life events inspired me, and there was no question in my mind that I’d go into gerontology as a career. I earned a master’s of social work degree (MSW) and became a geriatric social worker. I’ve been with AARP for 12 years – six of those in Idaho.

**IAPG:** What do you do for the organization?

**McDougall:** AARP focuses on issues such as caregiving, long-term care, senior hunger relief, low-income issues, consumer fraud protection and Medicare education. I help develop and implement programs that address those issues. As you can imagine, that involves educating the community, as well as managing both volunteers and various AARP events throughout the state.

**IAPG:** You’ve been a positive, productive member of the IAPG since the beginning; how did that come about?

**McDougall:** Everyone knows that Alzheimer’s and related dementias (ADRD) is a looming problem throughout the United States, and Idaho is no exception. When I learned about the IAPG’s goal of developing a state plan and the logical way they wanted to go about it, I signed on. AARP supports the development of a plan because Alzheimer’s is still somewhat “behind the curtain” and we have to get the word out about it. Lots of Idahoans feel alone and unsupported when faced with the disease, and that’s got to change. A plan will help bring the issue of ADRD to the forefront and get information out there that’s sorely needed. We also hope the plan will help save taxpayer dollars, as people with AD are able to stay at home longer instead of going into Medicaid-funded institutions. IAPG is all-volunteer and is truly dedicated to addressing these challenges. I particularly like their emphasis on innovative public/private partnerships. That makes sense to me and to AARP. So it’s a perfect fit.

**IAPG:** You’re obviously plugged in to your membership; what do AARP members in Idaho think about Alzheimer’s and other dementias, and are their concerns different from those of members in other states?

**McDougall:** Because it’s a rural state, Idaho has
special issues related to the availability of services, and it has certain advantages that larger, more urban states don’t always have, like strong, supportive local communities. Yet in most respects Idahoans feel and act the same way seniors do all across the country; in fact, in 2010 AARP conducted a national membership survey and the number one concern mentioned across the board was how to stay mentally sharp. So the rising prevalence of ADRD is definitely on everyone’s mind – so to speak!

IAPG: AARP is beginning to address that issue by talking up “brain health.” What does that mean?

McDougall: Researchers used to think there was nothing you could do to ward off Alzheimer’s or other dementias. To date there isn’t a magic bullet – or immunization – you can get to avoid the disease, and sadly, there is no known cure. But while we wait for scientists to come up with a solution, studies today are showing that we can all help mitigate symptoms by keeping our brains as healthy as possible [see “How to Maintain a Healthy Brain,” pg. 5]. Doing that means being proactive about what we eat, how we exercise – everything, in fact, that goes into staying generally healthy. So while there are no guarantees, at least we can take action that can only be a plus for our lives.

IAPG: You conducted brain health seminars across the state this past year; how successful were they?

McDougall: They were very well attended, and provided a great introduction to the topic. In 2013 we hope to organize ongoing social groups that will promote brain health activities, whether it’s to exercise our bodies or our minds more – hopefully both!

IAPG: Are we talking Sudoku Tournaments?

McDougall: (laughs) You never know!

IAPG: How can individuals get more information about AARP activities related to ADRD, or even get involved in what the AARP is doing?

McDougall: We’re looking for advocates to help support the state plan, long-term care choices, and our newest foray into caregiving. For more information about caregiving, they can go to http://www.aarp.org/home-family/caregiving, and for information about getting involved, they can email aarpid@aarp.org.
Supporting Partner Organizations and thanks to:

- National and Greater Idaho Chapter of the Alzheimer's Association
- Idaho AARP
- Idaho Commission on Aging
- Boise State University - Center for the Study of Aging

To learn more about IAPG and upcoming activities, please visit: [http://www.hs.boisestate.edu/csa/IAPG](http://www.hs.boisestate.edu/csa/IAPG)

To read the NAPA Act, please visit: [http://aspe.hhs.gov/daltcp/napa/#DraftNatlPlan](http://aspe.hhs.gov/daltcp/napa/#DraftNatlPlan)

To read Idaho Senate Concurrent Resolution 112 please visit: [http://www.legislature.idaho.gov/legislation/2012/SCR112.htm](http://www.legislature.idaho.gov/legislation/2012/SCR112.htm)

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Dementia: A Long-standing Problem:

About 2,400 years ago Plato described an illness that “gives rise to all manners of forgetfulness as well as stupidity.” Dementia in the Greco-Roman World also quotes the Roman poet, Juvenal, who almost 2,000 years ago characterized a phenomenon that’s easily recognized as dementia:

“Diseases of all kind dance around the old man in a troop. But worse than any loss in the body is the failing mind which forgets the names of [servants] and cannot recognize the face of the old friend who dined with him last night, nor those of the children whom he has begotten and brought up.” [Excerpt taken from A Place for Mom Newsletter, September, 2012]

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