

alzheimer's  association  
desert southwest chapter  
**Advocacy E-Newsletter**  
**July 2011**



**Advocacy is supporting a cause and having your voice heard by someone with the ability to make change.**

Greetings, fellow Alzheimer's Association advocates! This month's newsletter will focus on the reasons for being an advocate, and on opportunities you have to make your voice heard.

**Why I'm an Alzheimer's Advocate**

Ernie Otto, Alzheimer's Association Desert Southwest Chapter Volunteer

I'm an Alzheimer's advocate because I was a caregiver for my mother who died of the disease, and I watched my sister-in-law slowly fade away over 14 years because of the disease. There was nothing to be done to stop or slow the progression for either of them. I want what my mother and sister-in-law experienced to change. They can no longer say what they need, and I want to speak for them. I want to see people with dementia receive good care, but I most want to see a solution to the problem – an end to Alzheimer's disease.

I'm an Alzheimer's advocate because we are stronger together than we would be alone. Federal funding of research is what has led to breakthroughs for other diseases like cancer and HIV, and I want to see the same commitment to Alzheimer's disease research. Advocacy in the public policy arena is a very slow process sometimes, but I am doing this to improve things for my kids and my grandkids.

I have been involved with Alzheimer's advocacy for six years. Before I got involved I was not a "political person" at all. I voted, but that was it. Now I have been to Washington and met with legislators and their staff six times, and I am currently Alzheimer's Ambassador to Representative Trent Franks. I'm an Alzheimer's advocate because I can't imagine not being one.

### **National Alzheimer's Plan – Your Input Needed!**

The National Alzheimer's Project Act (NAPA) was signed into law by President Obama in January of this year. This law gives the Secretary of Health and Human Services responsibility for having a national plan developed to address the growing human and financial cost of Alzheimer's disease and related dementias. What do you think should go into such a plan? There are three ways you can give your ideas and opinions.

#### **Attend a NAPA Input Session in person:**

##### **Sun City (Phoenix metro area), Arizona**

Friday, August 26, 2011

9:30 AM-11:30 AM

Banner Sun Health Research Institute

Morin Auditorium

10515 West Santa Fe Drive

Sun City, AZ 85351

##### **Las Vegas, Nevada**

Thursday, September 1, 2011

9:30AM-11:30 AM

Humana Guidance Center, Summerlin

8975 West Charleston

Suite 100

Las Vegas, NV 89117

#### **Give your input online:**

Use this link: <http://napa.alz.org/share-your-feedback>.

#### **Participate in a national Tele-Town Hall by telephone:**

Thursday, August 4, 2011 5:00 PM local time

This event is free to the public, but space is limited. [Please Sign up today!](#)

## **Arizona Alzheimer's Task Force and Work Teams**

Four work teams with about 75 members across the state are participating in ongoing research, discussion, and recommendation activities regarding important issues, needs, and recommendations associated with dementia. Any Arizona resident is welcome to join one or more of these work teams at any time over the next three years. We welcome people with both professional and personal interest in these topics; we need your experience and ideas! These work teams are meeting about monthly (primarily by phone) until September 2014 to identify, discuss, and develop recommendations for the State regarding the issues within their topic areas:

- **Work Team One - Impact of the Disease on the State**
- **Work Team Two - Access to Services**
- **Work Team Three - Independence and Safety**
- **Work Team Four - Quality of Care Promotion and Regulation**

### **TO GET INVOLVED:**

Please send your contact information and work team preference to Cathy Griner, Arizona Alzheimer's Task Force Co-Chair, at [cathy.griner@alz.org](mailto:cathy.griner@alz.org).

Thanks for your willingness to become involved in this very important work that will profoundly influence the future of Arizona's dementia capability!

## **Nevada Alzheimer's Task Force and Subcommittees**

Planning for forming the task force and moving the work toward state plan development forward is underway, and updates on how residents of Nevada can get involved will be reported here as they become available.

### **Do you want to get involved with public policy advocacy but you don't know how? Attend advocate training by webinar.**

The next advocate training is scheduled for Tuesday, August 23 from 6:00 – 8:00 PM. This is a change from the previous schedule, which had the training taking place during the day, because of poor response. All you need to participate is a computer and a phone; you can be anywhere in the Chapter area (Arizona or Southern Nevada) and there is no charge. Topics covered will include the meaning of advocacy, why it's important, concrete public policy changes that have resulted from advocacy, and how you can effectively advocate for people with dementia and their families. Absolutely

no political knowledge or experience working with government entities is required. Contact Cathy Griner at 602-528-0545 ext. 229 or at [cathy.griner@alz.org](mailto:cathy.griner@alz.org) to register for the August training session.

**Are you 18-39 years old with a desire to help end this disease and make a difference for people with dementia and their families and you live in the Phoenix area? Become a young advocate.**

If you would enjoy attending social events to meet other young advocates and exchange information, you could be one of the newest members of our active and growing YAAA! (Young Advocates for the Alzheimer's Association) group. For more information please contact us at [yaaa.dsw@alz.org](mailto:yaaa.dsw@alz.org), or check out our webpage at [http://www.alz.org/dsw/in\\_my\\_community\\_20598.asp](http://www.alz.org/dsw/in_my_community_20598.asp).

## **IN CLOSING**

Because of your compassion and passion YOU are an ADVOCATE. Thank you for your commitment to the fight Alzheimer's disease and related dementias!

Please see [http://alz.org/join\\_the\\_cause\\_advocacy.asp](http://alz.org/join_the_cause_advocacy.asp) for a variety of information regarding advocacy efforts and results throughout the nation.

Please call me at 602-528-0545 ext. 229 or send an email to [cathy.griner@alz.org](mailto:cathy.griner@alz.org) if you have any questions or comments, or if you would like to be removed from this email distribution list.

Cathy Griner, LMSW  
Alzheimer's Association Desert Southwest Chapter Director of Program and Advocacy

Please visit us on our website at [alz.org/dsw](http://alz.org/dsw) or call our 24/7 Helpline at 1-800-272-3900.  
Thanks!