

alzheimer's advocacy day

**salem, oregon
feb. 11, 2014**

Why Advocacy?

- Policy is the way we can help every person in Oregon impacted by Alzheimer's
- Need to remind legislators that people affected by Alzheimer's live in their district.
- Every day they see paid lobbyists, people from other groups like ours, and they get pressure from many sources. Out of sight is out of mind, so we need them to see us.
- Most important thing to do is for them to remember that Alzheimer's is an issue that impacts people in their district.

Advocacy Day Logistics

Parking/Transportation

- Rides are being arranged from Portland, Bend, Medford, and Eugene. If interested in participating, be sure to let me know ASAP, but I plan on double checking with everyone.
- Parking near the capitol is pricey – about \$15 a day. There is a lot under the Capitol Mall, some surface lots, and plenty of street parking, but you need to be sure to keep the meter plugged. Salem parking enforcement is notorious.
- More details on parking can be found on the following websites:
 - http://www.oregonlegislature.gov/citizen_engagement/Pages/Visit-the-Capitol.aspx
 - <http://www.cityofsalem.net/Parking/>
 - http://www.oregon.gov/DAS/EAM/FPS/Pages/options_daily.aspx

Advocacy Day Logistics

Times

- 8:30 to 9:00 am – Meet at MICAH Center
- 9:00 to 10:30 am – Training/briefing
- 10:30 am – Walk to State Capitol – meetings begin
- 12 noon – lunch delivered in room 167A
- 4:00 pm – bus to Portland load for return

Advocacy Day Logistics

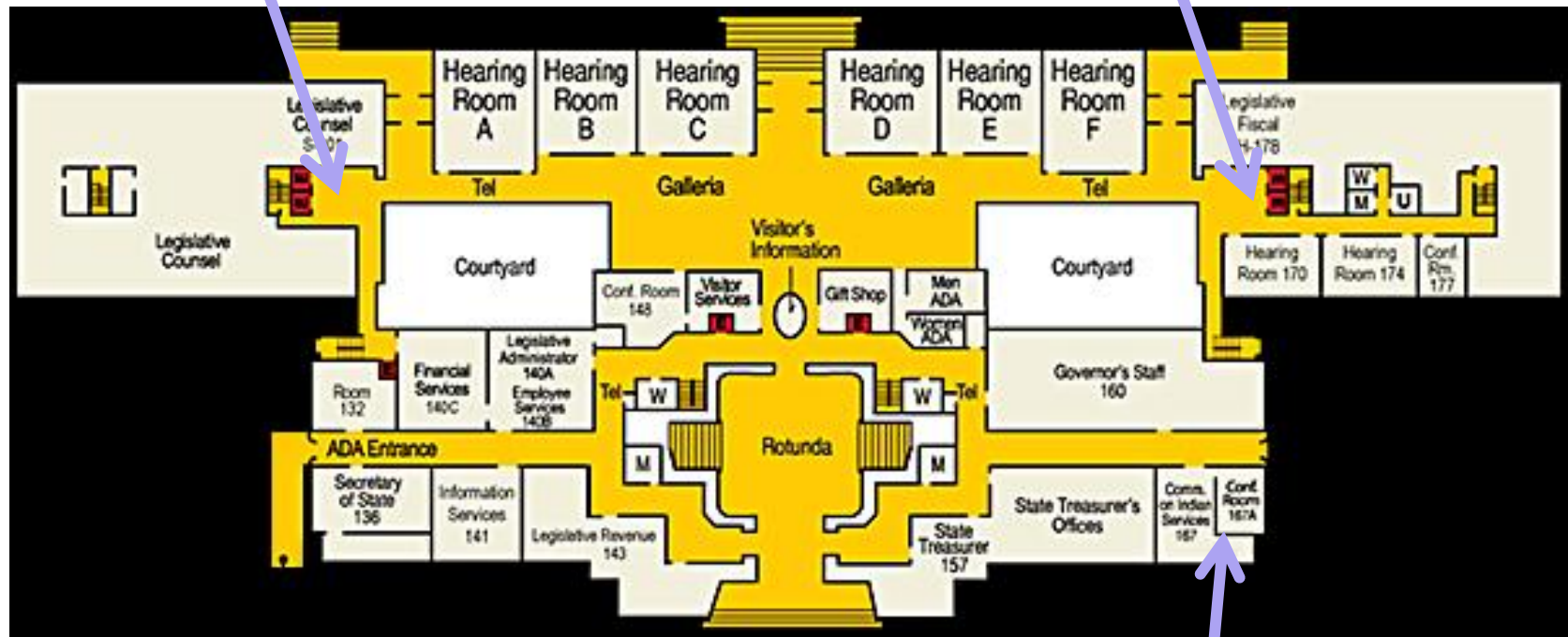
Locations



Advocacy Day Logistics

Senate elevators

House elevators



Room 167A – Lunch and base of operations

Advocacy Day Logistics

Between meetings

- Join other advocates – we don't want anyone going alone
- Come back to Room 167A and fill out a report from other meetings
- Explore the capitol
- <http://www.oregonlegislature.gov/>

Legislative Priorities

Protecting people with Alzheimer's who wander

- Sixty percent of people with Alzheimer's disease will wander. People with Alzheimer's may not remember their name or address, and they can become disoriented, even in familiar places.
- If a person with Alzheimer's wanders and is not found within 24 hours, there is a 60 percent chance that person will die or have a serious injury. The risk of death increases to 80 percent if the person is not found within 72 hours. Simply stated, it is dangerous when people with Alzheimer's wander.
- We want to ensure the safety of our most vulnerable citizens. The Alzheimer's Association has the Medic Alert Safe Return Program. We also provide information to the public about how to keep their loved ones safe. And we support safety standards in long term care settings where people with dementia reside. However, wandering will remain to be a problem.

Legislative Priorities

Protecting people with Alzheimer's who wander (cont)

- Law enforcement is frequently called on to respond to a wandering case. Many police and sheriff departments are well trained on what to do when they receive a report on a missing person with dementia. However, not all have formal policies or training.
- SB 1577 will require all police and sheriff departments in Oregon to adopt a formal policy by January of 2015 on how to respond to a case of a missing vulnerable adult. This policy should include:
 - Procedures for performing a search of a person with dementia
 - Description of the training officers will receive
 - Requirements for accepting missing persons reports
 - Protocols on involving the local media to have the public assist with a search
 - Protocols for coordinating with other agencies

Legislative Priorities

Protecting people with Alzheimer's who wander (cont)

- The Oregon Accreditation Alliance will craft a template policy that departments can adopt, or departments can adopt a policy they create from scratch or is adapted from the Alliance template. The Alliance is a body that exists to improve the quality of law enforcement agencies in the State of Oregon and ultimately the quality of services provided to the citizens of this state.
- If a department already has a formal policy that addresses the bill's requirements, then this legislation does not affect them. The legislation allows for flexibility and discretion for each department to determine what works best in their situation.

Legislative Priorities

Creating an office of the Oregon Public Guardian and Conservator

- Guardianship and conservatorship are court-ordered protections that are ordered for individuals who are not capable of protecting themselves. When a court finds that a person is incapable of making decisions about his or her own basic health, safety and financial needs such that serious physical injury or illness is likely to occur, a guardianship or conservatorship may be ordered. The basis for incapacity may stem from severe mental health conditions, developmental disabilities and/or age-related conditions.
- The Oregon Public Guardian and Conservator will provide needs-based guardian and conservator services for Oregonians who:
 - Do not have a friend or relative who is willing or able to assume the duties of guardianship or conservatorship and
 - Are assessed to lack the financial resources necessary to obtain a private guardian or conservator.
 - At-risk adults who are unable to care for themselves are vulnerable to continued abuse or neglect, which can yield various negative consequences, including repeated hospitalizations, stroke, heart attack, malnutrition, commitment to a psychiatric unit and premature death.
- To address this problem, many states have developed a “public guardian.” The Alzheimer’s Association supports legislation to create this resource — and corresponding office — in Oregon.
- **SB 1553**

Legislative Priorities

Funding for services for families affected by Alzheimer's

- In September 2013, the Oregon Legislature held a special session that reined in a tax break, which led to about \$26 million in resources set aside for services dedicated to seniors and people with disabilities. We support using some of these funds to help Oregonians affected by Alzheimer's in the following ways:
- **Caregiver training**
 - *\$1.6 million: Geriatric medication-competency training pilot*
 - *\$450,000: Specialized training for professional and family caregivers on best care practices for Alzheimer's and related dementias*
 - *\$400,000: Specialized training for caregivers on challenging behaviors*
 - *\$500,000: Specialized first-responder training on Alzheimer's and related dementias*
 - *\$350,000: Enhancing access to caregiver training statewide*
- **Public Guardianship program**
 - *\$925,000: Expansion of State Ombudsman office to manage Public Guardianship program and increase legal assistance*
- **Data, research, pilot projects**
 - *\$30,000: Collection and analysis of data on cognitive impairment and caregiving via annual BRFSS report*

How to Lobby

- Make sure to arrive at your meeting a few minutes ahead of time.
- **YOU ARE RESPONSIBLE FOR FINDING YOUR MEETING PLACE.**
- Decide *before* you go into the meeting who in your group will speak on what subjects. **Be sure everyone's voice is heard.**
- **Identify yourself as a constituent** or a resident of the region and your affiliation with the Alzheimer's Association. Identify any questions/concerns they may have, and thank them for their time and attention.
- **Be Courteous and Polite!** Keep it brief and to the point, **sticking to your key talking points** and sharing any personal connections or experiences you may have as someone impacted by Alzheimer's disease. This is invaluable information for them.

How to Lobby

- **Don't make up any facts.** If they ask you a question you can't answer, tell them you will have someone get back to them for the answer. Then let us know what the legislator needs.
- **Leave behind** the packet of information we provided (and flowers). If they say they want materials electronically, let us know and we will follow up.
- Be sure to **thank them** for their time!
- You sometimes won't catch legislators during this activity, and instead their legislative staff. **These staff relationships are just as important.** They typically have the ear and the confidence of the legislator and are most likely going to be doing most of the legislative work on the issue; and are often more accessible.

How to Lobby

- If you have a phone /camera, ask if you can have a picture taken. Email your picture to jon.bartholomew@alz.org
- If you need immediate help, call Jon at 503-358-3833.
- ***Let us know how your visit went and any information you learned by completing the meeting report and evaluation sheet.***

Promise Garden Flowers

- Give our Promise Garden flowers to legislators



State Ambassadors

- Please consider becoming a State Ambassador!
- State Ambassadors commit to contacting their legislators by phone or in person regularly.
- Send letters to the editor.
- Come to Advocacy Day each year