IAPG: INSIDE A GRASS ROOTS EFFORT TO BRING A STATE PLAN FOR ALZHEIMERS AND OTHER DEMENTIAS TO IDAHO

On September 13th, the Idaho Statesman ran a front page-headline: “Frantic families demand help with Alzheimer’s.” While the AP article dealt with the disease and its growing impact on our nation as a whole, an equally urgent story could be told about the challenge facing us right here in Idaho.

Today, Alzheimer’s patients throughout our state would fill Bronco Stadium – and because Baby Boomers are now reaching their mid sixties, that number is on track to double in just 14 years. For every dementia patient, there’s a family whose physical, emotional and financial resources are being stretched to the limit. Once those limits are reached, the state must step in to help, and as the number of patients grows, the strain on government resources will increase as well. What can be done?

THE IAPG...IS COMMITTED TO SEEING IDAHO STEP UP AND DO ALL IT CAN TO MEET THE CHALLENGE THAT MANY HAVE CALLED ‘THE DISEASE OF THE BABY BOOM GENERATION.’

DR. TROY ROHN

IAPG Activities:

Saturday, October 8
9:30 a.m. Walk to End Alzheimer’s – Veterans Memorial Park, Boise, ID. IAPG will enter a team and host a booth.

Thursday, October 13
9:15 a.m. Alzheimer’s Conference, Area Agency on Aging V, Pocatello, ID. Dr. Troy Rohn to give the Keynote address.

Saturday, October 15
8:30 a.m. Friends in Action – Family Caregiver Conference, Doubletree Riverside Hotel, Boise, ID. IAPG will host a booth.

Friday, October 21
9:00 a.m. Thomas Geriatric Symposium – Idaho State University, Idaho Falls, ID. IAPG will host a booth.
Approximately 35 states now have plans in place or in the works to address the needs of Alzheimer’s patients and their caregivers. Idaho isn’t one of them – yet. To help get the process started, several individuals formed a grassroots organization in the fall of 2010 called the Idaho Alzheimer’s Planning Group, or IAPG.

“We’re a diverse group with a common focus,” explained Mike Berlin, a clinical gerontologist and therapist in Boise, and one of the IAPG’s founders. “We’re getting to know the individuals and organizations that really care about this issue and want the best possible services for both patients and caregivers.”

Not Your Typical Approach

Many states with plans already in place opted for a “top down” approach in which the state not only paid thousands of dollars to create the plan, but many more thousands to implement it. The current economic climate precludes that for our state, besides which a high-priced government model just isn’t the Idaho way. Instead, the IAPG is working with Boise State University, the Idaho Commission on Aging (ICOA), AARP, the Alzheimer’s Association and other organizations to gather data in order to present a cost effective plan that will meet the needs of Alzheimer’s and other dementia patients and their families. The goal is to find community-centric, rather than government-mandated solutions.

“We’ve taken the ‘if you build it they will come’ approach,” said Dr. Sarah Toevs, director of BSU’s Center for the Study of Aging, and IAPG founding member. “Rather than wait for someone in government to say there ought to be a plan – a legislative process that can take quite a while - we’re moving ahead to determine in general what that plan should look like, based on feedback we’re collecting from across the state. Our legislators will
then have something substantial to evaluate.”

The work of the IAPG falls into three main categories: collecting data, pursuing a legislative track, and educating the public about the need for a state plan.

Communication is the key to accomplishing the latter. This newsletter, for example, will report quarterly on the progress of the IAPG; in addition it will contain interesting articles pertaining to Alzheimer’s and related topics. Information about the IAPG is also available as a link on the BSU Center for the Study of Aging website: http://aging.boisestate.edu/IAPG.SHTML

Finally, the group has created a speaker’s bureau consisting of Mike Berlin, MS Gerontology, LCSW; Dr. Sarah Toevs and Dr. Troy Rohn. Dr. Rohn, also an IAPG member, is a noted researcher on diseases of the brain and a professor in the Department of Biological Sciences at BSU. (see Q&A with Dr. Rohn below). In addition to presenting in front of state house and senate committees, the speakers are already scheduled to appear at events such as the October 8th Alzheimer’s Walk; an Alzheimer’s Conference in Pocatello; and a Geriatric Symposium in Idaho Falls. Members of the bureau are also available to speak at civic functions, or in front of private organizations or other interested groups (see newsletter or website for current activity log). If you are interested in having the IAPG give your group a presentation, please contact Mike Berlin at (208) 830-6775, or email gericare@cableone.net

“The IAPG is about real people coming together to bring about change for real people suffering from an all-too real disease,” said Dr. Rohn. “We’re all committed to seeing Idaho step up and do all it can to meet the challenge that many have called ‘the disease of the Baby Boom generation.’ The time to do something about it is now.”

Q&A with Dr. Troy Rohn

One of the founding members of the Idaho Alzheimer’s Planning Group, Troy Rohn earned a Ph.D. in Pharmacology from the University of Washington and worked in a number of post doctoral capacities, including a position at UC Irvine’s Institute of Brain Aging and Dementia. He is currently a professor and researcher in the Department of Biological Sciences at Boise State University, specializing in apoptosis in neurodegenerative diseases such as...
Alzheimer’s. Recently he was lauded for developing an antibody that will help researchers who are trying to determine triggers for Alzheimer’s and other degenerative maladies. His findings were published this summer in a special edition of the journal *Neurobiology of Disease*.

**IAPG Report**: Why did you decide to study diseases of the brain?

**Dr. Rohn**: I have my wife to thank for that. We were dating in Bozeman, Montana and she decided the winters were too cold, so she moved back down to Southern California. I followed her and ended up at UC Irvine working in a lab studying AD [Alzheimer’s disease]. Best move I ever made: not only did I get the girl, but I ended up researching a very important and timely subject, which I continue to work in today.

**IAPG Report**: How has the field of AD research grown since you’ve been in it?

**Dr. Rohn**: I don’t have the exact numbers, but this will give you some idea: In 1985 when the first international conference for AD researchers (ICAD) was held, there were maybe a hundred attendees, if that. In 2011, that number had risen to over 5,000. There’s definitely more interest in unlocking the secrets of Alzheimer’s than ever before.

**IAPG REPORT**: Where is current research leading, i.e. what questions are researchers trying to answer?

**Dr. Rohn**: For the past decade the main avenue of research has centered around “beta-amyloid plaques” you often hear about. Scientists have been researching ways to either prevent the formation of beta amyloid plaques, or remove them from the brain. Unfortunately several recent clinical trials in these areas that showed promise with animal models of Alzheimer’s ultimately failed when applied to humans. Researchers are still at it, but some of the current studies have also branched into the area of early detention and prevention.

**IAPG REPORT**: What surprises you most about the research being done today?

**Dr. Rohn**: Aside from the disappointing clinical trials, I’d have to say it amazes me that over a century after discovering the disease, we still don’t know precisely what causes it. Less than 5% of all AD cases are genetic, so clearly something about the aging process triggers the disease. I wish I could say we have a crystal clear idea of what that trigger is, but sadly we don’t – not yet, anyway.
**IAPG REPORT:** What do you find in the field that gives you hope?

**Dr. Rohn:** Disease-modifying drugs will play a critical role in managing AD; so will our ability to detect the disease earlier. Both of these ideas are close to becoming a reality. We know now that the pathology of AD begins to manifest years before the first symptoms; if we had a way of identifying those people and then had drugs that actually stopped the course of the disease, then we’ll put a big dent in the problem.

**IAPG REPORT:** What got you interested in the IAPG?

**Dr. Rohn:** My research involves working on a microscopic level most of the time, but the truth is, Alzheimer’s affects everyday people like you and me, often in debilitating ways. Being involved in the policy arena helps me to keep that perspective. I also know how important it is to educate the public about the disease and the kind of help that’s available for both patients and caregivers. I’m very proud to be associated with the IAPG because I know we’re all committed to seeing that our state puts a realistic plan in place to help all Idahoans who are touched by the disease.

**IAPG REPORT:** What would you like to see in a state plan for Alzheimer’s and other dementias?

**Dr. Rohn:** For starters, a state plan should have a component that helps educate the public about the disease and the kind of help that’s available for both patients and caregivers. I also know we’ll need to address AD issues as they relate to our rural population. But the real details of the plan will emerge after we perform a service gap analysis to see what resources we already have, and what we’ll need to develop in order to keep up with the increase in the AD population over the next 20 years.

**IAPG REPORT:** How can lay people help in the fight against Alzheimer’s?

**Dr. Rohn:** The best thing people can do is let their local and federal
government officials know how important this disease is and that we need more federal funding to support research – that’s the only way we’re going to discover effective treatments. You know, if you look at the economic impact of dementias, it far outstrips that of other diseases like cancer, heart disease and stroke. That’s because Alzheimer’s has such a long trajectory and involves so much caregiving. Yet the annual federal investment spent on dementia research is pitiful compared to other diseases. That’s going to have to change if we’re going to conquer this epidemic – and believe me, the epidemic is coming.

Note: If you would like to receive this quarterly newsletter electronically, please send an email request to: gericare@cableone.net.

The Idaho Alzheimer’s Planning Group is committed to improving the spectrum of prevention, diagnosis, treatment and caregiver support services for people with Alzheimer’s disease and other dementias. Our goal is to elevate Alzheimer’s disease and other dementias as a public policy priority in Idaho. We are working to educate leaders, legislators and the public about this growing health care issue, and we are advocates for a statewide strategic plan to address it.

IN PARTNERSHIP WITH:
Center for the Study of Aging
College of Social Sciences and Public Affairs
College of Health Sciences