FULL SPEED AHEAD:
IAPG MAKES PROGRESS ON ALL FRONTS

The Idaho Alzheimer’s Planning Group (IAPG) was founded in late 2010 to bring about a state plan for Alzheimer’s and other dementias. Since then the volunteer organization has made significant progress toward that goal in three areas: legislation, community input and public awareness.

A resolution on the move. Caring for Alzheimer’s patients throughout the life cycle of the disease can be very expensive. Many Idahoans don’t have the financial resources to pay for such care so it often falls to the state.

“THE IAPG RESOLUTION MAY BE ONE OF THE MOST IMPORTANT ISSUES HANDLED BY THE LEGISLATURE THIS SESSION.”

STATE SENATOR JOYCE BROADSWORD

Since the number of AD patients is growing, more and more pressure will be put on state budgets like Medicaid and the Division of Veterans Services to

IAPG Activities:
January 23 – IAPG focus group leader training session
February 7 – IAPG will facilitate three focus groups in conjunction with the annual IHCA/ICAL conference in Boise.
Administrators of assisted living facilities in three size categories (<15, 15-25 and >25 beds) will discuss issues related to serving residents with dementia.
treat these patients; a state plan will help allocate taxpayer dollars where they are needed most, as well as find ways to use funds more efficiently wherever possible.

But state plans don’t just magically appear. Typically a state will spend thousands of dollars to put together a “blue ribbon” panel of experts who will in turn oversee the collection of data and writing of such a plan.

The IAPG took a different approach. Over the past year, the grassroots group established a steering committee made up of experts including researchers, legislative advocates, service providers, caregivers and representatives from such organizations as AARP, the Alzheimer’s Association and the Idaho Commission on Aging — all of whom are volunteering their time for the cause.

Through the committee’s contacts, IAPG members were able to speak in front of the Senate and House health and welfare committees, as well as the Health Care Task Force, a bipartisan committee of state representatives and senators that advises the legislature on health-related issues. On January 6th of this year, the task force voted unanimously to support the efforts of the IAPG toward the creation of a state plan; a joint resolution stating the same support is now working its way through the legislature, championed by State Senator Joyce Broadsword [see Q&A on pg. 4] and co-sponsored by Senator and Dr. Dan Schmidt along with representatives Dr. Fred Wood, Carlos Bilbao and Dr. John Rusche.

“In my opinion the IAPG resolution may be one of the most important issues handled by the legislature this session,” said Senator Broadsword. “For sure, Alzheimer’s will have the farthest-reaching impact on our citizens in future years.”

Getting a resolution of support passed by the legislature and signed by the governor is only the beginning, however. Once the data is collected and a state plan is developed, it too will have to work its way through the system. But according to IAPG founder Mike Berlin, it’s a great first step.

“Having the ‘Good Housekeeping Seal of Approval’ of the state government gives us credibility moving forward,” Berlin explained. “We can use that credibility to apply for grants, for instance, that may be needed for special projects down the road; it will also help smooth the way as we turn to state agencies that will most likely be in
charge of implementing programs or services that arise from the state plan itself."

As the resolution moves through the legislative process, there may be opportunities for IAPG supporters to let legislators know how important the issue is to them. Such opportunities will be listed on the IAPG website.

What’s working, what’s not: data collection is underway. Since the fall of 2011, the IAPG research team has been canvassing caregivers and others throughout the state to determine how Idahoans are coping with Alzheimer’s. Hundreds of surveys have been filled out, with hundreds more yet to come. Preliminary results show some bright spots, and definite areas that need improvement.

“All the data isn’t in yet, but so far, most respondents feel a general satisfaction with the quality of service, which we hope is reassuring to AD patients and their families,” said team leader Dr. Sarah Toevs, director of Boise State University’s Center for the Study of Aging. “However, the majority of respondents have a problem with three different aspects of AD: affordability, access to information, and support for caregivers. Those are areas we ultimately hope to address with specific recommendations in the state plan.”

In addition to surveys, the IAPG, through the Center for the Study of Aging, engaged BSU student Lena Bush to conduct several in-depth telephone interviews with caregivers [see article on pg. 7]. And beginning in February, thanks to a grant from the AARP, IAPG will hold the first of several focus groups comprised of members from such institutions as skilled nursing facilities, hospitals and assisted living centers. Gathering data from the full spectrum of stakeholders – from patients, family members and caregivers to all levels of service providers – will enable the IAPG to make a comprehensive needs assessment from which to chart a course for the future.

Getting the word out. We’ve already seen through surveys that AD caregivers and family members would like to have greater access to information. Through its speaker’s bureau, the IAPG has already begun to shed some light on the disease. Since last October, Dr. Troy Rohn, noted biological researcher from BSU, has been the keynote speaker at several Alzheimer-related conferences sponsored by the Idaho Commission on Aging across the state. In addition to discussing the pathology of the disease
and the most promising research efforts, he has used his talks to encourage participation in IAPG’s research efforts by having attendees fill out surveys. He will continue his speaking tour this year, with added emphasis on “brain health.” While no cure or inoculation has yet been found for Alzheimer’s, there are ways in which individuals can perhaps lessen their chances of developing the disease.

“Wherever I go, people are thirsty for information about Alzheimer’s – what they can expect from it and what relief might be coming down the road,” said Dr. Rohn. “Whether they’re newcomers to the world of AD or veteran caregivers, they all want answers.”

The IAPG is dedicated to finding those answers and sharing them with the citizens of Idaho so that every AD patient – and caregiver – has what he or she needs to cope with Alzheimer’s and other dementias.

For more information about IAPG legislative efforts, community input and outreach programs, please check out our website at: http://aging.boisestate.edu/IAPG.shtml

Q&A with State Senator Joyce Broadsword

One of IAPG’s most recent supporters is Joyce Broadsword, a four-term state senator from the Sandpoint area. Broadsword isn’t your average Idahoan; her roots in this state reach back four generations – more than 100 years. Recently she talked with IAPG Report about public service, her concerns about Alzheimer’s disease, and the fact that learning never stops.

IAPG Report: Seems like most people go to college first and enter the work force afterward, but you chose another path.

Senator Broadsword: I did. For me there wasn’t time to go to college right out of high school. I help operate a family business – a log home manufacturing company – plus I run a courier service for a medical laboratory. I also have children and grandchildren. But getting a degree has always been one of my goals, so I’m currently attending North Idaho College. And, while I’m here in Boise for the legislative session, I’ll be taking some online courses. Keeps me busy.

IAPG Report: Let’s see: running two businesses and going to school...how did you find time to enter the world of politics?

Senator Broadsword: I’ve volunteered for just about everything that came along most of my life, from
the Chamber of Commerce to Rotary International. I really feel it’s our duty to help others in whatever way we can, so becoming a public servant was a natural outgrowth of that.

**IAPG REPORT**: How did it come about?

**Senator Broadsword**: Several seated legislators encouraged me to run for the senate. They felt our district needed someone who’d be willing to work hard for our part of the state. I said I’d give it a try and won the first time out.

**IAPG REPORT**: You must be doing something right; this is your fourth term.

**Senator Broadsword**: I have the good people of District 2 to thank for that!

**IAPG REPORT**: As a legislator, you no doubt have to deal with hundreds of issues that affect our state; why have you gotten involved with the needs of Alzheimer’s patients and their families?

**Senator Broadsword**: Sad to say, Alzheimer’s is very prevalent in my own family. My grandmother, her siblings and my uncle all died from complications of the disease. I’ve seen firsthand the way it steals the minds of your loved ones. I feel very strongly about it. In fact, it was with Alzheimer’s in mind that I wrote and got passed the Genetic Privacy Act in my second session, to ensure that Idahoans’ private genetic testing results cannot be used by insurance companies to set their rates.

**IAPG REPORT**: Given the fact that genetic testing for diseases like Alzheimer’s is on the rise, that one piece of legislation will probably save Idahoans thousands of dollars in the years ahead.

**Senator Broadsword**: I certainly hope so!

**IAPG REPORT**: We’re flattered that you chose to work with IAPG, but...why us?

**Senator Broadsword**: I was impressed last year when your group presented to the Senate Health and Welfare committee, which I co-chair. You gave another solid presentation to the Health Care Task Force this past November. The IAPG has a very strong presence, and your timing is right. Our population is both growing and aging; Idaho needs to develop a statewide plan for this disease now.

**IAPG REPORT**: We call you our “legislative champion” and it sounds like we’re sending you into battle. How do you actually go about getting a resolution passed?

**Senator Broadsword**: You have asked for a joint (that means both houses of the legislature) resolution to be passed that essentially supports and affirms IAPG’s goal of
creating a state plan for Alzheimer’s and other dementias. Getting that resolution to become law takes many technical steps, as well as several voting procedures. On January 17th the Senate Health and Welfare Committee voted unanimously to send the motion from “routing slip” status “to print,” which means it will become an official resolution with its own SCR (“Senate Concurrent Resolution”) number. The bill will then receive a full hearing, including testimony, before the same Senate committee. If it passes, the bill’s co-sponsor, Dr. Dan Schmidt, and I will carry it on the full Senate floor. If it passes the floor vote (and I expect it will!), the resolution will then go to the House and follow a similar procedure there. Once it has passed the floor of both houses it will go to the Governor for his signature. Come to think of it, maybe “cheerleader” is a better word than “champion” in this case, since I don’t think we’ll encounter too many adversaries—it’s too important an issue to be ignored.

**IAPG REPORT:** We’re exhausted just hearing about the procedures involved! But that’s just the beginning, isn’t it?

**Senator Broadsword:** Afraid so. Once the IAPG’s research is completed and a state plan is developed, it will have to go through the same process all over again. But I hope the plan will eventually be used to give our state agencies a strategy to prepare for the increasing numbers of Idahoans with Alzheimer’s and other forms of dementias. Dealing with this disease is expensive—and getting more so—for both individuals and the state. If we don’t have a plan to move forward with cost effective treatments and services, Alzheimer’s and its impact on both patients and caregivers has the potential to devastate our state budget, not to mention our citizens.

**IAPG Report:** One last question: despite your very busy schedule, you’ve responded to our many questions in record time; how can you be so efficient?

**Senator Broadsword:** I find if I don’t respond to requests like yours as soon as possible, they end up on the bottom of a growing “stack of stuff” and I forget all about them! But getting the word out about IAPG and its mission is especially important to me; I appreciate the work you’re doing and the value you bring to the process. I look forward to moving this issue from idea to reality.

**IAPG Report.** Thank you, Senator. We’re glad you’re on board!
Up Close and Personal: A Conversation with an Idaho Caregiver

It’s often said that the number of Idahoans with Alzheimer’s disease would fill Bronco Stadium, a number that will double in less than 14 years. But for every person suffering from dementia, there is at least one – and usually several – people whose lives are changed dramatically by the disease. These are the caregivers, and to understand their plight, it helps to go beyond the numbers.

Last fall, Boise State University student Lena Bush conducted an in-depth telephone interview of several caregivers of Alzheimer’s patients. Selected by the directors of Idaho’s six regional agencies on aging, the respondents represented all areas of the state. Bush asked each participant a series of questions, including how long they’d been caregivers, the type of support they had, their access to information, their biggest challenges, changes to their own lives, and finally, any advice they might have for others. Here are some of their responses:

Changes to their own lives: “What life? It always changes. [We] don’t go out to eat…. [my] spouse cannot comprehend anymore.” “Not being able to go out to dinner or other social events.” “…frustration, anxiety, and the loss of freedom. And that is pretty basic, I think, among most caregivers.” “You feel nailed down; no one comes around anymore.”

Their biggest challenges: “…for me it’s maintaining patience, strength. It don’t mean physical, but emotional strength – all the associated chores, bill pay, taxes, lots of financial things.” “…health care professionals that don’t know how to deal with Alzheimer’s.” “My husband suffers from incontinence and wandering.” “Basically, just dealing day to day with the changes. One day they are normal, the next day he does not know where he is.”

Advice for other caregivers: “…always
remember that the action and behaviors are the disease and not the person.” “Take care of yourself, eat right, get plenty of sleep, and get away for a couple of hours.” “The biggest one is: do not argue with them. If they say they are Santa Claus, do not argue with them because it gets them frustrated and angry. Just agree with them and walk away...”

As the sole caregiver for her own grandmother for ten years, Bush had to take special care not to inject her own bias into the interviews.

“I could relate to a lot of what the subjects were saying,” Bush recalled. “It was hard to remain neutral and not add my own story to the conversation.”

Overall, Bush noticed a clear distinction between those caregivers who had access to information and those who didn’t.

“You could really hear the stress and tension in those who didn’t know enough about how they could improve their situation; they seemed to feel their whole world was collapsing on them,” she explained.

“But those who were plugged in had much more positive attitudes. They felt there was some hope.”

The information collected by Bush will help put a “human face” to the quantitative data gathered by the IAPG research team, and is a prime example of effective research techniques. In fact, Bush’s study was selected from more than 3,000 entries for the 2012 National Conference on Undergraduate Research. The NCUR is an annual forum that gives outstanding undergraduate scholars from across the country an opportunity to showcase their research in all fields of study. Bush will present her findings at Weber State University, in Ogden, Utah, March 29-31.

“We’re All Family Here”

By Louise Berlin

My father spent the last three years of his life in the locked ward of a memory care unit. Last December he lost the ability to swallow and I shared the unforgettable experience with my family of caring for him during his final days. But this story isn’t really about my dad’s departure; it’s about those he left behind on the second floor, and two men who have convinced me that...
angels come in the strangest shapes and sizes.

My brothers, Russ and Reed, are both in their 60’s. They have worked for decades in a family business that requires physical strength, creative thinking, business acumen and people skills. Financially they are well to do. They are hunters and fishermen; they love bicycles and motorcycles, an occasional cigar and Maker’s Mark. They revered my dad and visited him often. In fact, the director of the memory care unit, which cares for about 25 residents, told us that our family paid more visits to my father than all of the other residents’ families – combined.

Such devotion is admirable enough, but my brothers went far, far beyond the call of duty. Over time they got to know virtually everyone on the second floor – staff members and residents alike. During the time I spent there, I got to know many of them through my brothers’ eyes.

“That’s Dora,” Russ says, pointing to a petite Hispanic woman. “She’s from Managua and used to own several beauty salons. Very astute businesswoman in her day.”

Dora looks around with a puzzled expression. “Why am I here?” she asks.

My brother shakes his head. “The fact that she asks the question answers her question, don’t you think?”

A slender, dapper gentleman sits at a table. Kenny was an RAF mechanic from the Battle of Britain through the end of World War II. He grew up in Portsmouth, England and his family owned a toy store. At my brother’s prompting he will relive the Glory Days.

“At the rat tat tat tat tat we would have to scurry into the trenches to avoid being injured,” he recounts in his proper British accent.

At other times Kenny asks Russ if he’s seen his wife.

“No I haven’t,” Russ always says, “but if I see her I’ll let her know you’re looking for her.” Kenny’s wife has been dead since 1994.

Peter comes prancing by. He is German and full of energy. He loves to sing and dance. He carries a flashlight wherever he goes, and on this occasion he’s worried because it’s not working. My brother Reed promises Peter he’ll bring him batteries next time – and he does.

Peter was in the German army, and one day Russ sat him down with my dad, whose
liberty ship was the last to be sunk by a German U-boat in the Atlantic in 1945. “Peter,” he pointed out, “your country’s navy sunk my dad’s ship in the war.”

“Oh, I’m sorry about that,” Peter replied, truly contrite.

My father waved his hand magnanimously. “All is forgiven,” he said. And in the world of the second floor, where the most reliable memories are over half a century old, that is saying a lot.

I’m walking down the hall with Reed and a head pops out of a room – at floor level. It’s Monroe, a P-51 mechanic in World War II and a diehard Dallas Cowboys fan. He forgets that he can’t walk and often slips out of his wheelchair onto the floor. I am panicked, ready to call for help.

“Hello Monroe,” Reed greets him, helping him back into his chair before continuing down the hall. “Happens all the time,” he tells me. “No biggie.”

During that final week with my dad I spent a lot of hours on the second floor. My brothers, their wives, my mother and other family members would come and go. Lunchtime would roll around and someone would run out for sandwiches for the group. We’d eat them in a small common room at the end of the hall, and during our meal, Wanda would sometimes join us, checking out our little party. Once a sergeant in the Air Force, Wanda is friendly, engaging and seems quite “with it,” except that she can’t remember much of anything about herself. But that doesn’t matter; Wanda is welcome anytime.

One evening as we sat at my dad’s bedside, a resident named Donna, who is wheelchair-bound, came rolling into the room. Normally very loving and clear-eyed, she was obviously upset.

“What’s wrong, Donna?” Russ asked, putting his arm around her. “Are you lost?” She looked up to him and nodded tearfully.

“I’ll take you back where you belong,” he said. “Don’t worry.” The gentle compassion in my brother’s voice made me want to weep.

Over several days my dad grew weaker. “He is actively dying,” the hospice workers told us. On one of his last nights, a woman named Toni wandered into the room. She is wraithlike, much too slender, with long gray hair; dementia has her securely in its clutches. She will often take Russ’s face in her
hands and say “Panos? Panos?” which is the name of her son. My brother will nod and she will coo lovingly to him in Greek.

Russ tells the story that one day he noticed that Toni was walking with a man who could be her son. “Are you Panos?” my brother asked him. The man looked surprised. “Yes I am.”

“So am I,” Russ said with a grin. The man began to apologize for his mother, but my brother stopped him.

“We’re in this together,” Russ said. “We’re all family here.”

When Toni wandered in that evening, the atmosphere was subdued. We were playing one of Dad’s favorite CD’s softly and the lights were low. We were all somber because we knew our vigil was coming to an end. Toni said nothing, but looked at all of us and gave the sign of the cross. And just as quietly she left. We felt we’d been given a gift.

The next evening my father died. Many of the staff members cried, but Rolando, the maintenance man, was serene. Days before, at my brothers’ request, he had given my dad a blessing. They have been around Rolando long enough to believe he’s a holy man...and they are probably right.

“You do not need to worry,” Rolando told me. “Your papa is in good hands.”

Alzheimer’s is an insidious disease that stealthily robs us of that which we value most: our sense of who we are in this world. But to the end, every dementia patient remains a person with a story – an individual who worked and loved and lived a worthwhile life. The number of patients with memory loss is growing, and we need more “angels” like my brothers; individuals from all walks of life who are willing to say to people who will never truly know them, “You matter to me, even now.”

The funny part is, both Russ and Reed will tell you angels have nothing to do with it. “They’re my friends,” Russ would say. And Reed would just roll his eyes, as if to say, “What’s the big deal?”

My dad is gone and there’s no reason for my brothers to visit the second floor anymore. But they still do. Russ talks to Dave, a former truck driver who used to race pigeons, and makes a mental note to bring Dave a book about the birds. And he meets a new woman, Aileen. He notices she has an accent and asks her where she’s from.

“France,” she replies.
“Where in France?”
“Bordeaux.”
“Ah,” Russ says.
“Wine-making country.”
“Oui,” she says, her eyes lighting up.
“Delicious wines.”
“So, Aileen, will you be my friend?” he asks.
She smiles. “Yes, I’ll be your friend.”
It’s as easy – and as awe-inspiring – as that.

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. 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.

What you can do to help:
- Provide feedback through surveys and focus group participation. You can complete a survey at: http://aging.boisestate.edu/IAPG.shtml
- Support our legislative plan/become an advocate for Alzheimer’s disease policy and legislation.
- Keep up-to-date and educate yourself by reading this and other newsletters about Alzheimer’s disease and other dementias.

Supporting Partners:
- National and Idaho Chapter of the Alzheimer’s Association
- Idaho AARP
- Idaho Commission on Aging
- Boise State University - Center for the Study of Aging