



**National Alliance for Caregiving**

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# **12th Annual Conference of Caregiver Advocates**

Engaging Caregivers Across  
the Lifespan



American Society on Aging – Aging in America  
San Francisco, California | March 26, 2018  
[caregiving.org](http://caregiving.org)

# SIGNED INTO LAW!

## **Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act - Public Law No: 115-119**

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### **Bill Summary**

Requires the Secretary of Health and Human Services to develop, maintain and update an integrated national strategy to recognize and support family caregivers. Brings together relevant federal agencies and others from private and public sectors to advise and make recommendations regarding the national strategy.

### **National Alliance for Caregiving Support**

We at the National Alliance for Caregiving endorsed the RAISE Family Caregivers Act because nearly 44 million family caregivers provide about \$470 billion annually in unpaid care to those in need. They take on challenges that impact their health, emotional wellbeing, and financial security. They help making it possible for older adults and people with disabilities to live independently in their homes and communities. Our research in 2015 found that 22 percent of caregivers felt their health had gotten worse as a result of caregiving. One in five caregivers reported a high level of physical strain resulting from caregiving, while two in five consider their caregiving situation to be emotionally stressful. These difficulties are further compounded by a lack of formal recognition from the health care system. Only one third of caregivers have ever had a health care provider—such as a doctor, nurse, or social worker—ask what was needed to care for their care recipient. Staggeringly, only 16 percent of caregivers say a health care provider has asked what they need to take care of themselves. All too often, family caregivers are not recognized and included in appropriate health and social service programs and are not receiving the care and support they require to serve in this role. A national strategy is necessary to effectively recognize the needs of all family caregivers, provide them with support, and include them in appropriate care models. Our country relies on the contributions that unpaid family caregivers make and we must recognize and support them. By supporting family caregivers, we can ensure people live at home where they want to be—helping to delay or prevent more costly care, unnecessary hospitalizations, and institutional care— saving taxpayer dollars.

### **Implementation**

According to the bill, the Advisory Council has 12 months to produce the first annual report and 18 months to come up with an initial strategy. The goals of the strategy include identifying actions that government, communities, health providers, employers and others can take to support family caregivers.

Now is the time for advocates to speak up and prepare recommendations to be included in the national strategy; we will then need to ensure that those recommendations are implemented.

# Program Agenda

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**9:00 AM Breakfast & Registration**

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**9:30 AM Executive Overview**

- » C. Grace Whiting, JD, President and CEO, National Alliance for Caregiving
- » Gail Hunt, Founder, National Alliance for Caregiving
- » 2018 NAC Scholarship Recipients

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**10:15 AM Keynote: Building Capacity for Caregivers Across the Lifespan**

- » Sandy Markwood, MS, CEO, National Association of Area Agencies on Aging (n4a)

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**10:45 AM The Caregiver-Friendly Community**

- » Moderator: Donna Wagner, PhD, Dean, College of Health and Social Service, New Mexico State University
- » Stephanie Firestone, MUP, Senior Strategic Policy Advisor, AARP Office of International Affairs
- » Dawn Simonson, MPA, Executive Director, Metropolitan Area Agency on Aging
- » Donna Benton, PhD, Associate Research Professor of Gerontology, USC Family Caregiver Resource Center

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**11:45 AM Break for Lunch**

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**12:00 PM Lunch Presentation: Building a 21st Century Workforce**

- » Facilitator: Michael Wittke, BSW, MPA, Director of Advocacy, National Alliance for Caregiving
- » Sharon Terman, JD, Director, Work and Family Program, Legal Aid at Work
- » Mark Herbert, BA, Small Business Majority
- » Vicki Shabo, MA, JD, Vice President for Workplace Policies and Strategies, National Partnership for Women & Families

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**1:00 PM Defining the Caregiver Journey**

- » Moderator: Jim Murphy, MS, Vice President, Medicare and Retirement, UnitedHealthcare
- » Sita Diehl, MA, MSSW, Principal, Sita Diehl Consulting, LLC
- » Liddy Manson, MBA, Director, Aging Well Hub Georgetown McDonogh School of Business
- » Laurel Rodewald, Program Director, The Elizabeth Dole Foundation

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**2:00 PM Workshop: Co-Creating Next Steps for Caregiver Advocacy**

- » Facilitator: Michael Wittke, BSW, MPA, Director of Advocacy, National Alliance for Caregiving

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**2:45 PM Closing Remarks**

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**3:00 PM End**

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# Recent NAC Work

## Congressional Stories of Family Caregiving

### CONGRESSIONAL STORIES OF FAMILY CAREGIVING

Challenges, Rewards, and a Call to Action

Tuesday, November 7, 2017 | Washington, DC

Proceedings of a Capitol Hill Briefing

Late last year, six members of the U.S. House of Representatives shared personal stories of their experiences with family caregiving. The Gerontological Society of America (GSA) partnered with the National Alliance for Caregiving and others to host the *Congressional Stories of Family Caregiving* Briefing. Supporters of the briefing included The John A. Hartford Foundation, AARP, and the Alzheimer's Association. The full proceedings report from the briefing can be found at

[https://www.geron.org/images/documents/congressional\\_stories\\_of\\_family\\_caregiving.pdf](https://www.geron.org/images/documents/congressional_stories_of_family_caregiving.pdf)

## Rare Disease

February 2018

### RARE DISEASE CAREGIVING IN AMERICA



**nac**  
National Alliance for Caregiving

IN PARTNERSHIP WITH  
**Global Genes**

The National Alliance for Caregiving, in partnership with Global Genes, released findings of an online study by Greenwald & Associates, conducted in late 2017, of 1,406 unpaid caregivers ages 18 and over living in the United States who provide care to a child or adult with a rare disease or condition. Findings from this first-of-its-kind national snapshot of caregivers of individuals with a rare disease or condition paint a picture of friends and families facing emotional, financial, physical, and social strain with little support from outside resources. It is estimated that at least 25 million Americans currently have a rare disease or condition; the National Institutes of Health estimates that there are approximately 7,000 rare diseases. The report and related materials are available at

<http://www.caregiving.org/rare>.

## Public Health

### From Insight to Advocacy:

Addressing Family Caregiving as a National Public Health Issue



**nac**  
National Alliance for Caregiving

January 2018

The National Alliance for Caregiving recently released *From Insight to Advocacy: Addressing Family Caregiving as a National Public Health Issue*. The report describes family caregiving and the major caregiving issues affecting public health, including actions that can be taken specifically by state and local coalitions, health systems, and policymakers. The report also cites common data sources, identifies barriers to providing care within the aging network, and offers strategies on what caregiving advocates can do to get engaged. The report is offered as one response to a critical emerging trend: eldercare is projected to be the fastest-growing employment sector within health care. With as many as 44 million people estimated to provide care to an older adult or person with a disability, current research has noted that unpaid family caregiving impacts not just individuals, but family units, communities, states, and the nation.

[caregiving.org/publichealth](http://www.caregiving.org/publichealth)

## Mental Health



Last year, the National Alliance for Caregiving released *Circle of Care: A Guidebook for Mental Health Caregivers*, developed with generous support from the Alkermes Inspiration Grant Program. The Guidebook emerged from *On Pins and Needles: Caregivers of Adults with Mental Illness*, a national study on mental health caregiving conducted with the assistance of the National Alliance on Mental Illness and Mental Health America, released in February 2016. Like our other resources for family caregivers, Circle of Care is designed to guide unpaid friends, family, and neighbors who care for someone with a mental health condition. The fact sheets are intended to assist these caregivers with finding help for the specific challenges identified in the On Pins and Needles study. Circle of Care can be found at

<http://www.caregiving.org/circleofcare/>.

## Falls Prevention



**FALLS PREVENTION**  
*You have the power!*

The National Alliance for Caregiving is honored to partner with the National Council on Aging on a series of resources for family caregivers of older adults. Many caregivers may not realize that 1 in 4 adults over the age of 65 falls every year, injuring themselves and often exacerbating other conditions of aging. Falls are the leading cause of fatal and non-fatal injuries for older Americans; they are costly—in dollars and in quality of life. Family caregivers and those at-risk for a fall can be partners and participants in falls prevention. One such resource is our *Falls Prevention Conversation Guide*, which can be used as a tool of empowerment for caregivers, allowing them to be partners and participants in falls prevention. Learn more about this guide and our other falls prevention resources at

<http://www.caregiving.org/resources/falls/>.

IACO

## International Study on Carers of Persons with Heart Failure



**CARERS OF PERSONS WITH HEART FAILURE  
A FOUR NATION STUDY**



**2017**

The International Alliance of Carer Organizations (IACO), supported by Novartis, has released a first-of-its-kind global study examining the role and impact of heart failure caregiving. Presented at the 7th International Carers Conference in Adelaide, Australia, the Carers of Persons with Heart Failure study analyzed data collected from more than 500 heart failure carers in Australia, Canada, the United Kingdom, and the United States to determine the key challenges that they face.

The research builds on existing evidence of the positive influence of caregiving on heart failure outcomes, including improvements in health-related quality of life, reduced rates of hospitalizations, and improved survival for the person with heart failure when the carer receives adequate support.

[internationalcarers.org/publications](http://internationalcarers.org/publications)



## Acknowledging and Aiding Carers: A Guide to Supporting Carers in Your Nation



**ACKNOWLEDGING AND AIDING CARERS  
A GUIDE TO SUPPORTING CARERS IN YOUR NATION**



IACO has released a global carers toolkit intended to foster the development and expansion of the infrastructure needed to support carers and the people for whom they care in countries around the world. The toolkit covers a wide range of topics drawing on the expertise of the carer nonprofits in the IACO member nations and other global examples of carer supports. The toolkit was funded by Merck KGaA, Darmstadt, Germany. Topics include: Starting a National Carer Organization, Creating a Strategic Plan, Communication and Carer Organizations, Impact of Caring on the Carers' Health, Caring and Employment, Young Carers, Rural Carers, Assessment of Carer Needs, Respite Care, Adult Day Services, Technology and Carers, and End-of-Life Issues Faced by Carers.

[internationalcarers.org/publications](http://internationalcarers.org/publications)

# 2018 NAC State & Local Scholarship Recipients

**The National Network of Caregiving Coalitions is a virtual network of 80+ state and local caregiving coalitions across the United States. In supporting this network, the Alliance provides technical assistance, quarterly webinars, guidebooks, and a scholarship to attend this conference as a means to assist coalitions in their work with family caregivers.**

## Our scholarship recipients this year are:


**Montana Lifespan Respite Coalition** - The Montana Lifespan Respite Coalition has been meeting on a regular basis since August of 2011 when they were awarded their initial Lifespan Respite grant. They currently have almost 100 members representing Montana caregivers.

 **Representative:** Vicki Clear, DEAP Lifespan Respite Program Director

 **Location:** Miles City, MT

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**Lake County CaregiverNet** - Lake County Caregiver Network is comprised of Not-for-profit Lake County, IL agencies serving family, friend, and community caregivers.

 **Representative:** Christine Damon, Co-chair/Executive Director of CareSmart Illinois

 **Location:** Wadsworth, IL

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**Montgomery County MD Caregiver Coalition** - Montgomery County MD Caregiver Coalition is administered by the Montgomery County Department of Health and Human Services. This program provides information and referrals to caregivers about available services, assistance to caregivers in accessing services, and education and training for caregivers.

 **Representative:** Lylie Fisher, Facilitator - Caregiver Support Program, Area Agency on Aging

 **Location:** Rockville, MD

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## Scholarship Recipients

**The Massachusetts Lifespan Respite Coalition** - The Massachusetts Lifespan Respite Coalition was formed in September 2010, with support from a Lifespan Respite grant from the U.S. Administration on Aging (AoA, nka Administration for Community Living, or ACL), in order to improve quality of life for the estimated 858,000 family caregivers in Massachusetts. The mission of the Coalition is to promote and support access to quality respite care options that enhance the lives of individuals and families with special needs throughout the lifespan. The Coalition is supported by a broad range of experts and advocates, including family caregivers, leadership from state health and human service agencies, and providers of home health and personal care.

 **Representative:** Emily Kearns, Coordinator of Dementia Friendly Massachusetts

 **Location:** Andover, MA

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**New York State Caregiving and Respite Coalition** - The New York State Caregiving and Respite Coalition (NYSCRC) is a partnership of dedicated organizations and individuals committed to supporting the millions of informal caregivers throughout the state. The coalition and its members are passionate about helping connect caregivers with the information, training and support services critical to successfully caring for a loved one at home. NYSCRC members are committed to addressing the current and future needs of those engaged in family caregiving across the lifespan.

 **Representative:** Doris Green, Director

 **Location:** Rochester, NY

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**Metropolitan Caregiver Service Collaborative** - The purpose of the Metropolitan Caregiver Services Collaborative is for caregiver service providers in the Minneapolis and St. Paul metropolitan area to come together to share knowledge, promote caregiver services, and strengthen public policies for family caregivers.

 **Representative:** Jenny West, Caregiving and Aging Community Educator at FamilyMeans

 **Location:** Stillwater, MN

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**Northern Colorado Respite Coalition** - The Colorado Respite Coalition (CRC) is a group of families and community partners who have joined together to support Colorado families who are caring for individuals of all ages with special needs.




They believe that family caregivers need a break and deserve our support. They promote Colorado's current respite care options and facilitate the development of new, safe, affordable, interactive and stimulating respite care choices.

 **Representative:** Jill Liken, Caregiver Support Program Manager for Volunteers of America – Northern Colorado Services

 **Location:** Fort Collins, CO

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**Alamo Caregiver Support Coalition/Hispanic Outreach Coalition** - The Alamo Caregiver Support Coalition is a sub-committee (Family Caregiver Support) of the Bexar Senior Advisory Committee which advises the Bexar Area Agency on Aging in matters related to seniors and persons with disabilities.

 **Representative:** Gloria Miranda, Program Manager for Caregiver SOS by the WellMed Charitable Foundation

 **Location:** San Antonio, TX

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**Virginia Caregivers Coalition** - Virginia Caregivers Coalition (VCC) works passionately to improve the experience of caregiving through education, advocacy and access to resources. They started with 22 founding members in 2004 and are nearly 200 members strong today. Their members include family caregivers, disability and aging community agency staff, state agency employees, and university and independent researchers.

 **Representative:** Kathy Dial, Vice-Chair/Executive Director for Kids, Kin 'n Caregivers, Inc.

 **Location:** Virginia Beach, VA

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**Bexar Area Agency on Aging Caregiver Coalition** - AACOG's Bexar Area Agency on Aging (BAAA) serves the City of San Antonio and Bexar County. The Bexar Area Agency on Aging is dedicated to building a community that supports older residents and allows them to age in place with dignity, security, and enhanced quality of life. The range of services provided includes caregiver support by assessing needs of caregivers and then coordinates available support services.

 **Representative:** Helen Flores, Director of Community Relations and Alternate Administrator for Caring Companions

 **Location:** San Antonio, TX

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## Speaker Bios

**Donna Benton, PhD,**  
Associate Research Professor of Gerontology, USC Family Caregiver Resource Center

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Donna Benton, PhD, is a research associate professor of gerontology at the USC Leonard Davis School of Gerontology. She is the Co-director of the USC Family Caregiver Support Center. Her research and clinical focus is on improving the Long Term Care system through better support for informal caregivers.

**Sita Diehl, MA, MSSW,**  
Principal, Sita Diehl Consulting, LLC

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Sita Diehl recently retired from the National Alliance on Mental Illness (NAMI) as Director of Policy and State Outreach. She has long been a NAMI member and a nationally recognized advocate for peers and families.

Ms. Diehl has co-authored reports on mental health parity, mental health legislation, supported employment, the state mental health budget crisis, military mental health, and Medicaid expansion. Prior to her tenure on the national staff, she served as Executive Director of NAMI Tennessee. She has developed mental health curricula for peers, families, providers, and criminal justice personnel. Her research experience includes a two-state comparison of women and children in public-managed behavioral health care, a multi-site study of consumer-operated services, and a longitudinal study of mental health services in Tennessee county jails.

She is a Licensed Advanced Practice Social Worker with an MSSW from the University of Tennessee and a Master of Arts in Community Psychology from Antioch University.

**Stephanie Firestone, MUP,**  
Senior Strategic Policy Advisor, AARP Office of International Affairs

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Stephanie Firestone is a Senior Strategic Policy Advisor for Health and Age-friendly Communities with AARP International. In this role she collaborates with international and national organizations to advance planning livable communities for all ages and healthy aging, and to combat ageism. Stephanie was previously Director of Livable Communities at the National Association of Area Agencies on Aging (n4a). As a 2015-2016 Health & Aging Policy Fellow, she worked with the US Department of Housing and Urban Development and the American Planning Association. Stephanie holds a Master of Urban & Environmental Planning degree from the University of Virginia.

**Mark Herbert, BA,**  
Small Business Majority



Mark Herbert directs Small Business Majority's operations throughout California. As California Director, he works with the state outreach team to build relationships with business organizations and small business owners. He also directs Small Business Majority's policy work by representing the voice of small business owners among policymakers in Sacramento. Previously, Mark served as the organization's Project Manager and Outreach Manager in California where he developed strong relationships with small business owners and business organizations across the state. Prior to joining the organization, he worked for state and federal lawmakers where he directed business operations and built relationships with small business owners and key stakeholders as they pertained to public policy issues. An entrepreneur himself, Mark runs a small consulting business

specializing in volunteer management and organizational capacity building.

**Gail Hunt, Founder,**  
National Alliance for Caregiving



Gail Gibson Hunt is the Founder of the National Alliance for Caregiving, a non-profit coalition dedicated to conducting research and developing national programs for family caregivers and the professionals who serve them. Prior to heading the Alliance, Ms. Hunt was President of her own aging services consulting firm for 14 years. She conducted corporate eldercare research for the National Institute on Aging and the Social Security Administration, developed training for caregivers with AARP and the American Occupational Therapy Association, and designed a corporate eldercare program for EAPs with the Employee Assistance Professional Association.

Prior to having her own firm, she was Senior Manager in charge of human services for the Washington, DC, office of KPMG Peat Marwick. Ms. Hunt attended Vassar College and graduated from Columbia University.

As a national expert on family caregiving and long-term care, Ms. Hunt served on the Policy Committee for the 2005 White House Conference on Aging, as well as on the CMS Advisory Panel on Medicare Education. She was the chair of the National Center on Senior Transportation. Ms. Hunt is also a commissioner for the Center for Aging Services Technology (CAST) and on the Board of the Long-Term Quality Alliance and the National Center for Creative Aging. Ms. Hunt is a member of the Multiple Chronic Conditions Workforce Technical Expert Workgroup. She co-chairs the NQF MAP Person and Family-Centered Care task force. Additionally, Ms. Hunt is on the Governing Board of the Patient-Centered Outcomes Research Institute (PCORI).

**Liddy Manson, MBA, Director,**  
Aging Well Hub Georgetown McDonough School of Business

Liddy Manson serves as the Director of the Aging Well Hub at Georgetown University's McDonough School of Business. The Aging Well Hub is a cross-sector collaborative whose goal is to connect companies, agencies, organizations, providers, and funders to create a shared framework for developing

## Speaker Bios



and deploying innovative products and services to enhance the lives of older adults. Liddy has spent over 25 years leading premier technology, health-tech, media, and information organizations. Most recently she was co-founder and President of BeClose, a pioneer of smart home technology designed to support people who are aging in place or living independently with disabilities. She led the company from its launch to its integration into its strategic investor, Alarm.com. Prior to joining BeClose, she served as CEO of DigitalSports, a web service providing detailed information and coverage of high school sports throughout the country. Prior to DigitalSports, she

served as the Chief Operating Officer of FreeWebs Inc. (now Webs.com). Previously, Liddy spent nine years as Vice President and General Manager at Washingtonpost.Newsweek Interactive, the online subsidiary of The Washington Post Company, and she started her career on the cutting edge of interactive media at Electronic Arts and the Discovery Channel. She serves on the boards of the Baltimore Symphony and Verite, an NGO dedicated to supporting US corporations in ensuring that their global supply chains comply with fair labor standards. Liddy holds an MBA and Certificate in Public Management from Stanford University and a BA in Music from Yale University.

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### **Sandy Markwood, MS, CEO, National Association of Area Agencies on Aging (n4a)**



Sandy Markwood is a national advocate for aging issues and a champion for ensuring that people have the best supports to age well at home and in their communities. As the CEO of the National Association of Area Agencies on Aging (n4a), she has been committed to ensuring that as a society we value and support people across the lifespan. That commitment has taken many forms including advocacy with multiple Administrations and on Capitol Hill for the passage of legislation aimed at supporting older adults including access to critical information, in-home services, and caregiver support. Sandy has also been a national expert in the design and development of age-friendly or livable communities for all ages. Under her leadership, n4a has worked with hundreds of communities to ensure that they are good places to grow up as well as good places to grow old. n4a's work in this area is expanding as they have taken on a leadership role with the national

coalition, Dementia Friendly America, launching Dementia Friends in the U.S. A passionate advocate, Sandy and her organization have launched campaigns focused on combating social isolation of older adults, promoting the health benefits of volunteering and engagement no matter your age, exploring new transportation and housing options as we age, among others. Her goal and the goal of n4a is to ensure that we all have the ability to age with good health, independence, and the quality of life we all deserve. Aging isn't just about adding years to our lives...it's about adding life to those years.

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### **Jim Murphy, MS, Vice President, Medicare and Retirement, UnitedHealthcare**



Jim Murphy is an Innovation leader within UnitedHealthcare's Medicare & Retirement division. Jim has over 20 years of experience in product development and marketing of highly regulated products and services--with a focus on health care solutions for the 50+ population. Jim serves on the Board of Directors for the National Alliance for Caregiving and is responsible for UnitedHealthcare's Solutions for Caregivers program. Jim holds a Bachelor of Arts degree in English with a concentration in business and technical writing from the University of Delaware, and a Master of Science in Marketing from Johns Hopkins University.

**Laurel Rodewald, Program Director,  
The Elizabeth Dole Foundation**



Laurel Rodewald serves as Programs Manager for the Elizabeth Dole Foundation, where she oversees several initiatives, including the National Coalition, the Impact Councils, the Hidden Heroes Fund, the Dole Caregiver Fellows program, and the Hidden Heroes Caregiver Community. Laurel interned for the Foundation during the summer of 2014, where she assisted in writing and compiling a grant proposal for the Foundation. She has previously interned for a political consulting firm, her university's study abroad programs department, and a public relations agency.

Laurel came to the Washington DC area from Southern California, where she graduated cum laude in 2015 from Pepperdine University, with a degree in International Studies.

**Vicki Shabo, MA, JD,  
Vice President for Workplace Policies and Strategies, National Partnership for Women & Families**



Vicki Shabo is vice president at the National Partnership for Women & Families and is one of the nation's leading experts on paid family and medical leave, paid sick days and the workplace policy advocacy landscape. She previously served for more than four years as the organization's director of work and family programs. Shabo is responsible for the strategic direction of the National Partnership's work to promote fair and family friendly workplaces and leads the organization's work on paid family and medical leave, paid sick days, expansion and enforcement of the Family and Medical Leave Act, workplace flexibility, fair pay and pregnancy discrimination. She

serves as a contact on workplace policy issues for key national allies, researchers, businesses and state and local advocates and has been quoted in the New York Times, Washington Post, Associated Press, USA Today, CNN and MSNBC, among other outlets.

Shabo brings a unique background in law and politics to her work: Prior to joining the National Partnership in 2010, she practiced law in the litigation department at WilmerHale, a large international law firm. Before embarking on a legal career, she worked with both Celinda Lake and Harrison Hickman, serving as a pollster and political strategist to political candidates, ballot campaigns, advocacy organizations and media outlets. Through this work, she developed research and communications expertise on issues of particular concern to women. Shabo's earlier professional experience includes a stint with the U.S. House of Representatives Judiciary Committee.

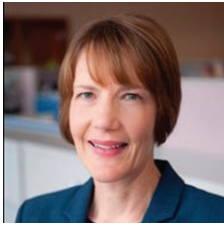
Shabo graduated summa cum laude with a Bachelor of Arts in politics and American studies from Pomona College, and holds a Master of Arts in political science from the University of Michigan. She earned her law degree with high honors from the University of North Carolina, where she served as editor in chief of the North Carolina Law Review. After law school, she clerked for the Honorable Michael R. Murphy on the U.S. Court of Appeals for the Tenth Circuit in Salt Lake City



## Speaker Bios

### **Dawn Simonson, MPA, Executive Director, Metropolitan Area Agency on Aging**

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Dawn Simonson is the Executive Director of the Metropolitan Area Agency on Aging, serving the Minneapolis and St. Paul region. With more than 20 years of experience in the field of aging, Dawn is recognized for her leadership and advocacy for integrating care delivery across health care and long-term services and supports. She is a respected voice in the aging policies and practices arena through her voluntary lead roles with the Minnesota Leadership Council on Aging, Minnesota's ACT on Alzheimer's initiative, Silos to Circles, and Dementia Friendly America.

### **Sharon Terman, , JD, Director, Work and Family Program, Legal Aid at Work**

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Sharon Terman is Director of the Work and Family Program and Senior Staff Attorney at Legal Aid at Work, a non-profit organization that promotes the workplace rights and wellbeing of low-wage workers and their families. Sharon provides free legal advice to workers in low-wage jobs, represents employees facing family medical crises, advocates for policy and institutional change to promote family-supportive workplaces, and engages in community outreach. She is an expert on family and medical leave policies and has helped craft several landmark laws, including expansions of Paid Family Leave to cover caregiving for siblings, grandparents, grandchildren, and parents-in-law, and increasing the benefit amount; a law mandating continued health insurance benefits during pregnancy leave; and a law requiring job-protected time off to visit or enroll children in school or childcare or to address a child care emergency. Sharon received her B.A. with highest distinction from the University of California, Berkeley, and her J.D. with distinction from Stanford

Law School. After law school, she clerked for the Honorable Richard A. Paez of the Ninth Circuit Court of Appeals before joining Legal Aid at Work as a Skadden Fellow. She is the 2011 recipient of the Stanford Law School Miles L. Rubin Public Interest Award, and was named a 2015 Northern California Rising Star by Super Lawyers. Sharon is the proud mom of a two-year-old girl.

### **Donna Wagner, PhD, Dean, College of Health and Social Service, New Mexico State University**

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Dr. Donna Wagner has examined issues of family caregiving and workplace eldercare programs since the mid-1980s. She is a Fellow of both the Gerontological Society of America and the Association for Gerontology in Higher Education (AGHE), previously serving as past President. Dr. Wagner's research has published in the areas of rural caregiving, older caregivers, and policy options to support caregivers, utilization of workplace programs and programs and services for older adults. She earned her BA in Psychology, as well as a MA and PhD in Urban Affairs from Portland State University where she was affiliated with the Institute on Aging. She currently serves on the Board of Directors for the Alliance as Treasurer. Dr. Wagner has led numerous national research projects using quantitative, qualitative, and mixed-methods of research in the field of family caregiving and aging since

the 1970s and published in peer-reviewed journals including the Journal of Gerontology and Geriatrics Education, Journal of Aging and Social Policy, Journal of Applied Gerontology, the Journal of Family Affairs, and Health Affairs, among others.

**C. Grace Whiting, JD, President and CEO,  
National Alliance for Caregiving**



C. Grace Whiting, J.D., is the President and Chief Executive Officer at the Alliance, where she leads the organization's business development, supports strategic planning, and develops relationships with key stakeholders in the family caregiving community. In her work at the Alliance, she managed the launch of the Caregiving in the U.S. 2015 report with AARP. Ms. Whiting has also contributed to several national reports on caregiving, including Caregiving in the U.S. 2015, Cancer Caregiving in the U.S. with the National Cancer Institute and Cancer Support Community, and Dementia Caregiving in the U.S. with the Alzheimer's Association. Ms. Whiting has spoken on coalition building at national and international conferences, including the keynote address at a National Institutes of Health workshop, "The Spectrum of Caregiving and Palliative Care in Rare Diseases" in June 2015, jointly hosted by the National Institute of Nursing Research and the Office of Rare Diseases Research.

In addition to her work at the Alliance, Ms. Whiting has served as the Advocacy and Communications Director at Leaders Engaged on Alzheimer's Disease (LEAD Coalition) and as the Director of Strategic Initiatives & Communications and as the Special Assistant to the Executive Director at the Alliance for Home Health Quality and Innovation in Washington, D.C.

She is currently a licensed attorney with the District of Columbia Bar and a member of Women in Government Relations and the American Society on Aging. Named an "Outstanding Law Student" by the National Association of Women Lawyers, Whiting earned her law degree from the University of Memphis School of Law and her undergraduate degree with honors in Communication Studies from Louisiana State University.

**Michael Wittke, MPA, Director of Advocacy,  
National Alliance for Caregiving**



Michael Reese Wittke manages the National Network of Caregiving Coalitions, including the Advocacy Task Force. He develops relationships with policymakers on Capitol Hill, federal agencies, the White House and participates in national coalitions on behalf of the Alliance. He also works to support and grow the Caregiving Champions program.

Prior to joining the Alliance, Mr. Wittke was the Associate Director of Government Affairs at the National Association for Home Care & Hospice. In this role, he followed legislative developments influencing end-of-life care, long-term care, home care and hospice. He was also the main architect of the Leadership Council of Aging Organizations 50th Anniversary of Medicare, Medicaid and Older Americans Act which featured more than 200 stakeholders and policymakers in the Washington area, among other Hill events.

Mr. Wittke previously served as Chair of the National Association of Social Workers (NASW) Political Action for Candidate Election Committee and as a member of the NASW Metro Chapter Board of Directors. He came to Washington through an internship with the Hinckley Institute of Politics. He earned a Bachelor's degree in Social Work at the University of Utah with honors and a Master's degree in Public Administration at American University.

# Key Federal Legislation

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## Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act

Public Law 115-1190

Requires the Secretary of Health and Human Services to develop, maintain and update an integrated national strategy to recognize and support family caregivers. Brings together relevant federal agencies and others from private and public sectors to advise and make recommendations regarding the national strategy.

**Sponsor:** Representative Gregg Harper (R-MS); Senator Susan Collins (R-ME)

**Last action:** Signed by President

## Family and Medical Insurance Leave (FAMILY) Act

H.R. 947 and S. 337

Provides workers with up to 12 weeks of partial income when they take time for their own serious health condition, including pregnancy and childbirth recovery; the serious health condition of a child, parent, spouse or domestic partner; the birth or adoption of a child; and/or for military caregiving and leave purposes. The benefit would be administered through a new Office of Paid Family and Medical Leave within the Social Security Administration. Payroll contributions would cover both insurance benefits and administrative costs.

**Sponsor:** Representative Rosa DeLauro (D-CT); Senator Kirsten Gillibrand (D-NY)

**Last action:** House—In Ways and Means Subcommittee on Human Resources; Senate—In Finance Committee

## Lifespan Respite Care Reauthorization Act

H.R. 2535 and S. 1188

The Lifespan Respite Care Program provides competitive grants to state agencies working in concert with Aging and Disability Resource Centers and non-profit state respite organizations to make quality respite available and accessible to family caregivers. This bill amends the Public Health Service Act to reauthorize the Lifespan Respite Care Program at \$15 million a year for five years.

**Sponsor:** Representative James Langevin (D-RI); Senator Susan Collins (R-ME)

**Last action:** House—In Energy and Commerce Committee;  
Senate—In HELP Committee

## Care Corps Demonstration Act

H.R. 3493

The Care Corps places volunteers in communities where they provide services that help seniors and individuals with disabilities remain independent. The legislation provides volunteers with health insurance and other benefits during their time of service, along with an educational award that can be used to pay education costs or loans.

**Sponsor:** Representative Michelle Lujan Grisham (D-NM)

**Last action:** House—Referred to the Subcommittee on Health, Energy and Commerce Committee



## Military and Veteran Caregiver Services Improvement Act of 2017

H.R. 1472 and S. 591

This bill expands eligibility for the family caregiver program of the Department of Veterans Affairs (VA) to include members of the Armed Forces or veterans who are seriously injured or who became ill on active duty prior to September 11, 2001 (currently, limited to service after September 11, 2001). Services to caregivers of veterans under such program are expanded to include child care services, financial planning services, and legal services.

**Sponsor:** Representative James Langevin (D-RI); Senator Patty Murray (D-WA)

**Last action:** Hearing held in Senate Special Committee on Aging

## Palliative Care and Hospice Education and Training (PCHETA) Act

H.R. 1676 and S. 693

Would increase the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, and other programs, including physician assistant education programs, to promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine.

**Sponsor:** Representative Eliot Engel (D-NY); Senator Tammy Baldwin (D-WI)

**Last action:** House—Energy and Commerce Committee; Senate—In HELP Committee

## Social Security Caregiver Credit Act

S. 1255

Provides a social security credit to be added to a person's total career earnings and used to calculate future social security benefits. This is a progressive benefit for caregivers who spend at least 80 hours a month providing care. This includes caregivers of a parent, aunt, uncle, grandchild, niece, nephew, spouse, or domestic partner.

**Sponsor:** Senator Chris Murphy (D-CT)

**Last action:** Introduced in Senate

## State Legislation

### The Caregiver Advise, Record, Enable (CARE) Act

1. Record the name of the family caregiver on the patient medical record.
2. Inform the family caregiver when the patient is to be discharged.
3. Provide the family caregiver with education and live instruction of the medical tasks he or she will need to perform for the patient at home.

# Get involved in a family caregiving coalition!



## What is a caregiving coalition?

A caregiving coalition is a community of representatives that has come together to address the needs of family caregivers across the lifespan. These coalitions support family caregivers, both families of origin or families of choice, with information and referral services, educational outreach, and advocacy. A caregiving coalition presents a united voice working to meet the complex social, medical, physical, financial, spiritual, and emotional needs of family caregivers.

The Alliance supports the National Network of Caregiving Coalitions, which includes approximately 80-100 caregiving coalitions across the U.S. We offer an annual conference, quarterly webinars, resource guides, 1:1 technical assistance, and a mentoring program.

### Typically, coalitions engage in these types of activities:

- Educational Resources for Caregivers
- Community Outreach
- Resource Fairs/Conferences
- Support Groups
- Social Media/Online Outreach
- Respite Care
- Legislative Action
- Caregiver Stipends



The Alliance also offers two guidebooks to help advocates like you in building a coalition. The first guidebook, *Planting the Seed* covers: coalition planning, developing the coalition's vision and mission statements, establishing goals and objectives, and more. The second volume, *Growing Your Coalition*, developed for already established coalitions, discusses strategic planning, project management, communications and social media, sustainability, and evaluation.




To learn more, visit  
[www.caregiving.org/coalitions](http://www.caregiving.org/coalitions)

or contact Mike Wittke, Director of Advocacy at  
[mike@caregiving.org](mailto:mike@caregiving.org).

## Other ASA Caregiver-related Events

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### **Dementia Caregiving in the United States**

-  Tuesday, March 27
  -  1:30-2:30 PM
  -  Hilton San Francisco Union Square | Union Square 3-4 (Tower 3, 4th Floor)
- 

### **\*Poster Session\* Rare Disease and the Impact on Aging Parents, Siblings and Spousal Caregivers**

-  Wednesday, March 28
  -  9-11 AM
  -  Hilton San Francisco Union Square | Golden Gate, Board 412
- 

### **The National Falls Prevention Action Plan: A Framework for Action to Reduce Falls Among Older Adults**

-  Wednesday, March 28
  -  3-4 PM
  -  Hilton San Francisco Union Square | Golden Gate 8 (Lobby Level)
- 

### **Family Caregiving Peer Group**

-  Wednesday, March 28
  -  6-7 PM
  -  Hilton San Francisco Union Square | Golden Gate 8 (Lobby Level)
- 

### **Recommendations From a Legislatively Appointed Task Force to Support California's Family Caregivers**

-  Thursday, March 29
  -  10-11:30 AM
  -  Hilton San Francisco Union Square | Golden Gate 8 (Lobby Level)
-

# Thank you to Our Sponsors!



## About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO).

Learn more at [caregiving.org](http://caregiving.org).

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