The National Alliance for Caregiving

and

MetLife Foundation

present the

2009

National Family Caregiving Awards

Profiles of Awardees

July 21, 2009

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Acknowledgments

The National Alliance for Caregiving is grateful to MetLife Foundation for its generous support of the National Family Caregiving Awards during the past four years. MetLife Foundation’s commitment to family caregivers has made it possible to identify exemplary programs around the country that offer support to and educate the legions of family caregivers who provide the backbone of long-term care services in the United States.

The National Alliance for Caregiving is appreciative of the numerous non-profit community-based caregiving organizations throughout the United States that participated in this competition. The Alliance is very grateful of the time and energy invested in completing detailed applications that gave our reviewers a full appreciation for the important work to support family caregivers around the country. The Alliance commends all applicants for their tremendous efforts in responding to the diverse needs of caregivers in their communities through innovative and effective caregiving programs.

Background

Non-profit organizations, agencies, and universities from around the country applied for the awards in the categories of caregiver support and caregiver education, either as a small community (with a population of 100,000 or fewer) or a large community (100,001 or more). Their detailed applications addressed a number of questions and were judged in the following categories: innovation, effectiveness or impact, basis in research, diversity, and potential for replication or adaptability. Many outstanding applications were received and numerous innovative and effective programs were identified.

Six programs—three caregiver support programs and three caregiver education programs—and one program intended to meet the needs of older caregivers caring for adult children with disabilities were chosen to receive the 2009 National Family Caregiving Awards. Each award winning program is honored with $25,000 to enhance its caregiver support or educational efforts.

This booklet provides a description of each award winning program. In addition, detailed information about these programs is posted on the National Alliance for Caregiving’s web site at www.caregiving.org.
2009 National Family Caregiving Awards

**Caregiver Support Awards**

*SAGE Caregiver Program*
SAGE - Services and Advocacy for GLBT Elders
New York, New York

*Caring for Caregivers*
The Pro Bono Counseling Project
Baltimore, Maryland

*Caregivers Community Network*
James Madison University
Harrisonburg, Virginia

**Caregiver Education Awards**

*Alzheimer’s Recognition Award*
*Dementia Skills Training for the Home Caregiver*
The Copper Ridge Institute
affiliated with The Johns Hopkins School of Medicine
Sykesville, Maryland

*DARTS Workplace Eldercare Seminars*
DARTS
Minneapolis, Minnesota

*Cultural Diversity Recognition Award*
*Native Caring: A Conference to Learn, Connect and Share*
Community Action Program of East Central Oregon
Pendleton, Oregon

**Older Caregivers Caring for Adult Children with Disabilities Award**

*Future Care Planning Services*
Lifespan, Al Sigl Center and
The Arc of Monroe County
Rochester, New York

**Honorable Mention Awards**

*MemoryCare Caregiving Program*
MemoryCare
Asheville, North Carolina

*AFA Teens*
Alzheimer’s Foundation of America
New York, New York

*Caring for the Caregiver*
The Kennedy Center, Inc.
Trumbull, Connecticut
In the Category of Caregiver Support (Large Community)

SAGE Services and Advocacy for GLBT Elders
New York, New York

SAGE Caregiver Program

The SAGE Caregiver Program is the only program in the country specifically designed to meet the complete care and support needs of non-traditional LGBT caregivers who are often marginalized from mainstream service and support.

The SAGE Caregiver Program is the only program of its kind and scale that focuses on supporting lesbian, gay, bisexual and transgender (LGBT) caregivers. In response to the frequent absence of “traditional” family structures, members of the LGBT community often create “families of choice.” These families can include biologically-related individuals, but also life partners, ex-partners, neighbors and friends. As members of these “families of choice” age, LGBT individuals often take on caregiving responsibilities above and beyond what is typical outside the LGBT context. LGBT caregivers face a two-pronged problem: caregivers, in general, do not avail themselves of the support available to make their responsibilities more manageable; and LGBT caregivers often do not find a supportive environment in mainstream organizations. SAGE’s innovative caregiver program is the first to address both problems by conducting community-wide outreach to LGBT caregivers and offering a host of LGBT-tailored services and programs.

Among the services offered to anyone caring for an LGBT older adult or an LGBT person caring for someone 60+, caregivers in the program can access one-on-one and peer support and assistance from individual counseling and weekly support groups. Additionally, financial assistance is provided to both caregivers and care recipients through benefits and entitlement screenings, home health aide respite services, and supplemental assistance to alleviate short-term financial hardships, such as medical co-pays, grocery expenses, rent arrears and transportation costs (e.g., monthly subway card). To serve the needs of homebound LGBT older adults without caregiving support, the SAGE Caregiving Program includes a Friendly Visitor Program which matches volunteer caregivers with homebound clients. The Friendly Visitor Program also provides these volunteers with supportive services to best manage individual caregiving responsibilities.

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Caring for Caregivers links low-income, uninsured, and under-insured caregivers with licensed mental health professionals who donate their time and skills for families of persons with cancer, Alzheimer’s disease, and multiple sclerosis, disabled veterans, among others.

In Caring for Caregivers, the Pro Bono Counseling Project reaches out to inform and train staff and community members and send information packets to various referral sources including hospitals, hospices, specific programs that respond to those diagnosed with life-long and terminal illness, houses of worship, senior groups, and others to apprise them of the free, professional mental health care offered to low-income and often at risk caregivers.

Caring for Caregivers focuses on families who have someone diagnosed with cancer, Alzheimer’s or multiple sclerosis, loved ones of veterans returning from Iraq and Afghanistan with disabilities, seniors who are parenting their grandchildren as well as their disabled children and spouses. More than 1,400 psychologists, social workers, marriage and family therapists, nurse psychotherapists, psychiatrists and professional counselors throughout Maryland have volunteered to donate their time to Caring for Caregivers. Since 2007, 193 professionals have donated 1,512 hours by taking one case each year into their private practices at no cost.

The Pro Bono Counseling Project clinical staff members (a licensed clinical social worker and a licensed graduate professional counselor) conduct intake interviews, provide information and referral and respond to requests for care within one business day. This team discretely links each caregiver within seven to 10 days with a participating licensed and insured clinician in their community who has expertise in their specific need. There is never a waiting list or limit on number of sessions. Local cabs are provided to take caregivers to and from their appointments when necessary. Data are collected following linkage with the client during one, three and six month interviews and quarterly with the clinician. Caring for Caregivers includes marketing, training, information and referral, documentation and evaluation of outcomes.

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In the Category of Caregiver Support (Small Community)

James Madison University
Harrisonburg, Virginia

Caregivers Community Network

In conjunction with a university service learning course, Caregivers Community Network teaches students about caregiving and provides respite and companion care services to families caring for frail or disabled older adults in rural Virginia.

Caregivers Community Network (CCN) partners with James Madison University Department of Nursing faculty to offer information and in-home respite and companion services to family caregivers who live with and/or care for frail elders and persons with dementia in a four-county area in rural Virginia. Students in varied Health and Human Service majors enroll in an elective course, “Issues and Applications of Family Caregiving.” Each semester the staff, in conjunction with course faculty, train and supervise more than 60 students who each provide 45 contact hours of respite care, serving 50 families. In 2008 student dyads or community volunteers affiliating with CCN provided 3,836 hours of respite care or other services to 50 families.

Since CCN began in 2001, more than 780 students and volunteers and 179 families have engaged in 4,269 visits totaling 21,421 hours. During visits, students and older adults engage in activities chosen according to clients’ interests and abilities. Faculty and staff have developed evidence-based “Activity Toolkits” that include music, tactile stimulation, aromatherapy, and reminiscence activities that serve both to educate students and to provide structured activities for relationship building during respite visits. CCN staff members conduct intake assessments, coordinate and monitor student visits, and maintain regular contact with family caregivers.

Older adults and their caregivers, understanding that they are helping students to learn, are more likely to accept respite services. Students, in turn, form powerful intergenerational relationships and challenge rural families’ stereotypes of college students. In 2006 CCN received the Virginia Commonwealth Council on Aging Best Practices Award in the education category, affirming the effectiveness of CCN to simultaneously meet the needs of three groups: caregivers in need of respite, care recipients who benefit from fresh ideas and the stimulation of contact with enthusiastic young people, and students from many majors in need of intergenerational, “hands-on” learning experiences.

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In the Category of Caregiver Education (Large Community)

Recipient of the Alzheimer’s Recognition Award

The Copper Ridge Institute affiliated with
The Johns Hopkins University School of Medicine
Sykesville, Maryland

Dementia Skills Training for the Home Caregiver brings practical training, problem solving skills and support to caregivers where they are, at home, via the Internet or on a DVD.

The Copper Ridge Institute is a nonprofit organization that conducts research on, and education about, the care of people with Alzheimer’s disease and other memory-impairing disorders. The Institute, affiliated with The Johns Hopkins University School of Medicine, developed a model of care with an underlying philosophy that the remaining cognitive and functional capabilities of the person with dementia should be maximized with a proactive approach that adapts to the person’s changing abilities. The multidisciplinary approach to care focuses on providing the highest possible quality of life and support for both the person with Alzheimer’s disease and the caregiver.

The Dementia Skills Training for the Home Caregiver is an educational tool whose purpose is not only to impart information about Alzheimer’s disease, but also to teach the home caregiver successfully researched skills and best practices and to develop the caregiver’s ability to problem solve. The hour long program engages the caregiver as they meet the “video” family that is, just like them, facing Alzheimer’s disease with a loved one. During the experiences of visiting a doctor, learning about Alzheimer’s disease and its progression, involving an adult child, interacting with grandchildren, and seeing the struggles of life’s daily activities, the home caregiver learns that he/she is not alone.

The challenges that are universal to the Alzheimer’s caregiver are addressed in specific segments of the program, which can be revisited as many times as needed for clarification and increased understanding. Whether the caregiver is learning via the Internet or the DVD, access is not limited to a specific time or order. The program addresses challenges with bathing and dressing, eating, toileting, sleeping, wandering, hoarding, aggression, hallucinations and delusions, delirium, medication, and recreational activities. There is no embarrassment or need for denial, just straight forward information about the disease and coping strategies developed from fifteen years of clinical work, research and practice at the Copper Ridge Institute.

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**DARTS supports caregivers in the workplace with education and resources, brings confidence to the caregiver, payback to the employer, and a needed spotlight on aging and caregiving.**

DARTS has a 35-year history of providing practical services and resources to older adults and their families. DARTS launched caregiver support services and education efforts in the late 1980s that have evolved into a comprehensive menu of offerings, including *Workplace Eldercare Seminars (WES)*. Since 2001, DARTS has partnered with 50 employers to provide education and support to employed caregivers. More than 3,000 working caregivers have attended 174 seminars.

The purpose of our WES program is to build working caregivers’ resourcefulness, competence, and confidence, and assist employers in providing work-life balance for working caregivers. Theories of adult learning are applied to WES that value development of learners’ self-concept, experience, orientation to learning, and readiness and motivation to learn. Beyond the seminars are supplemental services attendees can access, including referral to other providers. Working caregivers who attend report improved coping, improved ability to provide care, and an increase in the length of time they think they can provide care.

It is effective to support caregivers where they work. Caregivers find co-workers with similar challenges, gain new perspectives, access resources, become more confident and balanced caregivers, and more loyal employees. Employers identify caregivers who may need support, learn to recognize work-life challenges, and discover that business goals can be realized by supporting working caregivers.

Because of DARTS’ aging and caregiving expertise and its complementary suite of caregiver services, businesses see WES as a credible source of education and DARTS as a worthy partner in community-based services. WES has successfully established linkages with businesses and positioned caregiving as a workplace issue, allowing DARTS to imagine new program opportunities. DARTS creates meaningful possibilities for caregivers by supporting them where they work and beyond.

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In the Category of Caregiver Education (Small Community)

Recipient of the Cultural Diversity Recognition Award

Community Action Program of East Central Oregon Pendleton, Oregon

Native Caring: A Conference to Learn, Connect and Share

The Native Caring training conference provides workshops and activities integrally tied to spiritual, physical, mental and social harmony, which are key elements of the Native value system of care.

In 2005, a statewide committee comprised of representatives from the nine Oregon tribes, Oregon State Unit on Aging, and Area Agencies on Aging was formed. The purpose is to provide coordination of Older Americans Act Title VI and III Caregiver services, develop guidelines and standards, and hold joint staff trainings. A major facet of the committee is the planning of an annual training conference for Native American caregivers.

Individually, the Tribes of Oregon lack the ability and resources to provide meaningful and culturally relevant training for caregivers within their own service area. By combining financial and staff resources, it became possible to provide an annual training conference for caregivers. Each conference is held at tribal owned facilities throughout the state. This allows the opportunity to honor traditions such as prayer in native languages, drumming and dancing, and native foods, and to showcase the host tribe to other participants.

Workshops and activities are carefully tailored to meet the cultural needs of the caregiver participants. Topics include Alzheimer’s/dementia, diabetes, heart health, nutrition, financial fraud, falls prevention, preparing to care, depression, elder abuse, grandparents raising grandchildren, end of life issues, self-care, money management, humor, communicating with health care providers, and more. Nearly all of the presenters provide time pro-bono and represent a number of associations, individuals and agencies including, but not limited to, AARP, American Cancer Society, American Diabetes Association, universities, Coop Extension Service, Attorney General’s office, Social Security Administration, health professionals, the Department of Justice and the American Red Cross. Limited tribal resources are thereby freed up to be used to provide scholarships, per diem and lodging for the participants. Attendees not only benefit from learning, but are given three days of respite away from their caregiving responsibilities. This innovative approach to caregiving now reaches beyond Oregon’s tribes, and has included attendance from tribes in Washington, Idaho, California and Nevada.

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Future Care Planning Services (FCPS), born out of the reality that people with disabilities are outliving their caregivers in record numbers, was established in May 2002 as a legal joint venture among Lifespan, Al Sigl Center and The Arc of Monroe County. The union between the aging and disabilities fields in FCPS is a model for the country. The disabilities field traditionally advocates from a civil rights determination perspective. They use language and service models that focus on self-determination and self-help, while the aging network has traditionally focused on the “helping” service model. By joining forces, this unique collaboration is able to provide transparent assistance for both the aging caregiver and the aging person with a disability.

FCPS provides comprehensive life care, legal and financial planning services through a letter of intent that assure peace of mind for the caregiver while providing choices and autonomy for the person with a disability. The staff of FCPS works with each family to explore all legal and financial planning options with the primary goal of insuring the security and safety of their loved one. Staff recognizes from vast experience that providing manuals and classes does not meet the needs of this unique target population of caregivers. Caregivers of adults with disabilities experience multiple barriers to planning including fear of their own mortality, lack of confidence in other people’s abilities to care for their adult child, and the stress of daily care giving.

FCPS serves families regardless of the disability or connection to the delivery service system. The bulk of work is done with individual families as well as comprehensive community and professional seminars in order to engage more caregivers by providing choice. FCPS provides a place where everything can be tied together: legal concerns, financial issues, and information about available home health care resources. FCPS serves as a road map for caregivers and provides a positive planning process to allow caregivers of adults with disabilities to see beyond today.

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Honorable Mention

MemoryCare
Asheville, North Carolina

MemoryCare Caregiving Programs

MemoryCare is an innovative charitable organization established in 2000 to serve families in western North Carolina caring for a loved one with Alzheimer’s disease or other type of dementia. The mission of the program is to assess and treat older adults with memory disorders, support caregivers with education, counseling, and improved access to services, and provide community education. The program’s unique approach integrates the care of the person who has dementia with that of his or her caregivers, providing caregivers with a fuller understanding and greater capability to manage their loved one’s dementia. MemoryCare maintains a caregiver library and website and provides education to students, professionals and community members.

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Honorable Mention

Alzheimer’s Foundation of America
New York, New York

AFA Teens

Since 2003, the Alzheimer’s Foundation of America AFA Teens for Alzheimer’s Awareness program has been informing teens about Alzheimer’s disease, especially targeting teen caregivers living in families affected by the disease. Embracing teenagers’ thirst for the Internet, AFA Teens is an Alzheimer’s disease-specific online resource offering direct interaction with teens. Its hallmark is the dedicated Web site that conveys educational information about the disease and tips for caregiving in the easy-to-read and practical language that teens need. The site includes a message board where teens share their feelings and concerns. AFA Teens also promotes and supports teen volunteerism at the community level and provides an annual scholarship awarded to the college-bound student whose essay best captures the impact of the disease on a teen’s life.

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The Caring for the Caregiver program is an innovative approach to the caregiving concept. Unlike traditional caregiver programs, where the caregiver is identified as the parent who looks after a son/daughter with special needs or disabilities, the “caregiver” is identified as the adult son/daughter with cognitive disabilities, who provides assistance in completing household chores for his or her elder family member over the age of 60. Individuals with disabilities receive comprehensive planning and assistance needed to become more independent and confident of their caregiving skills. The Caring for the Caregiver program is an alternative for parents who worry about the future of their family members, and their ability to live independently in their own home.

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The National Alliance for Caregiving is very appreciative of our Advisory Committee members and reviewers. Their task was enormous, and they served the project well, with commitment, tenacity, and wisdom.

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*Previous National Family Caregiving Award winners
2009 National Family Caregiving Awards

National Alliance for Caregiving
Member Organizations

AARP
ALS Association
Alzheimer's Association
Alzheimer's Foundation of America
American Academy of Home Care Physicians
American Association of Homes and Services for the Aging
American Geriatrics Society: Foundation for Health in Aging
American Occupational Therapy Association
American Psychological Association
American Red Cross
American Society on Aging
CareOptionsOnLine (NavGate Technologies)
Center for the Advancement of Health
Children of Aging Parents
Easter Seals
Evercare
Family Support Center
Genworth Financial
GlaxoSmithKline
Hamacher Resource Group, LLC
   The Caregivers Marketplace™
   The Caregivers Advisory Panel®
Healthcare Leadership Council
Home Instead Senior Care
Johnson & Johnson
LifeCare, Inc.
Lighthouse International
Lupus Foundation of America, Inc.
Mather LifeWays
MetLife Mature Market Institute
n4a (National Association of Area Agencies on Aging)
Nat'l Association of Chain Drug Stores Foundation
Nat'l Association of Professional Geriatric Care Managers
National Association of Social Workers
National Center on Caregiving (Family Caregiving Alliance)
National Council on Aging
National Hospice and Palliative Care Organization
National Multiple Sclerosis Society
Older Women's League
Paraprofessional Healthcare Institute, Inc.
Parkinson's Disease Foundation
Partnership for Caring, Inc.
Pfizer Inc.
U.S. Department of Veterans Affairs (DVA)
Verizon
Well Spouse Association
Women's Institute for a Secure Retirement (WISER)
Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations that focuses on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance’s mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

**MetLife Foundation**

MetLife Foundation was established in 1976 by MetLife to carry on its long-standing tradition of corporate contributions and community involvement. The Foundation has been involved in a variety of aging-related initiatives addressing issues of caregiving, intergenerational activities, mental fitness, health and wellness programs and civic involvement. More information about the Foundation is available at www.metlife.org.

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