

The Caregiving Exchange

March 2013



Welcome Message

Welcome to the March 2013 newsletter!

The Alliance hopes everyone is getting ready for spring and beautiful weather. Over here in DC we are looking forward to the blooming of the cherry blossoms at the end of the month. We want to thank you all for your continued support of our work, as we strive to assist all of you and the good work each of you are doing in your own communities with family caregivers.

We also would like welcome two new members to the Alliance, [Caregiver's Survival Network](#) as well as [Shire Pharmaceuticals](#). The Caregiver's Survival Network is a free social network, dedicated solely to the welfare of caregivers. Shire Pharmaceuticals strives to lead the future of healthcare and enable people with life-altering conditions to lead better lives. Please go the [Members section of our website](#) to learn more about other member organizations and their support for family caregivers.

In this newsletter you can read Mona Gulino's, a scholarship award recipient, reflection of the 7th Annual National Conference for Caregiving Coalitions. We hope you enjoy reading about the Alliance's *Innovations in Caregiving* program as the applications enter the review stage. The News, Reports and Publications provides informative caregiving resources. In the Coalition News the Alliance is excited to announce the release of our new guide to assist with the establishment of new family caregiver coalitions. If you want to introduce your caregiving coalition in the next newsletter, please email stien@caregiving.org. The Legislative Update explains the automatic spending cuts that have been put in place due to the sequester.

Have a wonderful spring and enjoy reading,

Gail!

Gail Gibson Hunt
President & CEO

7th Annual National Conference for Caregiving Coalitions



We hope many of you were able to join us at our 7th Annual National Conference for Caregiving Coalitions. The conference was a big success with over 100 attendees! The day was filled with wonderful speakers, programs, and networking. We hope to see many of you at next year's conference which will be in San Diego!

To relive the conference visit our Facebook Page [here](#) to take a look at some pictures or download the PowerPoint presentations below.

- Stien Vandierendonck: [Family Caregiving Coalitions](#)
- Laurie Orlov: [Research Perspective: Boomer / Senior Technology Preferences and Users](#)
- Jim Durkan & Mike Bruni: [Leadership Boards...Do You Have a LOVE Connection](#)
- Kimaya Dixit: [Why "Care" about Social Media?](#)
- Doug Busch: [Multiplying the Care Team with Technology](#)
- John Schall: [Advocating for Caregiving From the Roots Up](#)
- Amy Friedrich-Karnik: [You as a Caregiver Advocate: How Coalitions Can Impact Federal and State Legislation Today](#)

Please enjoy this account of the day's activities from Mona Gulino and Roger Schilling from Caring for the Caregiver in New York:

Thanks to the encouragement of Reverend Gregory Johnson, founding member of the vibrant New York City Family Caregiver Coalition and champion of family caregivers everywhere. The Long Island Family Caregiver Coalition (LIFCC) applied for and was awarded a scholarship to participate in the 7th Annual National Conference for Caregiving Coalitions, Empowering Caregiving Advocates on March 13th.

Honored and invigorated by the energy and commitment of our fledgling group, we prepared to take the best advantage of this incredible opportunity! So, off we flew to Chicago for support and guidance from those who are expert in creating and nurturing caregiving coalitions.

Our experience began on Tuesday evening with a reception where we had an easy and relaxed chance to meet and network with other scholarship recipients, all anxious to share ideas, resources and discover strategies to enhance the success of their coalition's work.

Conference day began early with breakfast and a warm welcome from Gail Hunt, President and CEO, National Alliance for Caregiving (NAC) and Stien Vandierendonck, Manager of Programs and Communications, who shared some of the newest developments from NAC and challenged attendees to learn all they can to become stronger and more innovative caregiving advocates.

Impeccably organized by NAC's staff and skillfully moderated by Brian M. Duke, Secretary of the Pennsylvania Department of Aging, the day was truly dynamic! We heard from leading experts on national caregiving issues. Laurie Orlov, Founder of Aging in Place Technology, spoke of the application of technology to enhance the ability of people to "age in place", that is, "to remain where you want to be for as long as you want to be there."

Jim Durkin, Interim Director, Illinois Children's Healthcare Foundation and Mike Bruni, Partner, Non-Profit & Public Affairs Consulting Practice Services, provided clear recommendations as to how to connect leadership boards to the organization, using, "The 3M's...members, marketing and maintain (advocacy)." They posed poignant questions and outlined practical strategies for building and sustaining a more effective coalition through active engagement of members and leadership.

Kimaya Dixit, Managing Editor, Digital Outreach and Communications Manager, Men's Health Network raised our awareness about the endless ways social media can be used to create an effective advocacy campaign. She even helped us create our own social media profile...no small feat for those of us more technologically challenged!

During lunch, keynote speaker Doug Busch, Senior Vice President and COO, Intel-GE Care Innovations spoke of the incredible possibilities for multiplying the care team with technology. He encouraged attendees to use the consumer tools we already have and reach out to the tech community for new, purpose built technology solutions for caregiving.

Before the day was over, we learned much about how caregiving coalitions can impact federal and state legislation from a panel of most distinguished speakers. Anne Montgomery, Senior Policy Advisor, United States Senate Special Committee on Aging, John Schall, CEO, Caregiver Action Network and Amy Friedrich-Karnik, Legislative Consultant, National Alliance for Caregiving challenged us to harness our powerful potential as advocates to improve the quality of life for family caregivers throughout our great nation.

Speaking for ourselves, of course... but judging from the enthusiasm of the presenters, our peer caregiving advocates and the vendors we met, the day exceeded expectations! Moving forward...our first order of business has been to download the incredible new manual, [Planting the Seed: Establishing and Growing Your Family Caregiving Coalition](#), and share it with our coalition partners. We have much to discuss at our upcoming meetings as we process our new learning, focus our energies and prioritize our ideas on behalf of caregivers in our communities. Already looking forward to next year's excellent adventure!

We gratefully acknowledge our coalition support program sponsors:

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Innovations in Caregiving

Since 2006, the National Alliance for Caregiving, with generous support from the MetLife Foundation, has been recognizing exemplary caregiver programs and providing seed funding to non-profit organizations to replicate them. Since 2006, 49 community-based organizations have been awarded funding to expand their existing innovative programs or to replicate other award winning programs. These programs are found in the National Family Caregiving Awards Replication Guide [click here](#).

This year, the National Alliance for Caregiving will recognize 10 new community-based organizations and provide them with seed funding to replicate a best practice caregiver program. A webinar, featuring 5 previous award winners, was held in November of 2012. Applications were accepted until January 31, 2013.

A total of 55 applications were received this year. These applications were geographically distributed and came from 25 states and the District of Columbia. Applications came from a wide variety of organizations including home health and hospice agencies, faith-based organizations, area agencies on aging, hospitals, disease specific organizations, adult day services and one tribal organization. Many applications were focused on serving minority caregivers.

Applications were assigned to reviewers from our Advisory Committee in early February. Each application will be reviewed and scored by three reviewers. We anticipate announcing the ten award winning organizations in early May.

The ten award winning agencies will be recognized at a luncheon to be held at the [Annual Meeting of the National Association of Area Agencies on Aging](#), which will be held in Louisville, KY this July. Please keep checking our website for the exciting announcement.

News, Reports and Publications

USA Today Supplement on Family Caregiving

In the March 15-17 weekend edition of USA Today there is an 18 page supplement on Family Caregiving, called "Supporting Our Caregivers." Developed in partnership with Caregiver Action Network (CAN) and produced by Media Planet, the supplement reached 1.6 million readers of USA Today and many more through pass-alongs. The Alliance also contributed much of the research and other content. We are anticipating another insert in November, for National Caregiver Awareness Month. To view the insert [click here](#).

Alzheimer's Family Caregivers Video Series

The Caregiver Action Network (CAN) released a series of videos on the experiences of family caregivers of people with Alzheimer's disease. The videos look at the everyday stresses that caregivers of people with Alzheimer's experience across the country. To watch the videos [click here](#).

Family Caregiving and Transitional Care: A Critical Review

A new report from the Family Caregiver Alliance (FCA), looks at how technology can make education and information tools even more effective. Family caregivers play a critical role in helping the patient transition back to the home, but there are few care transition programs available to family caregivers. To read more [click here](#).

Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners

The Family Caregiver Alliance also released an inventory created by researchers and program developers to accurately capture the knowledge and well-being of family caregivers as they

execute tasks on behalf of their care recipient. To read more [click here](#).

Home Alone: Family Caregivers Providing Complex Chronic Care

This past October The AARP Public Policy Institute (PPI) and the United Hospital Fund with support from The John A. Hartford Foundation have released a study that unveils the numerous medical/nursing tasks that family caregivers are performing for their care recipients who have multiple chronic physical and cognitive conditions. The survey addresses the critical need, both collectively and individually, to help family caregivers handle these responsibilities. To read the national survey [click here](#).

A Family Caregiver's Guide to Surgery for Older Adults

Many older adults have planned surgery, such as hip or knee replacements, gall bladder removal, or heart bypass. Surgery can improve function and quality of life, but it also entails risks. Anesthesia risks are well known, but older adults also have longer recovery times and may be vulnerable to adverse drug reactions. "A Family Caregiver's Guide to Surgery for Older Adults," a new Next Step in Care guide, suggests what to ask the surgeon about treatment goals, pain, and physical limitations after surgery, as well as costs and post-discharge options. It also includes a checklist, adapted for family caregivers, from the American College of Surgeons and the American Geriatric Society, to assess older patients before surgery. This checklist asks questions about the person's cognitive status, history of falls, nutritional status, and other elements that may affect the surgery and its outcome. The guide is free and available in English, Spanish, Chinese, and Russian. For more information about this guide email clevine@uhfnyc.org. To read the guide [click here](#).

Coalition News and Updates

Planting the Seed: Establishing and Growing Your Family Caregiving Coalition

Produced by NAC, the purpose of this guide is to offer guidance both to individuals and organizations who want to establish a caregiving coalition in their community and to existing coalitions looking for tools to help them maintain, grow and strengthen their coalition.

Volume 1 is now available and covers what you need to know to start a coalition, from the planning steps, to creating a vision statement, mission statement, goals and objectives, and how to operationalize your coalition. Volume 2 will be available soon and focuses on growing and maintaining your coalition, with topics including: strategic planning, decision making, projects and activities such as advocacy, education/training, research, public awareness, information and referral, and evaluation and sustainability. To read the guide [click here](#).

Introduction of a Coalition:

Coalition of Caring Planning Committee (Rochester, New Hampshire)

The Coalition of Caring Planning Committee was created in October of 2006. Its mission is to promote and strengthen the well being of caregivers who provide care for a disabled or ill child, adult or senior through an annual caregiver's conference that is held in a different region of the state each year.

This coalition is comprised of organizations that support the elderly, children with disabilities, adults with disabilities, hospice patients and the chronically ill. It is their intention to continue to invite interested organizations to their committee as they continue community outreach.

The mission of the Coalition of Caring Planning Committee is to:

- Provide an annual statewide caregiver conference in New Hampshire to teach caregivers practical skills, like home-based caregiver skill building intervention and a Bridge Intervention that focuses on transitions from hospital to home for persons with dementia

and their family caregivers;

- Provide current information on supportive services and resources;
- Offer the opportunity for emotional support and recognition of family and unpaid caregivers;
- Raise community awareness of caregiving issues.

This year is the 7th year that the coalition is hosting a Statewide Caregiver's Conference. The coalition has learned over the years that if they continue to plan the conference with the #1 goal that caregivers will walk away feeling of value and of worth - it continues to be successful!

Reasons for the conference's success:

- The conference is always held during the month of November which is "National Caregivers Month." They schedule the conference for the first Wednesday of the month and try to host the conference at a venue that offers overnight accommodations so caregivers can have respite and stay the night before.
- This conference provides a wonderful opportunity for caregivers to network and socialize with other caregivers.
- Throughout the day there are free massage sessions, reiki and flu shots to caregivers.
- They also have an exhibitor area that offers services and/or products geared to the caregiver that are placed along the perimeter of the grand ballroom.
- At the start of the day there is a keynote speaker that speaks on a topic on caregiving or an inspirational story.
- The past few years the coalition has been able to offer a \$120 respite stipend to caregivers that need the funds to pay for caregiver support while they attend the conference. This money was secured through a grant that the coalition applied for.

Ellen M. Edgerly, Chair, Coalition of Caring, Brain Injury Association of New Hampshire.
603.332.9891, Ellenedge@metrocast.net, www.coalitionofcaring.org.

April Quarterly Family Caregiving Coalition Webinar

The April Quarterly Family Caregiving Coalition Webinar will on April 30 at 3:00pm EST. [Click here](#) to register.

During this webinar you will learn more about the BRAVE Awards, a unique international program designed to honor non-professional caregivers, celebrating the impact they have on others and our society. Recipients of a 2013 BRAVE Award each receive \$10,000. [Click here](#) if you want to read more about it.

There will also be a presentation on the 7th Annual National Conference for Caregiving Coalitions which was a great success. Two scholarship award recipients will share what they learned during the conference and how they want to apply these lessons learned to each of their coalitions.

This is a webinar you won't want to miss so mark your calendar!

If you missed the previous webinar and you want to watch the webcast [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.

Legislative update

National Family Caregiver Support Program Funding

On March 1, Congress failed to prevent a sequester, which set off automatic spending cuts that include a 5% cut in nondefense discretionary spending. According to information released by the Obama Administration, the Administration for Community Living, which oversees the Older Americans Act, will be cut by \$75 million. The Administration for Community Living has released estimates showing the funding cuts states can expect for each Older Americans Act program, including the National Family Caregiver Support Program (NFCSP), for the remainder of FY 2013. Since funding for OAA programs is distributed to states based on a formula, the rate of cuts will be slightly different in each state. Funding to states for NFCSP services will decrease between 3% and 6%.

For more information [click here](#).

On Tuesday, March 26, President Obama signed into law a Continuing Resolution that maintains last year's funding levels for federal programs for the next six months (through the current fiscal year). This move avoids a threatened government shutdown. The cuts caused by sequestration will still go into effect.

What to Look for in 2013

January 2013 marked the beginning of a new Congress. Members of Congress are currently reintroducing their priority bills, as well as introducing new legislation on a variety of topics. [Click Here](#) to see an in depth look at the Alliance's priority issues to watch out for as the 113th Congress proceeds with its work this year.

Alliance's Priorities:

- Older Americans Act Reauthorization
- National Family Caregiver Support Program (NFCSP)
- Long-Term Care Commission
- Lifespan Respite Reauthorization
- Implementation of the Affordable Care Act

Events & Opportunities

National Association of Area Agencies on Aging (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](#).

National Home & Community Based Services (HCBS) Conference

The National Association of States United for Aging and Disabilities (NASUAD) together with the District of Columbia Office on Aging, Maryland Department of Aging, and Virginia Department of Aging will be showcasing promising practices in long-term services and supports. The conference offers exceptional learning and networking opportunities for professionals who administer home and community based services throughout the country.

September 10-12, 2013, Arlington, Virginia. 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](#).

If you would like the Alliance's President and CEO, Gail Hunt, to present at your upcoming conference please email emilylubin@caregiving.org.

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