From the President's Desk

It's Cherry Blossom season here in Washington and we've got our own projects in bloom. Our benchmark study, Caregiving in the US, will be released in June. We have also begun the process of selecting the Advisory Committee for a study of Caregivers of Persons with Mental Illness, in partnership with Mental Health America.

On the advocacy front, we had a great meeting at the 2015 American Society on Aging conference. There, we hosted the 9th Annual National Conference of Caregiving Coalitions, From Caring to Caregiver Advocate. We officially launched the "Caregiving Champions" program, connecting caregiving advocates to persons of influence, including policymakers and other community leaders. I was excited to see so many caregiving advocates and supporters at the conference. If you couldn't make it, the conference materials are available here. Many thanks for the generous sponsorship from UnitedHealthcare, Easter Seals and Mass Mutual, Right at Home, and Mallinckrodt Pharmaceuticals.

In addition to naming the inaugural class of Caregiving Champions program, we have released videos featuring family caregivers discussing the need for leaders in this space. The videos of these interviews can be found on our YouTube channel. Advocates and caregivers can nominate champions here. The Caregiving Champions program is in place thanks to the support of Pfizer and Eli Lilly.

Thanks so much for your support of family caregivers and caregiving research.

Best,

Gail Gibson Hunt
President and Chief Executive Officer
New Research, Reports & Publications

- A poll released by AARP in conjunction with the launch of the Assisting Caregivers Today (ACT) Caucus found that more than three quarters of registered voters 40 and over (77%) say that Congress should make it a priority to improve resources for caregivers. Read more here.

- Palliative & Supportive Care published an article on the "emotional journey and lived experience" of caregivers through end-of-life for the care recipient. The results show some of the unmet needs of caregivers, and helps to explain how clinicians and others on the care team can view the journey.

- Research in the American Heart Journal set out to determine the costs and hours associated with caregiving for persons with heart failure. Researchers surveyed self-reported caregivers in this category and found that the cost and hours of caregiving after heart failure is significant: $3 billion. Read more here.

- Care Alliance Ireland has released the third version of their Family Caring in Ireland report, first published in 2010. The report brings together the key research, policy and practice developments on family caring in Ireland and abroad in one succinct publication. The report can be found here.

- The IOM convened a workshop in Fall 2014 on "The Future of Home Health Care". The workshop summary from the event is now available here. The 2-day public workshop brought together public & private stakeholders to discuss a number of topics around the role, impact, and future of home health care.

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Member Updates

WISER, together with the Social Security Administration, America Saves, and the American Savings Education Council has launched the "Campaign for a Secure Retirement: Helping Millions of Americans Plan and Save for Retirement". The campaign is a joint, national educational effort to encourage retirement planning and saving. Read the press release, check out WISER's blog, Facebook, or Twitter to join in and learn more.

The Social Security Administration adds that the campaign promotes the online Social Security Statement, available through my Social Security, as an important retirement planning tool. The joint campaign spans from America Saves Week, the last week of February, to my Social Security week in July. Organizations can join the effort and help the public understand the importance of saving for retirement by signing up at http://bit.ly/1MqN1hX.
Caring.com recently launched a first of its kind scholarship program for college students who are also caregivers. Three $1,500 scholarships will be awarded through an essay/video contest, on the student’s caregiving journey. More information on the scholarship program, including essay questions and eligibility requirements, can be found at https://www.caring.com/scholarship. The scholarship application deadline is May 31, 2015. Follow the social media conversation on the scholarship by using the hashtag #CaringScholar.

The American Psychological Association has just completed an extensive update of the APA Family Caregivers Briefcase. Launched initially in 2011, this online resource provides tools and resources for psychologists and other health care providers to assist family caregivers. It also contains a resource section that is valuable for family caregivers of individuals across the lifespan. In addition, a Briefcase supplement on HIV, Aging and Caregiving is currently under development. In addition, a new resource sheet was developed by the Office on Aging, Psychological Practice with Older Adults and their Caregivers and distributed to all state psychological associations and state psychology licensing boards. The Office also regularly offers educational programming for APA Staff on family caregiving and related topics such as optimal aging.

New Members

We are pleased to welcome three new members to the Alliance. Learn more about the new members below. If you represent a national organization and would like to find out more about membership, please email stephanie@caregiving.org.

Biogen develops, markets, and manufactures a portfolio of therapies for patients and families with multiple sclerosis and hemophilia, among other neurological, autoimmune, and hematologic disorders.

The Aging in Motion Coalition is a diverse group of patient, caregiver, health and aging groups working together to press for greater levels of research and innovation to develop treatments in the area of sarcopenia and age-related functional decline.

ACT-AD, Accelerate Cures and Treatments for Alzheimer’s Disease, is a coalition of national organizations representing patients, providers, caregivers, consumers, older Americans, researchers, employers and health care industries seeking to accelerate the development of potential cures and treatments for Alzheimer’s disease.

Legislation & Advocacy Updates

As we head into the 114th United States Congressional session, we continue to monitor legislation that impacts family caregivers. Below is a list of some of the federal and state legislation in 2015 of significance as well as other noteworthy news related to family caregiving policy.
Older Americans Act Reauthorization Act of 2015 - S.192
On January 28th, 2015, the Senate health committee unanimously approved the Older Americans Act Reauthorization Act of 2015, bipartisan legislation by U.S. Senate health committee Chairman Lamar Alexander (R-Tenn.) and Ranking Member Patty Murray (D-Wash.) with Senators Richard Burr (R-N.C.) and Bernie Sanders (I-Vt.) to support social and nutrition services for nearly 12 million seniors, including elder abuse prevention efforts, transportation services, and program coordination among other services.

Family And Medical Insurance Leave ("FAMILY") Act of 2015
Sponsored by Rep. Rosa DeLauro (D-CT) and Sen. Kirsten Gillibrand (D-NY), the Family And Medical Insurance Leave (FAMILY) Act would ensure people have some income during family or medical leave by insuring 12 weeks of paid leave a year to take care of a dependent family member, care for a new child, or to care for oneself. The Alliance supports this bill.

Caregivers Expansion and Improvement Act of 2015
Senator Dick Durbin (Ill.) introduced the "Caregiver Expansion and Improvement Act" (S. 657) on March 3, 2015. The bill would expand the current Department of Veterans Affairs (VA) Caregiver program to include all family caregivers who care for service-connected severely disabled veterans. Currently, the program only applies to veterans who have been severely disabled since September 11, 2001. Expanding the VA Caregiver program will help all of America’s military and veteran family caregivers.

Lifespan Respite Care program in the FY2016 Appropriations Bill
The Lifespan Respite Care Program (LRCP) provides competitive grants to state agencies working in concert with Aging and Disability Resource Centers and non-profit state respite coalitions or organizations to make quality respite available and accessible to family caregivers regardless of age or disability through the establishment of State Lifespan Respite Systems. The Alliance strongly supports the President’s budget request of $5 million for the Lifespan Respite Care Program in fiscal year (FY) 2016.

The Caregiver Advise, Record, Enable (CARE) Act - Model State Legislation
The CARE Act has three components: 1) it requires a recording of a family caregiver’s name at admission to a hospital or rehabilitation facility; (2) notifies the family caregiver if a loved one is going to be discharged to another facility or home; and (3) requires a facility to provide an explanation (and instruction) of the medical tasks a patient requires that the family caregiver will likely perform at home, like medication management, injections, wound care, and transfers. States that have recently passed the CARE Act in 2015 include: New Jersey, Oklahoma, and Virginia.

States Establish Family Caregiving Task Forces
Mississippi, Hawaii and Delaware have all recently established Family Caregiving Task Forces to study and make findings recommendations to support family caregivers in their states.

White House Conference on Aging (WHCOA)
The White House Conference on Aging has hosted its regional conferences, with the final regional conference happening later this month in Cleveland, and in Boston in May. No date has been set yet for the national conference, but check for updates at www.whitehouseconferenceonaging.gov.

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Caregiving Coalitions Corner
Charlotte Dodge, Advocacy Coordinator

The National Alliance for Caregiving held its 9th Annual National Conference of Caregiving Coalitions in Chicago, on March 24th. This year's focus was building capacity and energizing caregiving coalitions across the country. We are happy to report
that despite the snow in Chicago complicating travel, the conference had about 75 attendees.

Alliance staff C. Grace Whiting, Director of Strategic Partnerships, and Gail Gibson Hunt, President and CEO, presented on advocacy, coalition, and policy updates from the Alliance. Ms. Whiting also presented on the Alliance’s Caregiving Champions Program - our new initiative to connect caregiving coalitions on the state level with leaders and persons of influence, both nationally and within their state who are raising awareness of the issues facing family caregivers.

The conference attendees had the opportunity to hear from Jed Johnson, VP of Strategic Initiatives at Easter Seals; Paul Blom, the Board Vice-Chair of Training to Serve; and Tamar Heller, PhD, a professor and Head of Disability and Human Development at the University of Illinois at Chicago and co-founder of the Sibling Leadership Network, on the important need of supporting caregivers of special populations such as military caregivers, persons with disabilities, and those working with LGBT persons.

Karen Marshall of the Kadamba Tree Foundation moderated a panel on creative solutions to help grow your coalition, alongside Faith Unger of Caregiver U in central Texas, Toula Wootan of the Caregiver Coalition of Northeast Florida, and Sue Coyle of the Outagamie Caregiver Coalition in Wisconsin.

Brian Duke, the former Secretary of Aging of Pennsylvania, provided a powerful keynote address that touched on the importance taking the next step from caregiver to caregiver advocate. He spoke of his own caregiver journey with his mother, Monica, and how it inspired his work during his tenure as Secretary of Aging.

Attendees also heard a fascinating panel discussion on how new technologies are changing the landscape of family caregiving. David Inns, the CEO of Great Call and Ravi Nemana, who recently served as chief strategist and head of business development for 360Fresh, Inc., both presented ideas and perspectives on how technology continues to interact with family caregivers. Alliance President and CEO Gail Hunt moderated.

The conference had several networking opportunities, including a "Table Topics" lunch with topics ranging from Caregiving and Pain Management to Supporting Rural Caregivers.

We want to thank UnitedHealthcare, Pfizer, Easter Seals and Mass Mutual Financial Group, Right at Home, and Mallinckrodt Pharmaceuticals for their generous support in making this year's Caregiving Coalitions Conference possible.


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Upcoming Events in Caregiving & Aging

2015 BIO International Conference
June 15-18, 2015 | Philadelphia, PA
The largest, most influential biotech meeting in the world is coming to Philadelphia, June 15-18, 2015, offering powerful business partnering, invaluable education sessions and networking with the industry’s best and brightest. Join the global biotech community at BIO 2015 and fuel the extraordinary. Register now at convention.bio.org.

2015 n4a Conference - Answers on Aging
July 11-15, 2015 | Philadelphia, PA
Join n4a in Philadelphia for its 40th Annual Conference & Tradeshow to see the most innovative policies, programs and services that assist older adults, persons with disabilities
and their caregivers lead independent and productive lives showcased. Registration is now open - [learn more here](https://ui.constantcontact.com/visualeditor/visual_editor_preview.jsp?agent.uid=1120522158654&format=html&printFrame=true).

**Alzheimer's Association International Conference 2015**  
**July 18-23, 2015 | Washington, DC**  
The Alzheimer's Association International Conference (AAIC) is the world's largest forum for the dementia research community. International investigators, clinicians and care providers gather annually to share the latest study results, theories and discoveries to bring the world closer to breakthroughs in dementia science. [Learn more here](https://ui.constantcontact.com/visualeditor/visual_editor_preview.jsp?agent.uid=1120522158654&format=html&printFrame=true).

**6th International Carers Conference**  
**September 3-6, 2015 | Gothenburg, Sweden**  
Themes for the International Carers Conference include: the health, social care, and well-being of caregivers; combining work and care; paying for care; and technology-enabled care and support. Registration for the conference is now open - [learn more here](https://ui.constantcontact.com/visualeditor/visual_editor_preview.jsp?agent.uid=1120522158654&format=html&printFrame=true).

**GSA's 68th Annual Scientific Meeting**  
**November 18-22, 2015 | Orlando, FL**  
GSA's 68th Annual Scientific Meeting brings together more than 4,000 of the brightest minds in the field of aging. This meeting is the premier gathering of gerontologists from both the United States and around the world. They participate in over 400 scientific sessions including symposia, paper, and poster presentations. The 2015 theme is "Aging as a Lifelong Process," which highlights the fact that what gerontologists study is actually the cumulative outcome of lifelong events that culminate during old age. [Learn more here](https://ui.constantcontact.com/visualeditor/visual_editor_preview.jsp?agent.uid=1120522158654&format=html&printFrame=true).

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

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