

Alzheimer's Advocate E-Newsletter April 2009

We had a fun and productive time in Washington D.C. last month at the Alzheimer's Association Public Policy Forum. We had eight attendees from the Desert Southwest Chapter, six from Arizona and two from Nevada. For Arizona we were successful in securing appointments with eight of our members of Congress and their staff. As we build our relationship with our sister Chapter in Northern California (that Chapter covers the Northern part of Nevada) to further our Nevada legislative initiatives, four out of five members of Congress were visited. Our objectives were clear and further assistance from our advocates will be needed to help us achieve our goals.



(L to R): Mary McDonald, Sylvia Stevens, Ernie Otto, Jami Goldman, Cindy Vargo, Gus Farias and Luis Carrillo: Public Policy Committee Members, Volunteers and Staff attend the Annual Candlelight Vigil at the steps of the Lincoln Memorial in Washington DC.



(L to R): Lorena Llamas (Public Ally), Mary McDonald, Sylvia Stevens, Ernie Otto, Jami Goldman, Cindy Vargo and Luis Carrillo pose for the Chapter group photo.



Preparing for our hill visits: (L to R): Mary McDonald, Cindy Vargo, Sylvia Stevens, Gus Farias (far right corner), Luis Carrillo and Angie Pratt (Advocacy Staff from Northern Nevada).

Our call on Congress this year was to address the grave threat that Alzheimer's disease poses to the well-being and financial security of American families by:

1. Increase fiscal year 2010 Alzheimer research funding at the National Institute of Health (NIH) by \$250 million with a goal of reaching \$1 billion in funding by fiscal year 2011.
2. Establishing the Alzheimer's Solutions Project Office within the federal government backed by an appropriate scale of investment.
3. Phasing out Medicare's two –year waiting period so individuals with Alzheimer's are eligible for Medicare immediately after they receive their determination of disability.

We also provided information on local programs and services, such as support groups, education programs, etc. offered by the Desert Southwest Chapter so that any constituent who may call their Congress person for information will receive an informed referral.

Below is where our legislators stood on the three issues after our visits.

State	Congressional District (e.g. AL01)	Elected Official's Title (Sen. / Rep)	Elected Official's First Name	Elected Official's Last Name	1 - Supports increase in Alz research with NIH funding?	2 - Supports establishing Alz Solutions Project Office?	3 - Co-sponsor ending 2-year Medicare wait period?
AZ	AZ JR	Sen.	Jon	Kyl	N	Not sure	Not sure
AZ	AZ SR	Sen.	John	McCain			
AZ	AZ01	Rep.	Ann	Kirkpatrick			
AZ	AZ02	Rep.	Trent	Franks			
AZ	AZ03	Rep.	John	Shadegg	N	Not sure	Not sure
AZ	AZ04	Rep.	Ed	Pastor	N	Not sure	Not sure
AZ	AZ05	Rep.	Harry	Mitchell	Y	Not sure	Y
AZ	AZ06	Rep.	Jeff	Flake	Not sure	Not sure	Not sure
AZ	AZ07	Rep.	Raul	Grijalva	Y	Not sure	Y
AZ	AZ08	Rep.	Gabrielle	Giffords	N	Not sure	Not sure
NV	NV JR	Sen.	John	Ensign			
NV	NV SR	Sen.	Harry	Reid	Y	Not sure	Y
NV	NV01	Rep.	Shelley	Berkley	Y	Not sure	Y
NV	NV02	Rep.	Dean	Heller	Y	Not sure	Not sure
NV	NV03	Rep.	Dina	Titus	Y	Not sure	Y

As you can see there is reasonable support for the increase in funding to NIH, but lots of unsure answers for supporting the project office and even ending the two-year wait period for Medicare. Your help is needed. Below and attached is the Alzheimer's Association statement on the Medicare Wait Period that you can print and send to your Representative and Senators to ask them to support and even co-sponsor the legislation that removes this two-year waiting period. The actual bill is the *Ending the Medicare Disability Waiting Period Act of 2009* (S. 700/H. R. 1708) and can be found at: <http://www.govtrack.us/congress/billtext.xpd?bill=h111-1708>

	The Honorable Harry Reid	333 Las Vegas Blvd. South	8016	Las Vegas, NV 89101	(702) 388-5020	(702) 388-5030	http://reid.senate.gov/
		600 East William Street	302	Carson City, NV 89701	(775) 882-7343	(775) 883-1980	

Statement that can be sent or forwarded on to your legislator:

Association Statement on Medicare Wait Period

4.7.09

The Alzheimer's Association commends Sen. Jeff Bingaman (D-N.M.) and Rep. Gene Green (D-Texas) for their important legislation phasing out the two-year wait period for Medicare for those under age 65 who qualify for Social Security Disability Insurance (SSDI). We also appreciate the original co-sponsors of the legislation — Sens. Susan Collins (R-Maine) and Sherrod Brown (D-Ohio) and Rep. Lee Terry (R-Neb.) — for their support.

There are more than 5 million Americans living with Alzheimer's disease, and up to a half million of these individuals are under age 65 and have younger-onset Alzheimer's or a related dementia. After working full-time and paying into Medicare like all other employed Americans, many of these individuals lose their jobs and with it their employer-based health coverage. As these individuals grapple with the challenges an Alzheimer diagnosis brings to their lives, they also discover that federal law requires them to wait two additional years after their disability determination to become eligible for Medicare benefits.

The Alzheimer's Association urges members of Congress to cosponsor the Ending the Medicare Disability Waiting Period Act of 2009 (S. 700 and H.R. 1708). Phasing out the waiting period for Medicare benefits for people disabled by Alzheimer's disease would reduce the problem of lack of health insurance and high out-of-pocket expenditures for this vulnerable population. It would ensure access to critical healthcare services that can help to manage the disease and help to maintain independence.

There are more than 1.5 million people with disabling conditions suffering through two long years for much needed Medicare coverage. Nearly 40 percent of these individuals are without health insurance coverage at some point during their wait for Medicare and 24 percent have no health insurance during this entire period. These are important gaps in the healthcare system that can no longer be ignored.

Alzheimer's disease poses tremendous burdens on individuals and families, burdens made worse by lack of healthcare coverage. The Alzheimer's Association is grateful for the leadership of Sen. Bingaman and Rep. Green and urges bipartisan support and swift enactment of this important legislation that provides invaluable health coverage and peace of mind for those with Alzheimer's and other disabling, fatal diseases.