

The Caregiving Exchange

July 2013



Welcome Message

Welcome to the July 2013 Newsletter!

The Alliance hopes everyone had a relaxing July 4th weekend with family and friends. We are looking forward to the upcoming *Innovations in Caregiving Awards Luncheon* on July 30th, which honors the 2013 National Family Caregiving Award Recipients. This event, co-hosted by MetLife Foundation, will celebrate the winners of the New Innovations in Caregiving Grants Program. The Alliance luncheon will take place in the next few days at n4a's 38th Annual Conference and Tradeshow in Louisville, KY. November marks National Family Caregiver month, and the Alliance would like to hear about any exciting events your organization is planning to celebrate during this special time.

The Alliance would also like to welcome Intel-GE Care Innovations as our newest Corporate Alliance Member. This company represents a partnership between Intel Corporation and GE to create innovative solutions that shifts in accordance with the evolution of our healthcare system. Care Innovations is revolutionizing the practice of caregiving with a line of products designed for patient care management. To learn more about all our members and their support for family caregivers, please go to the [Members section of our website](#).

We are excited to introduce Paul DeIPonte as our new Director, and we hope you'll join us in welcoming him. You can read about his strong background and fundraising experience in the Alliance News section. We are also pleased to profile one of our members, Shire, and their commitment to family caregiving. The News, Reports and Publications provides informative caregiving resources. In the Coalition News, Sibling Leadership Network introduces their coalition headquartered in Chicago, Illinois. The legislative update will provide information on the National Plan to Address Alzheimer's Disease (NAPA) and the draft rule to expand worker protection to home care workers. If you want to introduce your caregiving coalition in the next newsletter, please email emilylubin@caregiving.org.

Have a great end to summer and enjoy the newsletter!

Gail

Gail Gibson Hunt
President & CEO

Alliance News and Updates

Welcoming Our New Director

The Alliance is pleased to introduce Paul DelPonte as our Director of Development, Programs and Operations. Paul is a great addition to the Alliance, and we hope you will join us in welcoming him to our team.

Paul brings a strong background in advocacy and social marketing to the National Alliance for Caregiving. He was previously the Executive Director of the National Committee to Preserve Social Security and Medicare Foundation. While in this position, he helped to create Patients Aware, a public education campaign designed to educate seniors and family members about the benefits made available by the Affordable Care Act. As both a consultant and long time staff member for the Alliance for Aging Research, Paul spearheaded Project Independence for Older Americans. This project led to securing \$1 billion in federal research. As a communications consultant, he has started two successful public relations firms where he directed award-winning campaigns in national health education. These campaigns--including the Community Voices Initiative for the W.K. Kellogg Foundation and the Men's Health Campaign featuring Morgan Freeman--served to promote increased awareness and access to care.

Paul lives in Montgomery County, Maryland, where he is also a Commissioner on Aging. In that role he is helping the county implement, "A Community for a Lifetime", a plan to meet the needs of an aging population. Paul can be reached at our office, (301) 718-8444, or by email at paul@caregiving.org.

Member Profile

Shire is an international specialty bio pharmaceutical company that places an emphasis on creating therapies to treat patients with life-altering rare conditions or illnesses. As an international company Shire employs 5,300 individuals in 29 countries, and ensures that their products are available in 50 countries throughout the world. Their tag line, "To be as brave as the people we help," embodies the company philosophy: an aim to satisfy the needs of specialist physicians and patients and their families alike. Among the most successful drug therapies they have created are products for ADHD, HIV, and Alzheimer's disease. Shire understands and reflects the importance of patient-centered treatments and works hard to create value for society through their medical therapies.

As an organization strongly rooted in the needs of patients and family caregivers, Shire recognizes the often overlooked role of caregivers. In 2011, the company began an online contest called the Shire Brave Awards, a program built to honor family caregivers who provide excellent care to a loved one. Matt Cabrey who leads communications and public affairs campaigns, explains that "Shire focuses on the therapeutic needs, but also does what I call 'going beyond the obvious'. That is how we came up with the Brave Awards." Winners of the Shire Brave Award receive not only the praise they deserve, but are also awarded \$10,000 for their efforts. Now in its third year, the Brave Awards have had 29 recipients and are in the midst of selecting up to 20 recipients for the current 2013 contest.

The Shire Brave Awards program celebrates the aid that caregivers provide to those in need, recognizing distinguished nominees who provide exceptional care to loved ones. As an effort to maintain the integrity of the program, there are almost no limitations or restrictions--no quotas or specific criteria--to those who can be elected. As an international contest, the Brave Awards program will award up to 10 recipients from the Americas and up to 10 recipients from Europe and Australia. The current year's nomination period ended on June 30; however, winners will be announced in November, and another round of the Shire Brave Awards will begin next year.

To learn more about Shire, [click here](#) , and to learn more about the Brave Awards, [click here](#).



News, Reports and Publications

Care Innovations Launches Connect Caregiver Beta Program

The National Alliance for Caregiving and Care Innovations™ invite you to participate in the free Care Innovations [Connect Caregiver beta program](#). You will receive early, complimentary access to secure, online caregiving tools. Most importantly your feedback and recommendations will help shape the product and help other caregivers. Connect Caregiver is a suite of tools designed to help connect multiple caregivers, allowing them to work together to manage a loved one's care at home. A calendar, medication organizer, bulletin board, care diary and access to local services help you stay organized, and share caregiving responsibilities. For more information about how to register and qualify for a \$20 Amazon gift card, [click here](#).

AARP Public Policy Releases Report on Family Caregiving and the Workplace

The AARP Public Policy Institute released a new report documenting issues family caregivers face in the workplace. The report, [Keeping Up with the Times: Supporting Family Caregivers with Workplace Leave Policies](#), highlights public policy solutions that serve to extend protections for working caregivers and reduce worker turnover. To read more, [click here](#).

AARP Public Policy Institute Blog Updates

The AARP Public Policy Institute has developed a [series of blogs](#) on topics pertaining to the relevant issues being tackled by the newly formed Long Term Care Commission. There are numerous entries addressing issues of family caregiving, Medicare and Medicaid Long-Term Services, and other issues of elder care. To read more, [click here](#).

UHF Releases Action Agenda

The United Hospital Fund released [Transitions in Care 2.0: An Action Agenda](#), a 10-item list of improvements to renovate transitions in caregiving. This agenda outlines ways in which health care professionals and administrators can ease the burden of transition in care, better preparing caregivers for the tasks that befall them while caring for a loved one. To read the action agenda, [click here](#).

UHF Issues Caregiving Transitions Report

The United Hospital Fund issued a report on caregiving transitions, which promotes a three-year initiative, [Transitions in Care-Quality Improvement Collaborative](#) (TC-QulC). Through this initiative, 45 health care provider teams provided support and assistance for family caregivers as a means of researching the strengths and needs of transition care as it functions in the current healthcare framework. To read the full report, [click here](#).

Annual Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds Report Released

The [2013 Annual Trustees Report](#) concerning issues of federal medical insurance trust funds was just released. The report announced that Medicare is projected to be solvent for an additional two years-through 2026. Cost controls implemented by the Affordable Care Act have been instrumental in slowing the projected spending per beneficiary of these programs. To read more, [click here](#).

Pew Research Center Released 2013 Caregiving and Technology Report

The Pew Research Center released [Family Caregivers are Wired for Health](#). Their new study incorporates the responses from a nationwide survey of adult caregivers. This study boasts new

knowledge of caregiver demographics and focuses largely on the key role technology plays in supporting caregiving. To read the full report, [click here](#).

Coalition News and Updates

Introduction of a Coalition: **Sibling Leadership Network (Chicago, IL)**

The Sibling Leadership Network (SLN) is a national nonprofit with state chapters dedicated to providing information and support for siblings of individuals with disabilities across the lifespan. The SLN was founded in 2007 in order to address the challenges of individuals caring for siblings with disabilities by providing support through social networks, education, research, policy and advocacy. Currently, there are 13 state chapters of the SLN and additional chapters are being nurtured throughout the country. Chapters serve as the grassroots of the organization and maintain more personal contact with people, ensuring that they obtain the information and support they need. The SLN has a network of over 3,700 members from across the country, including a dedicated core of volunteer leaders.

The SLN knows that the sibling relationship is often the most enduring lifelong relationship and can have a profound influence throughout a person's life due to shared experiences and memories. Siblings usually share the responsibilities that arise as parents age, which can be a challenge for those individuals caring for children as well. When these individuals also take on the role of caring for disabled siblings, a new level of support becomes necessary. Addressing the needs of siblings and their caregivers will lead to better outcomes for both people with disabilities as well as their families.

The SLN invites everyone who is invested in better outcomes for families to join this cause. While the SLN focuses on the unique role that siblings play in caregiving, parents and other family members, professionals and other sibling supporters are also welcome. The SLN provides:

- information and resources to help families begin and maintain dialogues about future planning
- insight on the latest research findings related to siblings of people with disabilities
- a passionate and informed community committed to advocating for better policies for families

There is a wealth of information and resources at their website. Read more at:

www.siblingleadership.org.



Are you a part of a state or local family caregiving coalition? If you would like to join NAC's network of family caregiving coalitions to support family caregiving coalitions, please email: coalitions@caregiving.org.

Legislative Update

National Plan to Address Alzheimer's Disease: An Update

In June 2013, the Department of Health and Human Services (HHS) released an update on the

National Plan to Address Alzheimer's Disease (NAPA), initiated in May 2012. Mandated by law, the 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. The update reflects progress toward achieving the five goals and sets out new and revised action steps. Highlights of the past year include the launch of a website, www.alzheimers.gov, to increase public awareness about important resources and the implementation of federal grants that support training for health care providers on topics from dementia diagnosis to effective behavior management for people with dementia and their caregivers. Additional action steps for the national plan include developing a unified Alzheimer's disease training curriculum for primary care providers, which will help them deliver high-quality dementia care; expanded detection of elder abuse and neglect through demonstration grants for legal services to groups that assist families and communities impacted by Alzheimer's; and an expanded Dementia Capability Toolkit will be developed for state and local health networks. For more information, [click here](#).

Advocates Renew Efforts to Expand Worker Protections to Home Care Workers

With the 75th Anniversary of the Fair Labor Standards Act (FLSA) in June 2013, many advocates renewed their efforts to push for minimum wage and overtime protection for home care workers. Currently, home care workers are excluded from such protections, but in 2011, the U.S Department of Labor (DOL) proposed a new rule that would end that exclusion. After receiving 26,000 comments on the proposed rule, the DOL sent a draft rule to OMB for review in January 2013. Although the Obama Administration has expressed support for ending the exclusion, the new rule has yet to be enacted. Such a rule would impact many families that employ home care workers to care for older adults or adults with disabilities. For more information, [click here](#).

Events & Opportunities

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](#).

International Federation on Ageing (IFA) International Istanbul Initiative on Ageing

The International Istanbul Initiative on Ageing (IIIA) will afford attendees the opportunity to hear from a panel of featured speakers and discuss the interactions between the youth and the ageing population by way of the Trade Show Forum, the Congress Forum, and the Age-friendly Cities and Communities Forum.

October 4-6, 2013, Istanbul, Turkey. More Info: [Conference Info](#).

Alzheimer's Foundation of America (AFA) National Memory Screening Day

The Alzheimer's Foundation of America (AFA) is offering free, confidential memory screenings at community sites throughout the nation. These screenings will be administered by qualified healthcare professionals as a part of an annual initiative called National Memory Screening Day.

November 19, 2013, across the country. More Info: [Initiative info](#).

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

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