



# *Advocating for Caregiving:*

8<sup>th</sup> Annual National Conference of Caregiving Coalitions

National Alliance for Caregiving

March 12, 2014



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**Advocating for Caregiving**  
**8<sup>th</sup> Annual National Conference of Caregiving Coalitions**  
2014 Annual Conference of the American Society on Aging



**MEETING AGENDA | MARCH 12, 2014**

- 7:00 – 7:30 am**      **Registration & Breakfast**
- 7:30 – 8:00 am**      **Welcome Message & Conference Overview**  
**Introduction of Scholarship Recipients**  
Gail Hunt, President & CEO, National Alliance for Caregiving (NAC)  
Mary Ellen Kullman, MPH, Vice President, The Archstone Foundation
- 8:00 – 9:10 am**      **Engaging Family Caregivers in Education & Advocacy**  
**Moderator:** The Honorable Brian Duke, MHA, MBE, Secretary of Aging, Pennsylvania  
**Panelists:** John Schall, MPP, Chief Executive Officer, Caregiver Action Network  
Alejandra Ceja-Aguilar, MA, Caregiver Coalition of San Diego  
Martha Rañón, Director of Education & Outreach, Southern Caregiver Resource Center  
Adrienne R. Smith, President & CEO, New Mexico Direct Caregivers Coalition
- 9:10 – 10:20 am**      **The Rise of the “eCaregiver”: How Technologies Can Support Family Caregiving**  
**Moderator:** Sandy Markwood, MS, Chief Executive Officer, n4a  
**Panelists:** Marcus Grindstaff, Vice President, International Markets, Intel-GE Care Innovations™  
Andy Cohen, MBA, Co-Founder & CEO, Caring.com  
David Besst, Arizona Division of Aging & Adult Services and Arizona Caregiver Coalition  
Thomas E. Edes, MD, MS, Director of Geriatrics and Extended Care for Clinical Operations,  
Department of Veterans Affairs (VA)
- 10:20 – 10:30 am**      **Break**
- 10:30 – 10:45 am**      **Update from the National Alliance for Caregiving**  
Gail Hunt, President & CEO, NAC  
C. Grace Whiting, JD, Manager, Programs & Communications, NAC
- 10:45 – 11:25 am**      **Interactive Workshop – Growing Your Coalition: What To Do After You’ve Planted the Seed**  
Rick Greene, MSW, Acting Director, NAC  
C. Grace Whiting, JD, Manager, Programs & Communications, NAC
- 11:25 – 12:10 pm**      **Interactive Workshop – Coalitions: Communicating Impact**  
The Honorable Brian Duke, MHA, MBE, Secretary of Aging, Pennsylvania
- 12:15 – 1:15 pm**      **Lunch & Keynote: “Supporting California Caregivers through Expanding Paid Family Leave”**  
The Honorable Hannah-Beth Jackson (D – Santa Barbara), California State Senate
- 1:15 – 1:30 pm**      **Closing Remarks**  
Gail Hunt, President & CEO, NAC

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**Keynote Speaker:**  
**The Honorable Hannah-Beth Jackson**



Hannah-Beth Jackson is an educator, former State Assembly member, former Deputy District Attorney, and small business owner. She was elected to the California State Senate in 2012 to represent the 19th Senate District, which includes all of Santa Barbara County and western Ventura County. From 1998 to 2004, she represented the 35th Assembly District in the State Assembly. Hannah-Beth also co-founded two non-profit organizations, has served as policy-maker in residence at UC Santa Barbara and currently serves as adjunct professor at Antioch University.

In the Senate, she is chair of the Senate Judiciary Committee, and serves on key committees, including the Budget Committee, the Environmental Quality Committee and the Natural Resources Committee. She's also chair of the Select Committee on Passenger Rail, the Joint Legislative Committee on Emergency Management and she is vice-chair of the California Legislative Women's Caucus.

During the six years she served in the State Assembly and now as a State Senator, Hannah-Beth is an effective advocate for improving public education, increasing public safety, improving access to health care, promoting job growth in green industries and others, protecting the environment and protecting the privacy and rights of consumers.

During her time in the State Assembly, Hannah-Beth served as Chair of the Assembly Committee on Natural Resources and Chair of the Assembly Select Committee on Coastal Protection. She served as Chair of the bipartisan Legislative Women's Caucus and was Chair of the Assembly Environmental Safety and Toxic Materials Committee from 1999-2002. She served on a number of standing committees including the Budget Committee, Judiciary Committee and the Higher Education Committee. She worked with Democratic and Republican Governors, and authored more than 60 bills that were signed into law.

She was named "Legislator of the Year" by the Consumer Federation of California for her strong advocacy on behalf of consumers, particularly in the areas of health care and privacy rights. Jackson was also named "Legislator of the Year" by the Congress of California Seniors for advocacy against elder abuse and health care issues and "Environmental Hero" by the California League of Conservation Voters for her unwavering protection of our natural resources and public health. The California Teachers Association named her "Outstanding Public Official" for her leadership in improving our schools. She was named "Legislator of the Year" by the National Organization for Women for advancing women's health issues and equal opportunity and by the Junior League of California for her work on domestic violence and issues effecting children. Californians Against Waste named her legislator of the year after the passage of her bills to do with pesticide use and the recycling of electronic- waste. Hannah-Beth earned other awards including "Guardian of the Coast" by Vote the Coast, the "Outstanding Public Service Award" by the California School Employees Association, and Planned Parenthood's "Giraffe Award" for sticking her neck out to do what is right.

Hannah-Beth is married to George Eskin, retired Superior Court Judge. She has a daughter, two stepchildren and five grandchildren. The family has resided in the district for more than 35 years.



## **Our Panelists and Presenters**

### **David Besst**

**Family Caregiver Programs Specialist, Arizona Division of Aging and Adult Services**  
**Founding Member, Arizona Caregiver Coalition**

<http://www.azcaregiver.org>



David Besst had a very successful 25 year career in the business community, Mr. Besst was introduced to caregiving the way many caregivers are...through an aging parent. His experience caring for both of his parents over a 10 year span inspired him to go back to school, where he earned a degree in the Gerontology Program at Phoenix College in 2005. After serving a five month practicum/internship with the Governor's Advisory Council on Aging, Mr. Besst started his current position as Caregiver Programs Specialist for the State of Arizona in the Division of Aging and Adult Services. He is also currently serving as Project Director for three Administration on Aging (AoA) discretionary grant projects that seek to enhance caregiver support throughout Arizona.

He is often considered a maverick in his field and a system changer for caregivers, ADRC's and the Lifespan Respite Programs including respite vouchers programs. From 2006 to 2008, Mr. Besst provided leadership to a sub-committee of the Governor's Advisory Council on Aging that developed and launched the Arizona Caregiver Coalition (ACC), Arizona Lifespan Respite Program. For more on the Arizona Caregiver Coalition, please see the "About Our Scholarship Winners" section of this packet.

### **The Honorable Brian Duke, MHA, MBE** **Secretary of Aging, Commonwealth of Pennsylvania**



Brian Duke was nominated by Governor Tom Corbett to be the Secretary of Aging on February 3, 2011, and confirmed by the Pennsylvania Senate on May 3, 2011. Secretary Duke has a wide background in aging issues as well as hospital administration. Prior to his nomination, he served as Director of the Bucks County Area Agency on Aging. Before that he served as Executive Director of the New Jersey Foundation for Aging, a statewide public charity dedicated to improving the quality of life of older persons.

Previous to his work with the Foundation, Mr. Duke served as a consultant working with the US Administration on Aging and the AARP Foundation in the development of statewide caregiving coalitions in 12 states. Mr. Duke has also served as consultant with the Family Caregiver: Outreach and Assistance in Our Communities Project with the Pennsylvania State University, Agricultural and Extension Education, Intergenerational Programs and Aging. He is the author of Caregiver Coalitions Advocacy Guide: Uniting Voices, Building Community with the National Alliance for Caregiving. Duke participates at the national, state and local level to foster effective strategies to support family caregivers, encourage aging well and build effective community partnerships.

While serving as Secretary of Aging under Governor Corbett, the Department of Aging has been able to provide services to over one million older Pennsylvanians. The Department has also implemented a Healthy Steps for Older Adults Falls Prevention program and Healthy Steps in Motion exercise program to reduce the risks for falls. Following a University of Pittsburgh research study, the falls prevention program was awarded evidence-based status by the US Admin. on Aging.



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**Alejandra Ceja-Aguilar, MA**  
**Caregiver Coalition of San Diego**  
<http://www.caregivercoalitionsd.org>



With more than ten years of experience in education and training and six years in counseling, Alejandra has taken her skills to help support family caregivers, professional caregivers, and other health and social service professionals. Her passion toward the empathic care of adults facing cognitive impairments and her experience as a family caregiver, make it possible for her to develop curriculum that is both educational and compassionate. Today, Alejandra is the Education and Training Consultant for Beyond the Sky Solutions, a consulting firm that helps supports family caregivers, seniors, residential communities, and other senior care agencies.

The Caregiver Coalition of San Diego is an alliance of agencies that provide services for Family Caregivers through education and advocacy. The coalition's mission is "to identify and address the needs of Caregivers through advocacy efforts and collaboration of a broad coalition membership in order to improve the overall quality of life for Caregivers, their families and the community." The coalition meets monthly and plans education events and forums.

**Andy Cohen, MBA**  
**Co-Founder & Chief Executive Officer, Caring.com**  
<http://www.caring.com>



Andy Cohen, Chief Executive Officer and a co-founder, oversees the company's operations and finances, with the goal of establishing Caring.com as the premiere website for people taking care of their parents and other aging loved ones. Andy has launched four successful web businesses, taking them from start-up to tens of millions of dollars in revenue. In a 20-year career before founding Caring.com, he held leadership positions in management, marketing, and sales with S.C. Johnson Wax, Intuit, Peapod, Instill, and SuccessFactors. He serves on the Board of Directors of the National Alliance for Caregiving and the Advisory Board of the Harvard Medical School Health Policy Department.

Andy grew up in Glencoe, Illinois. He now lives with his wife and two teenage children in the San Francisco Bay Area, where he enjoys cycling in the foothills above Silicon Valley. While caring for his mom during her losing battle with lung cancer, Andy realized there wasn't a comprehensive website that helped people figure out how to handle in-home care, choose products to help with daily living, and make the right financial and legal decisions. Caring.com was founded to meet those needs, and to make a difficult journey a little bit easier.

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**Thomas E. Edes, MD, MS**

**Director of Geriatrics and Extended Care for Clinical Operations**

**Department of Veterans Affairs (VA)**



Thomas E. Edes, MD, MS, is Executive Director of Geriatrics and Extended Care Operations for the Veterans Health Administration, US Department of Veterans Affairs (VA). He has national responsibility for operations and management of VA's spectrum of services, providing care to our nation's veterans with complex, chronic disabling diseases in all settings, including geriatric clinics, adult day health care, home-based primary care, purchased skilled home care, veteran-directed home care, homemaker/home health aide, respite care, dementia care, and various residential care settings, among others.

Under his leadership since 2000, the number of veterans receiving home-based primary care has tripled, palliative care has become an established program in every VA medical center, and medical foster home care has grown from a pilot to a national program operating at 98 VA Medical Centers in 43 states and territories. Prior to taking this position

at VA Central Office in Washington, DC, Dr. Edes was Chief of Geriatrics and Extended Care at the Harry S. Truman Memorial VA Medical Center and Associate Professor of Medicine at the University of Missouri in Columbia. He was also Medical Director of the VA Nursing Home Care Unit and the Home-Based Primary Care program.

Dr. Edes served as Associate Director of the 1995 White House Conference on Aging Office, and served for the Secretary on the Policy Committee for the 2005 White House Conference on Aging. He was instrumental in the VA End of Life Care initiative, and was a project manager for the Institute for Healthcare Improvement MediCaring collaborative on improving care for persons with advanced chronic disease. Dr. Edes received his Doctor of Medicine and MS degree in nutrition from the University of Illinois in 1981. He holds board certification in internal medicine and in geriatric medicine, and is a fellow of the American College of Physicians and the American College of Nutrition. In 2010, Dr. Edes was elected as President of the American Academy of Home Care Physicians.

**Rick Greene, MSW**

**Acting Director**

**National Alliance for Caregiving**

Rick Greene, MSW, is an expert on aging, having worked at the U.S. Department of Veterans Affairs and the U.S. Administration on Aging. His work with family caregivers was partly the model for the National Family Caregivers Support Program (NFCSP), which he supported as the first Director of the program and was responsible for developing training materials and workshops for the States, overseeing special grants, as well as approximately \$150 million to the States. Following his work with NFCSP, Rick worked with the Veterans Administration to implement the Medical Foster Home Program, expand Home-Based Primary Care in rural areas and to develop programs for Native American veterans.

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**Marcus Grindstaff**

**Vice President, International Markets, Intel-GE Care Innovations™**

**<http://www.careinnovations.com>**



Marcus is responsible for International Markets for Intel-GE Care Innovations™, a partnership between Intel and GE that brings healthcare into the home so that people can live confidently and stay engaged in their own health. In this role, he drives company strategy and business execution across all markets outside of the United States. Prior to this role, Marcus led strategy and product marketing for Care Innovations.

Marcus joined Care Innovations at its formation in 2011, from the Intel Digital Health Group. A 17-year Intel veteran, Marcus held a variety of positions including leadership roles in both Intel Capital and Intel's core semiconductor business. Marcus also served as the Technology Director in Intel's Ultra-mobility Office of Big Ideas, where he was responsible for building the Low Power Chipset team, delivering Intel's first low power chipset for the Atom\* microprocessor.

Throughout his career, Marcus has focused on growing exceptional teams chartered with delivering strategy, technology, marketing and product execution throughout the United States, Asia and Europe. He is also a passionate spokesperson for reforming the healthcare delivery system, and serves on the Board of the National Alliance for Caregiving. Marcus earned a Bachelor of Computer Engineering Degree from the University of California, Davis.

**Gail Gibson Hunt**

**President & Chief Executive Officer**

**National Alliance for Caregiving**



Gail Hunt is President and Chief Executive Officer 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 NAC, 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 in New York. She 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 is 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. Additionally, Ms. Hunt is on the Governing Board of the Patient-Centered Outcomes Research Institute (PCORI).



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**Sandy Markwood, MS**  
**Chief Executive Officer, n4a (National Association of Area Agencies on Aging)**  
<http://www.n4a.org>



Chief Executive Officer Sandy Markwood has more than 30 years of experience in the development and delivery of aging, health, human services, housing and transportation programs in counties and cities across the nation. Prior to coming to n4a in January 2002, Sandy served as the Deputy Director of County Services at the National Association of Counties where she took a lead role in research, training, conference planning, program development, technical assistance and grants management.

As CEO, Sandy is responsible for n4a's overall management. She sets strategic direction for the staff, oversees the implementation of all policy, grassroots advocacy, membership and program initiatives. She also leads n4a's fund-raising efforts and engages corporate sponsors to support critical initiatives, including an aging awards/best practices program and the Leadership Institute for Area Agency on Aging staff. Externally, Sandy forms strategic partnerships with federal agencies and organizations in aging, human service and health care arenas to enhance the role and recognition of Area Agencies on Aging and Title VI programs. Sandy holds Bachelor's and Master's degrees from the University of Virginia.

**John Schall, MPP**  
**Chief Executive Officer, Caregiver Action Network**  
<http://caregiveraction.org>



John Schall is a public policy and communications professional with noted expertise in a wide range of policy fields, including healthcare, labor, education, economic development, taxation, and budget policy. He became Chief Executive Officer of the Caregiver Action Network (formerly the National Family Caregivers Association (NFCA)) in June 2012. Prior to CAN, Mr. Schall was Deputy CEO of the Parkinson's Action Network.

John also brings to CAN a wealth of experience in senior federal government positions, including serving as former Sen. Bob Dole's chief budget advisor; chief of staff of the U.S. Department of Labor in the early 1990s; and as deputy of the White House Domestic Policy Council under President George H.W. Bush. He holds a Master of Public Policy degree from Harvard University's John F. Kennedy School of Government, and is a graduate of the University of Michigan.

The Caregiver Action Network serves a broad spectrum of family caregivers ranging from the parents of children with special needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer's disease. CAN (formerly the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

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**Adrienne R. Smith**  
**New Mexico Direct Caregivers Coalition**  
**<http://www.nmdirectcaresupport.org>**



Adrienne R. Smith is President and CEO of Education and Workforce Consultants, LLC. Her work includes development of national strategies to serve in-school and out-of-school youth in Honduras, Brazil and Indonesia through U.S. Agency for International Development and assistance to national and statewide nonprofit organizations. She has a Bachelor's in Biology and a Masters in Public Policy Administration specializing in International Administration.

Ms. Smith also serves as Executive Director of the New Mexico Direct Caregivers Coalition, a statewide organization that advocates for and advances the professional development and workforce issues of New Mexico's wage-earning and unpaid family caregivers. The organization reaches 4,500 direct care workers, advocates and family members of caregivers statewide. She has conducted several seminars that bring staff together from workforce development and disability agencies together to share best practice for changing systems for persons with disabilities.

**Martha Rañón, Director of Education & Outreach**  
**Southern Caregiver Resource Center (San Diego)**  
**<http://caregivercenter.org>**



Martha Rañón has acquired over 16 years of experience in the areas of public policy and advocacy. She brings a unique blend of professional experience having worked for numerous local and state legislators as well as several social service agencies. Her first-hand knowledge of the legislative process coupled with her understanding of community needs and goals of local non-profits has served her well in crafting, promoting and managing advocacy campaigns. Her efforts have brought awareness to local elected officials, facilitated the support of proposed legislation at the State level, aided in the crafting of policy changes as well as testified at state and federal hearings all while building strong relationships with community leaders.

Established in 1987 as a non-profit 501c3, the Southern Caregiver Resource Center is the leading provider of FREE comprehensive caregiver support services for San Diego County, serving over 30,000 clients annually with a wide variety of services that include education, case management, counseling, respite care and support groups. All services are available in Spanish and English.

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**C. Grace Whiting, JD**  
**Manager, Programs and Communications**  
**National Alliance for Caregiving**



Grace is a strategic communications professional and an attorney member of the District of Columbia Bar. She is passionate about improving patient and family caregiver access to an increasingly complex U.S. health care system and empowering caregivers. Prior to joining the National Alliance for Caregiving, Grace served as the Director of Strategic Initiatives & Communications and Special Assistant to the Executive Director at the Alliance for Home Health Quality and Innovation in Washington, D.C. Grace has also worked as a Communications Manager for the Louisiana Family Recovery Corps in the aftermath of Hurricanes Katrina and Rita.

Named an “Outstanding Law Student” in 2011 by the National Association of Women Lawyers, Grace earned her law degree from the University of Memphis Cecil C. Humphreys School of Law and her undergraduate degree from Louisiana State University.



## **2014 Scholarship Winners**

### **Arizona Caregiver Coalition**

Glendale, Arizona  
Elizabeth Harris, M.S.W.

### **California Coalition for Caregivers**

Burbank, California  
Stefanie Elkins, M.A., M.M.

### **Caregiver Coalition of Northeast Florida**

Jacksonville, Florida  
Toula Wootan, M.S.H.

### **Caregiver Support Network of Ashland and Bayfield Counties**

Washburn, Wisconsin  
Carrie Linder, Certified Social Worker

### **Caregivers Respite**

Memphis, Tennessee  
Janice Williams, R.N.

### **Community Senior Services**

Claremont, California  
Angelika Pittet, AS, Q.D.C.P., DCPA

### **Hawaii Family Caregiver Coalition**

Honolulu, Hawaii  
Leanne Clark-Shirley, Ph.D.

### **Ocean County Caregivers of New Jersey**

Trenton, New Jersey  
Jessica Goldsmith-Barzilay, M.S.W.

### **Outagamie Caregiver Coalition**

Appleton, Wisconsin  
Susan Coyle, C.M.C., C.O.T.A.

### **The Senior Sage**

Henderson, Nevada  
Debbie Carroll



## About Our Scholarship Winners

**AZ Caregiver.org**

**Arizona Caregiver Coalition**  
**www.AZCaregiver.org**  
Glendale, Arizona  
Elizabeth Harris, M.S.W.

The Arizona Caregiver Coalition is a community-based organization that was founded to support and advocate for family caregivers in Arizona. The coalition was developed through the Governor's Advisory Council on Aging and serves a mandated role as part of the Arizona Lifespan Respite Program. The mission of the Arizona Caregiver Coalition is to be the catalyst for improving the quality of life for family caregivers and loved ones through collaboration, advocacy and access to supportive and education resources. The vision of the Arizona Caregiver Coalition is for all Arizona family caregivers to have sufficient knowledge and access to resources which support the caregiver and their loved ones to live full and healthy lives.

### Recent Coalition Accomplishments

The Arizona Caregiver Coalition has sponsored a statewide Caregiver Resource Line that is operated by volunteers. Volunteers answer calls and emails Monday-Friday and on-call every weekend. They have answered over 1,000 calls in less a year and countless emails. The group also recently hosted its annual Respite Summit, for agencies and community stakeholder. On November 7, 2013, the group re-launched its website ([www.AZCaregiver.org](http://www.AZCaregiver.org)) and new logo for the Arizona Caregiver Coalition. Over 750 new members have joined the Coalition since launching the website Nov. 7, 2013.

The Coalition also works to distribute Statewide Respite Vouchers for family caregivers including Kinship Caregivers. These Respite Vouchers are available by calling the Caregiver Resource Line and being pre-screened, completing an application and participating in an Evidence Based, Caregiver Assessment Tool, pre and post tests are to be conducted before and after Respite are provided. Furthermore, the Coalition is working with Rewarding Work and the ACC which launched the first West Coast, on-line registry for caregivers, PCA, Direct Care Workers on the Arizona Respite Registry. This was created in connection with the statewide Respite Vouchers in order to make respite services accessible for all caregivers throughout Arizona. When a caregiver is awarded the respite voucher, they can self-direct the selection of a respite provider. For many, due to the rural parts of Arizona, the on-line registry can be the only available access they might have to respite workers. In addition, this online registry increases the work force of respite providers including Direct Care Workers throughout Arizona.



### About Elizabeth Harris

Elizabeth earned a Bachelor of Arts Degree in Aging and Lifespan Development (Gerontology) from Arizona State University, earned a Master Certificate in Gerontology from the University of Arizona (U of A) and a Masters in Social Worker from Arizona State University (ASU) in 2013 while she worked part-time for the Arizona Caregiver Coalition and responsible for the development and establishment of the statewide Arizona Caregiver Resource Line.

Elizabeth worked over 12 years in the Senior Health Care Services throughout Arizona and California before returning to college. She also worked her way through college as a paid caregiver, in undergrad, She developed a love and passion for family caregivers after her mother became a family caregiver to her father.

She is passionate about the work they do on the coalition and shows her compassion for long-term caregivers providing support to their loved ones by training the volunteers that answer calls statewide on the Caregiver Resource Line. She advocates for family caregivers across the lifespan and is passionate about finding them resources and options while coping with the stressors of caregiving. Elizabeth holds several positions in the field of social services including a Medical Social Worker, Per Diem for a home health care agency and has been serving the Arizona Caregiver Coalition as a Board Member since 2011.



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#### **California Coalition for Caregivers (CCC)**

Burbank, California

Stefanie Elkins, M.A., M.M.

The vision of the California Caregiver Coalition (CCC) is that Caregivers and Care Recipients will have the best possible quality of care. CCC is dedicated to ensuring that caregivers' concerns are effectively recognized and addressed through advocacy, education and empowerment. The coalition's goals are threefold: (1) to advocate for caregiver-friendly policies and programs; (2) to increase public awareness of contributions and needs of

caregivers; and (3) to empower caregivers to mobilize and advocate on their own behalf.

#### **Recent Coalition Accomplishments**

The California Caregiver Coalition (CCC) has representation on the California Collaborative for Long Term Services and Supports which meets every Friday in Sacramento and via telephone. The collaborative discusses all long term care services with state officials, legislators and its members. This past year, CCC supported California Caregiver Resource Centers this past year for legislation AB 753 Lowenthal. This legislation updated the Caregiver Resource Center statuses to be more reflective of current practices of these vital community based services.

CCC leading membership organizations (Alzheimer's Association, Bet Tzedek, Caregiver Resource Centers, Caregiver Action Network, Leeza's Care Connection, Riverside County on Aging, USC Davis School) are active in the community in raising awareness on family caregiver issues.



#### **About Stefanie Elkins**

Stefanie Elkins has made it her personal and professional mission to empower and educate individuals to make a difference in their own lives and the lives of others. Over the last 8 years, she has worked on a local and national level for the Leeza Gibbons Memory Foundation and is currently the Program and Outreach Director for the two Leeza's Care Connection (free resource and support center for family caregivers) in Los Angeles. Stefanie has a Masters Degree in Management in Human Services and Masters Degree in Jewish Communal Service from Brandeis University and a BA in Social Relations from UC Riverside. She is also a Powerful Tools for Caregiver facilitator and is certified in Well Coaches Core training and completed Grief Specialist training. She has been part of the CA Coalition for Caregiver since 2007.

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**Caregiver Coalition of Northeast Florida**  
**<http://www.mycaregiverconnection.org>**  
Jacksonville, Florida  
Toulia Wootan, M.S.H.

In 2008, seeing the impact of limited resources and support on so many of our patient families and caregivers, Community Hospice took the lead in developing a program to reach family caregivers and increase their knowledge of available services and support, starting in Duval County. As we saw the need was greater than what we could address alone, we partnered with other local organizations serving seniors and caregivers to be more efficient and effective in reaching those outside of our care who needed help.

The Caregiver Coalition of Northeast Florida is comprised of seven Northeast Florida nonprofit organizations – Community Hospice of Northeast Florida, ElderSource, City of Jacksonville – Adult Services Division, Mayo Clinic Florida – Memory Disorders Clinic, Alzheimer's Association – Central and North Florida Chapter, The Age Well Institute at Baptist Health and Aging True. Coalition partner organizations serve family caregivers in Baker, Clay, Duval, Nassau and St. Johns counties. Community Hospice serves as the lead fiscal agent for the Coalition.

The mission is to promote awareness and knowledge of, sensitivity to and support for family caregiving in Northeast Florida. Its vision is that all family caregivers will have knowledge of and access to resources that support them and those in their care.

#### **Recent Coalition Accomplishments**

To date, the Coalition has implemented over 38 free Caring for the Caregiver workshops with the goal of providing Northeast Florida residents with caregiver training, support and education on pertinent topics from qualified speakers. Attendees learn about how to access community services and government resources, and find a supportive place to meet and share experiences with other caregivers.

Shortly after its inception, the Caregiver Coalition launched the “Caregiver Connections” newsletter for caregivers in the Jacksonville and surrounding area. Caregiver Coalition partners contribute valuable information on many aspects of the caregiver role every other month, as well as information on upcoming events and workshops. E-newsletters reach nearly 2,000 individuals, many of whom are previous workshop attendees. In addition, “hard copies” are mailed to individuals without regular Internet access. The print version has a circulation of 17,000.

The Caregiver Coalition held its inaugural Caregiver Expo on April 21, 2012. It was the first event of its kind in Northeast Florida. Strategically moving beyond the intent of the “Caring for the Caregiver” workshops, the Expo was a place where we were able to treat the caregiver. With over 600 attendees, we knew we had created something special for caregivers in our area. The 2013 Caregiver Expo had as many attendees. This day consisted of health screenings for the caregiver as well as many fun activities such as Zumba classes, massages, treats from area restaurants, hair styling, chocolate tastings, etc. Attendees enjoy a variety of activities designed to renew their spirits, ensure they get the support they need, and let them know they are not alone!

In addition, we have a “Caregiver Hotline” that is available for area caregivers. We receive many calls each week asking for assistance and resources. The Caregiver Coalition of Northeast Florida has made incredible progress in bringing together resources and developing services, support, and information to help caregivers and their loved ones in our community.

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#### **Caregiver Support Network of Ashland and Bayfield Counties**

Washburn, Wisconsin

Carrie Linder, Certified Social Worker

The Caregiver Support Network of Ashland and Bayfield County was organized as a result of community meetings held in 2000 that intended to identify community services available to assist families impacted by dementia. In 2001, the Caregiver Support Network was formalized as a collaborative group from Ashland and Bayfield Counties which would advocate for and support the role of all caregivers. The ultimate goal of the Network is to help ensure that caregivers will have the opportunity to live a quality life while taking care of the needs of their loved ones.

There are four specific objectives in activities and programs sponsored by the Network. They include:

- Compiling available caregiver resources.
- Securing new caregiver resources.
- Collaborating to maximize utilization of services.
- Provide and/or promote caregiver educational activities.

#### **Recent Coalition Accomplishments**

The Caregiver Support Network has planned and hosted an annual Caregiver Conference for the past 11 years. A wide variety of topics include working through grief, coping with depression, understanding dementia, understanding long term care supports, healthy eating, navigating Medicare, etc. The Caregiver Support Network also provides training on caregiver issues, including “Powerful Tools” trainings and “Final Affairs” Workshops to help caregivers and individuals with end-of-life planning and issues.

The Network recently hosted a caregiver town hall meeting, which included a panel presentation on current issues facing caregivers. The keynote speaker was former Wisconsin state Senator Robert Jauch. The meeting helped caregivers gain confidence in carrying out their roles and shed light on the issues surrounding caregiving for public officials. Proclamations recognizing caregivers have been brought forth to County Boards and local committees, raising awareness of the time, energy, and efforts caregivers have given to keep their loved ones safe and healthy. Knowledge regarding issues of caregiving and the workplace has slowly begun to take place in our region. Some employers have invited members of the coalition to their health fairs to share information and be available to working caregivers. Public officials are beginning to understand caregiving and the impact it has on the health and wellbeing of the community.

Because of our sparsely populated area (16 people per square mile) coupled with an overall lack of resources to serve caregivers formally, outreach and advocacy has assisted in the development and sustained importance of community organizations such as Faith in Action and CORE Community Resources (volunteer based nonprofit organizations) who have come to understand the significant need for supporting caregivers to prolong the need for publically funded long term care services.

#### **About Carrie Linder**



Carrie Linder has been the Aging and Disability Services Manager in Bayfield County, located in far northern Wisconsin, for ten years. Previous experience includes serving as the Nutrition Program Director for the Bad River Tribe and as Executive Director for the Ashland County Aging Unit. Throughout her career she has focused her areas of expertise on Older American’s Act programming, long-term care services, caregiver matters and most recently development of the county office of the Aging and Disability Resource Center of the North. She was one of the original organizers of the Caregiver Support Network, which has been working collaboratively supporting caregivers in the area for 13 years. Carrie has been married for 10 years and has a 4 year old son. Carrie is active in her community and serves as a volunteer Emergency Medical Technician for the Mason Area Ambulance Service. When not busy saving lives, she is busy chasing her 4 year old, kayaking Lake Superior and gardening.

## Advocating for Caregiving

### 8<sup>th</sup> Annual National Conference of Caregiving Coalitions

2014 Annual Conference of the American Society on Aging



**New Coalition!** Caregivers Respite  
<http://www.caregiversrespite.org>  
Memphis, Tennessee  
Janice Williams, R.N.



Caregiver's Respite was founded in November 2010 by Janice Williams, RN. The organization is devoted to the encouragement, education, and motivation of caregivers from all walks of life. Its goal is to help caregivers take better care of themselves as they take care of their loved ones. The organization accomplishes this mission through the Caregiver's Rest Conference, monthly support group meetings, and other services.

Janice started the Caregiver's Rest Conference out of her own experience of care-giving for her father. After moving from her role as daughter to caregiver for him she quickly learned how caring for a loved one can be so overwhelming. The conference is geared toward giving a caregiver a break. And after 8 conferences they are so excited about seeing caregivers, succeed by being more informed and taking better care of themselves.

In 2014 Caregiver's Respite launched the *Preparing to Care Campaign*. The campaign is geared toward caregivers to learn new things to help **them prepare and move forward** in taking care of their loved ones. The Care Campaign consists of 12 months of information and events to make sure that the caregiver is ready to meet the ever changing needs of the person that they are taking care of.

### Community Senior Services

Claremont, California

Angelika Pittet, AS, Q.D.C.P., DCPA



I was born in Neukirchen Vluyn, Germany and earned a BA in Physical Therapy at the University of Duesseldorf. I worked as a Physical Therapist in hospitals and privately in Switzerland before my move to San Francisco in 1990. In 2005, I moved to Southern California and enrolled at Chaffey College where I obtained my AS degree in Gerontology. I speak fluent German and French and I love to spend time following other countries' options for older adults with memory impairment. I also love spending time with my children and grandchildren

In 2007, I was hired as the Enrichment Center Coordinator for Community Senior Services. The Enrichment Center provides a safe and loving environment for memory impaired older adults. I also facilitate many support groups for families who are caregiving for loved ones, and I provide caregiver workshops that emphasize education on the stages of dementia to consumers and organizations that Community Senior Services works with. In 2012, I obtained my certificate as a Qualified Dementia Care Professional (Q.D.C.P.) and in 2013 I was promoted to Director of the Enrichment Center.

Our agency has several support groups for caregivers. In addition we work together with other agencies to educate caregivers. We also have created a "Yesteryear's Café" where caregivers and people affected by dementia come together and do enjoyable and meaningful activities together. Last year in November, we prepared emergency kits for isolated seniors in the City of Claremont. Those kits will help seniors to survive for 3 days in case a catastrophic event strikes. Last year, we also offered twice to the community a "Virtual Tour for Dementia" to let caregivers experience what it could mean to be affected by dementia. In our first tour we reached about 12 caregivers and in our second run we had over 40 caregivers attending.

# Advocating for Caregiving

## 8<sup>th</sup> Annual National Conference of Caregiving Coalitions

### 2014 Annual Conference of the American Society on Aging



#### Hawaii Family Caregiver Coalition (HFCC)

Honolulu, Hawaii

Leanne Clark-Shirley, Ph.D.

The Hawaii Family Caregiver Coalition (HFCC) is a volunteer-based organization that focuses on advocacy and educational outreach to Hawaii's growing family caregiver population. Coalition members and leadership represent state and county agencies, academic faculty members, not-for-profit and for-profit service providers, private businesses, retired professionals, and informal caregivers.

We are in our tenth year of publishing the annual Aging & Disability Issues guidebook for the state legislature, organizations, and citizens, and will host the tenth annual Caregiver Day at the state capital on March 25th, during which groups of advocates, family caregivers, and professionals in the aging and disability services field will meet one-on-one with lawmakers. In addition, we regularly sponsor speakers, resource fairs, and educational workshops for our coalition members and the larger community, often with co-sponsorship from other local organizations working to improve the lives of Hawaii's older adults, persons with disabilities, and those who care for them.

For the next two years, HFCC's priority focus area is on issues faced by employed caregivers. Specifically, we are developing strategies to reach out to and include Hawaii's business leaders and labor organizations in conversations about employees who are managing work and informal caregiving responsibilities. Throughout this initiative we hope to educate the business community on the challenges faced by employed caregivers, identify various ways that employers can assist their employees now and in the future, and promote incentives that encourage businesses to implement caregiver-friendly policies and practices.

#### Advocacy Work

Each winter, at the beginning of the legislative session, teams of HFCC members pay unscheduled visits to legislators at the State Capital to briefly discuss these priorities and leave behind written information. In early spring, HFCC publishes the Aging Issues booklet that highlights key caregiving statistics, public and private programs, services, and resources available to support family caregivers and care recipients, and personal stories of caregiving across the state. The release of the booklet coincides with HFCC's Annual Caregiver Day at the State Capital, which typically falls in late-March as legislation is moving into funding committees. Throughout the remainder of the year, HFCC members prepare and present testimony on family caregiving issues, and regularly participate in the Kupuna Caucus—a grassroots advocacy organization that meets at the Capitol to discuss issues critical to Hawaii's older population. These activities have provided information to decision-makers and the public for 9 years.

This year's legislative priorities include supporting continued development funding for Hawaii's Aging and Disability Resource Centers; restoring full funding to Kupuna Care—Hawaii's state-funded program to deliver home-and-community based long-term services and supports to elders; supporting a proposal for Paid Temporary Family Leave for employed caregivers; and supporting a bill mandating the inclusion and training of family caregivers in hospital discharge planning.



#### About Leanne Clark-Shirley

Leanne Clark-Shirley, Ph.D., is a social gerontologist and researcher at the University of Hawaii Center on Aging, and newly-appointed Board Member of the Hawaii Family Caregiver Coalition. Before coming to the University of Hawaii, she worked as an aging and long-term care policy researcher in the private sector, specializing in program evaluation projects for clients including the Centers for Medicare & Medicaid Services, Administration on Aging, and the Administration for Community Living. She has extensive education and experience in researching the continuum of long-term support services (LTSS) at the state and national level, and has expertise in socio-cultural aspects of aging, and formal and informal systems of care. Her dissertation examined work outcomes of registered nurses

who were engaged in family caregiving in addition to active employment as a nurse. She received her Ph.D. in Gerontology from the University of Maryland, Baltimore County in 2012, and also holds a Master of Gerontological Studies from Miami University in Oxford, Ohio.



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#### Ocean County Caregivers of New Jersey

<http://njcaregivers.org>

<https://www.facebook.com/OCCaregiverCoalition>

Trenton, New Jersey

Jessica Goldsmith-Barzilay, M.S.W.



Caregivers of New Jersey (CNJ) was formed in response to the growing number of caregivers within the state. With more than 1.1 million caregivers in the state, CNJ works to shed light on the mounting needs of caregivers and the increased need for support. CNJ works with all 9 NJ Caregiver Coalitions and is currently working to support the establishment of 3 new Caregiver Coalitions.

CNJ is the lead agency in the Ocean County Caregiver Coalition. The Coalition is a group of caregivers, family members and professionals who support and advocate countywide for caregivers in the aging, disability,

chronic illness and mental health communities. Ocean County NJ has more seniors per capita than any other county in the state and is 2<sup>nd</sup> as the county with the largest number of individuals with disabilities. Based on this, it is assumed that Ocean is the county in NJ with the largest number of caregivers. In addition, Ocean County caregivers were greatly impacted by, and still recovering from, Super Storm Sandy.

#### Recent Coalition Accomplishments

In January 2013 The Ocean County Caregiver Coalition held its 2<sup>nd</sup> annual Caregiver Awareness Night. This event was initially postponed due to Super Storm Sandy. Therefore, it was reconfigured to discuss caregiver resources in emergencies and entitled "Caregivers After the Storm." The 3<sup>rd</sup> annual Caregiver Awareness night was held in November 2013 and featured Deputy Commissioner of NJ Department of Human Services plus dozens of local resources for caregivers. In March 2013 the Coalition held a meeting dedicated to health and well-being for caregivers and care recipients. It was conducted to help educate providers on health and wellness resources in the community. This spring the Coalition will offer Mental Health First Aid to agencies in the Coalition-free of charge. MHFA is an 8 hour training designed to provide key skills to assist someone who may be developing an emotional problem, or experiencing a mental health crisis- which is seen so often in the caregiving population. The Ocean Coalition meets monthly and is proud to share that there has been at least 1 first time participant at every meeting since its inception.

#### About Jessica Goldsmith Barzilay

Jessica Goldsmith Barzilay, MSW is the Assistant Director of Caregivers of New Jersey. Jessica is a representative of both Caregivers of NJ and the Ocean County Caregiver Coalition. Jessica oversees operations and state contracts and develops grant funding. She has worked with individuals with intellectual and developmental disabilities and their caregivers for over 18 years. During that time she spearheaded the NJ Social Security Alliance and The NJ Get FIT Statewide Coalition. Her focus is on creating policies, infrastructure and programs that increase person centered opportunities for people of all abilities. Jessica also worked in the for-profit sector and has been an adjunct professor in the field of social welfare policy.



### **Outagamie Caregiver Coalition**

Appleton, Wisconsin

Susan Coyle, C.M.C., C.O.T.A.

The Outagamie Caregiver Coalition is a network of organizations dedicated to assisting people with identification as caregivers and providing needed support through comprehensive education and resources. The Coalition is just over three years old. Our vision has been to empower families and friends to care for their loved one and our mission is to provide support through education and resources.

### **Recent Accomplishments**

Some of the projects that the Outagamie Caregiver Coalition has done include:

- A marketing campaign for the area ADRC as the first stop in caregiving, in which tear-off tablets were developed and distributed to area clinics, hospitals, etc.
- Quarterly community presentations of AARP's *Prepare to Care* program, which provides materials and suggestions on gathering and communicating potential care information
- Quarterly community presentations about *Share the Care*, a program of coordinating care groups for persons in health crises
- Various community presentations by group members
- Collaborated with Occupational Therapy Assistant students from the local technical college on developing a "caregiver toolkit" that included basic information on resources, programs and services that could benefit caregivers. This "toolkit" was given out at an "Adult Care Resource Fair" that the students coordinated and the Coalition members took part in as resource vendors. We are elaborating on that same project this year by doing a larger distribution of the toolkits to community churches, offices, etc. Our Care Resource Fair this year will also include more active education components and will likely have speakers related to caregiving. This has been a win-win project that has helped the Coalition accomplish our goals of providing education and support for caregivers, and it has benefitted the OTA students by giving them valuable experience in planning a community service and education.

Sue is proud and passionate about her work with caregivers, and is thankful for the scholarship opportunity to be a part of the National Alliance for Caregiving Coalition's 8<sup>th</sup> National Conference.



### **About Sue Coyle**

Sue was a founding member three years ago of the Outagamie Caregiver Coalition in Appleton, Wisconsin and has been the chairperson of the group for the last two years. She has been integral in the formation of a team of professionals from the area who gather with the intent of providing programs and services to educate caregivers about programs, services, and resources to support them in their caregiving.

Sue has her own business as a Certified Geriatric Care Manager, *Coyle Care Management and Consulting, LLC*. She has worked all of her 30 plus years in serving Older Adults in some capacity. As an Occupational Therapy Assistant by background, she worked for about 15 years in rehabilitation, and then in many other aspects of Senior living such as independent living, assisted living, a coordinator of a dementia unit within a skilled nursing facility, and coordinator of community programs. Most all of these roles have involved assisting Older Adults and/or their caregivers to improve or maintain their optimum level of health, safety, and independence, and thus caregiving is near and dear to what she has always done in her career.

**Advocating for Caregiving**  
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**New Coalition!** The Senior Sage  
<http://www.theseniorsage.com>  
Henderson, Nevada  
Debbie Carroll



According to KSNV MyNews3.com on January 16, 2014, "A national report card from Families for Better Care (a nonprofit advocacy group) gave Nevada a grade of F. The report is now the focus of a state legislative committee that looks at senior issues in Nevada."

Because Nevada ranks at the absolute bottom I feel that our legislature is now receptive to helping families care for their seniors. Nevada's senior population is expected to double in the next 15 years and this will only add to the burden of caregivers in Nevada.

The Senior Sage was formed in 2013 to support caregivers in the Southern Nevada community and was a direct result of my personal experiences. My mom moved to Nevada to be closer to me and my family after the death of my father. Several months passed and initially I thought that mom was experiencing the stress of two major life events, moving and the death of her spouse. However, at a neurologist's appointment my mom and I heard the diagnosis of dementia and I was quickly thrust into the up and down world of caregiving.

Fast forward a few years, I was working full time as a Development Director for a nonprofit organization while caring for my family and my mom. I knew the community, and no one could tell me if there was an organization or group of people who could help me with hands on support for family caregivers. I joined an Alzheimer support group and learned all that I could to help myself and others cope with the disease. I found organizations in isolation that could offer me tidbits of information that helped me with my mom's care. However, my days were often disrupted trying to help her with doctor's appointments and her day to day needs, all while trying to juggle the needs of my family and work obligations. Ultimately I resigned from my full time job to care for my mom. When it became obvious that she could no longer remain in her home, I researched many options and chose an assisted living facility. Through the years I learned which rehab facilities were good, which doctors worked well with seniors, and how to navigate the insurance maze, as well as how to choose hospice care.

What I hear most often is that caregivers have no idea who to turn to for support, advocacy and help. I am currently not affiliated with a coalition, simply because Nevada doesn't appear to have one. However, I am interested in working with organizations and key individuals to help caregivers in Nevada start a coalition. Since receiving the scholarship to attend these conferences I have talked to many people who feel that a caregiver coalition would be invaluable to caregiving families in Nevada.



## About Our Sponsors



**The Archstone Foundation**  
**<http://www.archstone.org>**

The Archstone Foundation is a private foundation formed in 1985 through the conversion of a non-profit health maintenance organization, then known as FHP, Inc., to a for-profit corporation. The Foundation became a non-profit grant making organization focused on the broad issues of health and health care delivery through the endowment resulting from the conversion agreement between the State of California and the FHP Corporation.

From 1995-1996, the Foundation undertook an extensive assessment of its first 10 years, its mission and governance. Through this process the Archstone Foundation's Board of Directors determined that it should target the focus of the Foundation's work and concentrate exclusively on issues of aging. While aging has always been a part of the Foundation's work, the Board determined that a concentrated effort in a more limited number of areas would allow the Foundation to have a greater impact. In the years that have followed, the Archstone Foundation has taken a leadership role in the field of aging. It has also served a key role in building the capacity of Grantmakers in Aging and in encouraging other funders to partner with us in preparing society to meet the needs of an aging population.

After two decades of operation and over 800 grants, the Foundation's grant making commitment has surpassed the initial endowment with over \$86 million in grants awarded. The mission of the Archstone Foundation is to contribute toward the preparation of society in meeting the needs of an aging population.



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