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# The Caregiving Exchange

## January 2013



### Welcome Message

#### Welcome to the January 2013 newsletter!

Happy New Year! The Alliance wants to thank you for your support of our work, as the Alliance strives to support you in your work with family caregivers in your communities.

In 2013, we will continue to build on our long tradition of pioneering research and of supporting state and local caregiving coalitions. The work of these coalitions is vitally important in terms of direct outreach to caregivers and as front-line advocates. NAC is expanding resource materials and training to these coalitions to help them be even stronger, more impactful advocates in the months ahead.

We want to thank our new and renewing Corporate Alliance Members for their extraordinarily generous support... Eli Lilly, Pfizer, PhRMA and UnitedHealthcare. As well as all of our renewing Sustaining members. Please go the [Members section of our website](#) to learn more about these organizations and their support for family caregivers.

In this newsletter you can read about the initiatives from other organizations in recognizing family caregivers during this past November's National Family Caregivers Month. You can find in the News, Reports and Publications section some great new resources. Read also about the 6th annual Innovations in Caregiving Program. If you are a 501c3, non-profit organization and you want to replicate a winning innovative caregiving program, please apply! In the coalition news we introduce a new family caregiving coalition that recently joined our network. If you want to introduce your caregiving coalition in the next newsletter, please email [stien@caregiving.org](mailto:stien@caregiving.org). In the legislative update, we highlight the National Plan to Address Alzheimer's Disease (NAPA) and the budget sequestration and "Fiscal Cliff".

May your New Year filled with joy!  
Enjoy reading,

Gail!

Gail Gibson Hunt

President & CEO

## 7th Annual National Conference for Caregiving Coalitions



Plan NOW to join us at ASA in Chicago on **Wednesday, March 13, 2013** for the 7th Annual National Conference for Caregiving Coalitions! This one-day event is for family caregiving coalitions across the country. We will offer insights on policy issues, "how to" workshops to strengthen your coalition and improve your outreach, and loads of opportunities to network with others in the field.

We proudly present the 10 scholarship award recipients for the 7th Annual National Conference for Caregiving Coalitions. Some of them are new, others developed innovative advocacy or educational campaigns and, they are geographically spread.

1. Community Caregiving Outcomes Alliance (CoCOA) - IL
2. The Caregivers Coalition of Bergen County - NJ
3. California Coalition for Caregiver - CA
4. "We Care" La Crosse Caregivers Coalition - WI
5. CaregiverU - TX
6. Larimer County Caregiver Coalition - CO
7. Long Island Family Caregiver Coalition - NY
8. Coalition of Caring - NH
9. Caregiver Coalition of Northeast Florida - FL
10. CareGivers'Hope - GA

Join the scholarship award recipients and register now for the 7th Annual National Conference for Caregiving Coalitions by clicking [here](#).

## November National Family Caregivers Month Activities

A lot of organizations and individuals acknowledged family caregivers and the vital role they fulfill during **November National Family Caregivers Month**. In the October newsletter we asked to share your actions. Below are a few examples of the many efforts organizations and people undertook to recognize family caregivers.



The **Pennsylvania Department of Aging** kicked off a caregiver webinar series on 11/19/2012. November National Family Caregivers Month was the ideal time for them to launch their new webinar series until the fall of next year to recognize family caregivers. Topics such as basic legal and basic medical information, tips for caregivers to keep healthy, caregiving for those with Alzheimer's Disease and others will be discussed. To view the November webinar click [here](#).

The **South Central Town Hall Caregiver Coalition** (Hastings, Nebraska) organized a "the Blessing of Caregiving" Thanksgiving Dinner for their local caregivers. The Mayor of Hastings came and presented the proclamation declaring November to be "Family Caregiver Awareness Month in Hastings."

On the state level, Nebraska's Lt. Governor, Rick Sheehy signed 5 proclamations declaring November to be Family Caregiver, Respite, Hospice, Home Care and Alzheimer's month in Nebraska.

The **Area Agency on Aging** (Byesville, Ohio) organized a Caregiver Appreciation Luncheon in four of the nine counties. At these luncheons, the caregiver and a guest are given a complimentary meal, mini-massages, door prizes, entertainment, and support from other caregivers. They also have exhibitors around the perimeter of the room, with information (about respite, coping with stress,...) to make their caregiving journey easier.

## News, Reports and Publications

**TEDMED**, part of the TED Conferences group (also called "TED talks"), solicited 20 Great Challenges to health care from the public for 2013. "The Caregiver Crisis" was one of the 20, and Peter Arno, Carol Levine, Suzanne Mintz, Barry Jacobs, Cheri Lattimer, and Alan Blaustein were chosen to be the Challenge Team. Visit and explore the TEDMED "The Caregiver Crisis" website [here](#). Members of the Great Challenge Team, The Caregiver Crisis gathered on a Google + Hangout and Twitter chat (the Alliance participated in that Twitter chat) to discuss the topic in a virtual roundtable event. Watch their discussion [here](#).

### Balancing Work and Family Care of Older Persons: Videos on Issues Related to Work and Eldercare

The primary objective of this series of video training modules is to help employers create work environments that are supportive of families and households simultaneously engaged in work and elder care. Professor Clifton Barber, Associate Dean for Outreach and Extension in the School of Human Ecology at the University of Wisconsin-Madison, received funding from the Meta Schroeder Beckner Endowment to develop the videos. To watch the videos click [here](#). Resources related to each video are available via link after each video description.

### New Patient and Caregiver Treatment Summaries from AHRQ's EHC Program

Family caregivers often face difficult health care decisions, often with little information and little time. It can be hard to find clear, reliable information about different medicines or other treatments.

AHRQ has developed many easy-to-use tools for patients, caregivers and health care

professionals that help decide the best course of action. Materials help caregivers and patients understand:

- What does this diagnosis mean?
- Which test is best?
- Which medicine will help most with the fewest side effects?
- When is surgery the best option?

These materials help caregivers and patients:

- Have better conversations with family and health care professionals.
- Confirm they are already getting the best treatment, or discover that another option may be better.
- Make sure their voices are heard.

Free patient treatment summaries are available on:

- Antipsychotic Medicines for Children and Teens: A Review of the Research for Parents and Caregivers - click [here](#)
- Medicines for Early Stage Chronic Kidney Disease: A Review of the Research for Adults With Kidney Disease and Diabetes or High Blood Pressure - click [here](#)
- Methods for Delivering Insulin and Monitoring Blood Sugar: A Review of the Research for Children, Teens, and Adults with Diabetes - click [here](#)
- Preventing Blood Clots After Hip or Knee Surgery: A Review of the Research for Adults - click [here](#)
- Progestogen To Prevent Pre-Term Birth: A Review of the Research About Progestogens for Women at Risk - click [here](#)

For more information on new patient materials, subscribe to the EHC Inside Track newsletter or visit the Effective Health Care Program website, [www.effectivehealthcare.ahrq.gov](http://www.effectivehealthcare.ahrq.gov).

### Innovation in Caregiving

The National Alliance for Caregiving, with generous support from the MetLife Foundation, is pleased to present the 6th annual Innovations in Caregiving Program. Ten organizations will be awarded \$10,000 in seed funds to replicate one of the previous winning programs. One example of a previous winning program is the "Ride Partners and Repairs with Care" which empowers older adults to remain independent in their own homes through a time-exchange network where assistance is available to older adults and their caregivers for neighborly tasks such as transportation and household repairs, thus enabling all participant to contribute to the well-being of each other. The National Family Caregiving Awards Replication Guide, which contains descriptions of previous award winners, can be opened [here](#). Eligible applicants must be a 501c3, non-profit organization. The request for applications can be found [here](#). The deadline for applications is January 15, 2013.

The 2013 Innovations in Caregiving grantees will also attend and present at a caregiving workshop in conjunction with the n4a Annual Conference in July 2013 at which the information about their caregiving programs will be presented.

The November 29th webinar on the 2013 Innovations in Caregiving Awards can be viewed [here](#) for the next 90 days. Five previous winners of these awards presented their creative programs that serve caregivers of older adults.

For additional information or questions, contact Rick Greene at the National Alliance for Caregiving, [nac.innovations@gmail.com](mailto:nac.innovations@gmail.com) or (443) 962-7497.

### Tell Washington...We Must fight Alzheimer's!

We are asking everyone, especially caregivers, to send a message to Capitol Hill to not let up on fighting Alzheimer's Disease (AD). We know how challenging caregiving can be. Across the country, more than five million people ages 65 and older currently are living with AD. Over 15

million more Americans - family members, friends, neighbors and volunteers - provide unpaid care for someone with AD. Unless we find new treatments or find a cure, by 2050 over 16 million Americans, plus their families, will be facing the devastation of Alzheimer's.

It is vitally important that Congress fulfill its commitment to fight this disease by carrying through on the National Plan to Address Alzheimer's Disease, which was adopted this summer. This is why The National Alliance for Caregiving is asking one minute of your time - one minute to read and sign a petition. Please click on the image below and sign the petition. Then we ask that you pass this message along to everyone you can in your network - colleagues, coalition members, caregivers, friends and others.



## Coalition news and updates

We want to give the readers of this newsletter the opportunity to get to know the family caregiving coalitions in our network. This month we would like to introduce CaregiverU of Texas.

**CaregiverU** is a collaboration of twenty partner agencies that provides education and support to caregivers, older adults and their families in the Central Texas region. CaregiverU was founded and is managed by AGE of Central Texas, a social services non-profit organization that has provided education, advocacy, resources, and support to seniors and their family members for over 25 years.

CaregiverU represents an expansion of the caregiver educational seminars (e.g. Powerful Tools for caregivers, conferences, and support services) that AGE has offered since 2004. Due to growing demand for its caregiver services, AGE decided that the best way to reach even more family caregivers was to form the CaregiverU coalition in 2011. Now nearing the completion of its second year, 20 non-profit, faith-based and government partner agencies offer caregiver educational classes throughout a four county area to an increasingly diverse group of caregivers, especially low income and rural caregivers. In 2012, CaregiverU added fall prevention classes to its educational curriculum.

CaregiverU is funded by a generous grant from the St. David's Foundation, the charitable arm of one of the local hospital systems. The Area Agency on Aging of the Capital Area has also provided funds to purchase some of the books used in classes. There is no charge for participants to attend classes but partner agencies do receive a modest stipend to cover the expenses of offering classes.

Representatives from CaregiverU partner agencies receive training and certification to teach Powerful Tools for Caregivers classes and A Matter of Balance at no cost to those receiving the training. CaregiverU supports the class leaders through ongoing training and communication to be sure their instruction provides the most current information and best teaching practices. Collaboration members support each other through sharing of information and materials through email, audio conferences, and periodic meetings.

Powerful Tools for Caregivers is a 6-week educational series designed to help family caregivers take care of themselves while caring for a relative or friend. A Matter of Balance, an eight session

class, emphasizes practical strategies to manage falls and maintain an active, healthy lifestyle. Both are small group discussion classes co-led by two trained CaregiverU class leaders.

CaregiverU encourages its partner agencies to coordinate their advocacy efforts in order to generate awareness and support for family caregivers. Several of the partner agencies do provide input to governmental and other organizations to increase resources for caregivers.

For more information about the CaregiverU coalition, visit the CaregiverU website [here](#). You may also contact Faith Unger, CaregiverU project coordinator at (512) 451-4611, extension 244 or [funger@ageofcentraltx.org](mailto:funger@ageofcentraltx.org).

The next **Quarterly Family Caregiving Coalition Call** will be on **January 30 at 3PM EST**.

Earlier this year, the Department of Health and Human Services created a new Administration for Community Living, which brought together the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities. This new agency is focused on increasing access to community supports and achieving full community participation for people with disabilities and older adults.

With that context, this webinar will explore the composition of caregiving coalitions. Join us to hear from coalitions what their focus is (e.g. across the lifespan) and hear from other coalitions that include a diverse array of members (businesses, organizations, physicians, social workers,...).

You will learn how they face various challenges and the value they experience in being an inclusive and diverse coalition. If you have any specific questions you would like the speakers to address - or you feel you have an experience with your own coalition that we can all learn from - please feel free to submit those ahead of time to [stien@caregiving.org](mailto:stien@caregiving.org).

If you missed a previous call and you want to refer back to the PowerPoint slides, please click [here](#).

**Are you a part of a family caregiving coalition?** If you would like to join NAC's network of family caregiving coalitions to support family caregiving coalitions or if you know a coalition that is not yet listed, please email: [coalitions@caregiving.org](mailto:coalitions@caregiving.org).

## Legislative update

### National Plan to Address Alzheimer's Disease (NAPA)

On May 15, 2012, the Department of Health and Human Services (HHS) released the first-ever National Plan to Address Alzheimer's Disease. This plan sets forth five goals, including the development of effective prevention and treatment approaches for Alzheimer's disease and related dementias by 2025. It also addresses caregiver needs. In order to help reach those goals, President Obama's FY 2013 budget request to Congress included \$100 million for Alzheimer's research, education, outreach and support activities. Many advocacy groups, including the Alzheimer's Association and others, are urging caregivers, people with Alzheimer's disease and others to contact their Members of Congress and ask them to support that funding request.

With regard to family caregivers, the third goal of the plan is to "Expand Supports for People with Alzheimer's Disease and Their Families." Strategies under this goal include ensuring that caregivers receive culturally sensitive education, training, and supporting materials; enabling caregivers to continue providing care while maintaining their own health and well-being; and assisting families in planning for future care needs. The Alliance, along with several other organizations and stakeholders, provided input for the plan as it was being developed.

For more information, visit:

Alzheimer's Association - National Alzheimer's Plan From Act to Action - click [here](#)

National Plan to Address Alzheimer's Disease - click [here](#)

### Budget Sequestration and the "Fiscal Cliff"

Congress passed and President Obama recently signed a bill to avoid temporarily across-the-board federal funding cuts under a sequester (the "fiscal cliff"). The sequester would have imposed cuts of \$54.7 billion annually over 10 years to nearly every federal discretionary program. However, the new law merely delays these cuts by two months. If Congress fails to act by then, coming up with a more refined set of spending cuts, and the automatic spending cuts are imposed, all services and supports under the Older Americans Act will be affected. Specifically, the National Family Caregiver Support Program could be cut by \$12.5 million. It is currently funded at \$152 million. Those cuts mean that thousands of families could lose their respite, counseling and support, information services and more. The National Alliance for Caregiving has expressed concern over these potential cuts to the Administration.

For more information about potential cuts to senior programs and services by state, visit:

National Council on Aging - click [here](#)

## Events & Opportunities

### ASA's 2013 Aging in America Conference.

Each year the field of aging faces numerous challenges and opportunities, and the Aging in America Conference is the place to meet and discuss them. Learn about the latest research and best practices, network with colleagues and stay on top of what's going on in the field. *March 12 - 16, 2013, Chicago, Illinois*, More info: [Conference info](#)

### 7th Annual National Conference for Caregiving Coalitions.

Please join with fellow state and local family caregiving coalitions for an exciting day of networking, training and sharing great ideas designed specifically to help you improve the success of your coalition's work. *March 13, 2013, Chicago, Illinois*, More info: [Conference info](#)

### n4a 38th Annual Conference & Tradeshow.

Attendees have the unique chance to move to the front lines of aging and explore the latest advances in critical topics like long-term services and supports, care transitions, evidence-based health promotions and livable communities. *July 27 - 31, 2012, Louisville, Kentucky*,

More info:

[Conference info](#)

### World Parkinson Congress 2013.

The 3rd World Parkinson Congress is a forum for bringing together the international community to help build awareness and increase collaborative efforts to find a cure for Parkinson's disease (PD).

*October 1 - 4, 2013, Montreal, Canada*, More info: [Conference info](#)

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