News from the Alliance:

NAC is seeking Family Caregivers of Veterans for a New Study! This study will provide an opportunity for family caregivers of Veterans to be heard and to improve services for other caregivers of Veterans now and in the future. If you know of family caregivers of Veterans in your coalition, and they would like to take part in this study, please have them sign up at: www.gwsurvey.com/caregiversofveterans.html

The study will collect information through focus groups, telephone interviews, and an Internet survey of caregivers of Veterans. NAC is looking for caregivers to participate in the focus groups living in or near the following cities: San Diego, San Antonio, and Washington, D.C. Cash incentives will be available for study participants and Veterans who refer them. Information obtained from the focus groups, telephone interviews, and Internet survey will be completely confidential. The deadline to sign up for the focus groups is May 10, 2010. For more information, please contact Kathy Cameron at kathleen56@caregiving.org or 703-585-6607.

Applications are being accepted for the 2010 National Family Caregiving Awards Program! The request for applications is available online at: http://web.raffa.com/nac/caregiver_awards. Now in its fifth and final year, the program is intended to improve the quality of life for family caregivers by recognizing and supporting the important work of community agencies and other organizations that support family caregivers as a significant part of their mission.

Nine awards will be given in three categories: Caregiver Education Awards; Caregiver Support Awards; and Older Caregivers Caring for Adult Children with Disabilities. Each award will carry a cash value of $20,000 that will be designated for use in the awardees’ caregiver program. In addition, two special recognition awards will also be presented to award recipients that have already met the other criteria in the award category in which they have applied. The deadline for applications is May 7, 2010.

The details of the nine awards can be found in our Resources, Events and Opportunities section of the newsletter.

Gail Gibson Hunt
President & CEO
National Alliance for Caregiving
Coalition Updates

Fourth Annual Conference for Caregiving Coalitions
The Alliance hosted its Fourth National Conference for Caregiving Coalitions on March 15, 2010 at the Annual Conference of the American Society on Aging (ASA) and the National Council on Aging (NCOA). Over 150 people attended this event again this year and we would like to thank our sponsors for making this conference possible: Evercare, the Langeloth Foundation and Pfizer.

This half-day event discussed the recently released "Survey of the Economic Downturn and its Impact on Family Caregiving" and "Caregiving in the U.S. 2009".

U.S. Congresswoman Jan Schakowsky, a leading voice in health care reform and sponsor of the Retooling the Healthcare Workforce for an Aging America Act of 2009 also attended this event to discuss the importance of sustaining advocacy and coalition work during these tough economic times.

Two Coalition leaders from the NAC Advocacy Task Force presented during the conference, addressing how their Coalitions have sustained their advocacy efforts in this tough economy. To view these presentations please visit our website: www.caregiving.org and click on the Coalitions Tab.

Hawaii Family Caregiving Coalition
Hawai’i’s Family Caregiver Coalition has developed, Aging Issues, a guide for its Legislators, Organizations & Citizens. This guide addresses the impact of Hawai’i’s fiscal crisis, principles underlying aging policy and legislative decisions, personal stories, high priorities for the 2010 legislative session and information & resources. You can find this PDF online on NAC’s website: http://www.caregiving.org/coalition/Hawaii_Booklet_Aging_Issues_2010.pdf

Caregivers Coalition of Morris County, NJ
The Caregivers Coalition is hosting monthly meetings that are open to the public on family caregiving issues. These meetings are held on the second Wednesday of each month and center on topics such as:

- Balancing Work, Family and Caregiving
- Caring for Yourself: Why it’s Important & How to Find the Time to Do It
- Partnering with a Health Care Professional: Getting the Most out of a Doctor’s Visit
- Work/Life Balance

These are free, on-site workshops that are available to any community group, organization, or business. The meetings are facilitated by professionals in the field. For more information, contact Lori Rubin at 973.993.1160 ext 139.

KC4 Aging in Community Coalition
The KC4 Aging in Community Initiative is a coalition of individuals and community organizations determined to plan today for tomorrow’s aging Kansas City. This coalition focuses on five aspects of everyday life: civic engagement, housing, mobility, caregiving, health services and technology. This year, seniors in three targeted neighborhoods will begin telling the coalition what they consider to be the most important characteristics of an aging friendly community, what priorities to give to those characteristics, and strategies they want to see implemented to achieve them. For more information about this initiative, call the Center for Practical Bioethics at: 816-221-1100 or visit: www.practicalbioethics.org
Hastings, NE: South Central Town Hall Caregiver Coalition
SCTHC Coalition is hosting an informative resource fair for caregivers. Those who are caregivers for any age are encouraged to attend. This year’s speakers will focus on safety within the home, and mental and physical well-being. For questions or registration information please call: 1-800-955-9714

Upcoming CMS Quarterly Caregiving Conference Call: June 15, 2010 at 1pm EDT!
Call in number: 877-267-1577
PIN code # 118104

If you would like to share information about the creation of your caregiving coalition or other information about your coalition’s activities, please email Jordan Green: Jordan@caregiving.org

Legislative Update

Support for Caregivers in the Health Reform Law:
The historic health care legislation signed by the President on March 23 sets in motion sweeping measures to expand access to health insurance and institutes a number of health improvement, prevention and wellness initiatives—all in an effort to promote patient-centered care, particularly for individuals with multiple chronic care conditions.

For family caregivers, perhaps the most significant change for caregivers is the inclusion of the CLASS Act, legislation long championed by the late Senator Ted Kennedy. In simple terms the CLASS Act is a new voluntary long-term care insurance program for workers that provides a cash benefit to purchase caregiver services – perhaps to have someone help with meal preparation, grocery shopping, dressing, or even transportation. The intent of the program is to allow someone who is elderly, or disabled remain independent for a longer period of time. Financed through monthly premiums that will be paid on a voluntary basis through payroll deductions; working Americans will automatically be enrolled (beginning January 1, 2011) unless they opt out. After five years of contributing premiums into the program, individuals who become disabled will receive a cash benefit up at least $50 a day, depending on the degree of impairment. Most importantly, receiving benefits from the CLASS Act does not have any effect on eligibility for other government programs.

Caregivers are also consumers of health care, and the new health reform law (PL 111-148) provides a number of health reforms that will provide better access to care – through patient-centered care approaches, and through new insurance reforms. Approximately 9 million informal caregivers ages 19 to 64 report having health problems of their own, or report they cannot afford the health care they need. The Patient Protection and Affordable Care Act enacts a number of changes to make private health insurance more affordable through either an expansion of Medicaid services, or through high risk pools, and new insurance “exchanges” where consumers can compare insurance products. To make coverage affordable, the new law provides subsidies to purchase private insurance.
To support caregivers who rely on Medicaid services for their loved ones, the new law provides additional new incentives for states to offer more home and community based care. Right now there is a bias in the Medicaid program in favor of institutional care, rather than home and community-based care. Under the new law, that bias is reversed. Under a new program, the Community First Choice Option, States can elect to provide more home and community-based attendant services care.

The health reform law also creates numerous Medicare pilot programs aimed at helping patients and caregivers successfully negotiate the transition from a hospital stay to their homes or other care settings. It also provides new funding for a new program, called the Aging and Disability Resource Centers, which will provide information and assistance to caregivers and people with long-term care needs.

These are just a few examples of programs contained in the health reform law designed to help caregivers. There are many more, and that taken as a whole, these reforms will signal the beginning steps towards a system of care that emphasizes prevention, coordination, wellness, chronic care management, integration and patient-centered care. As this new law enters a new phase – implementation stage – the Alliance will shift our focus to working with regulators in the Department of Health and Humans Services and other federal agencies to ensure that regulators understand the vital role that family caregivers play in our health care system.

News, Reports and Publications

Who Are the Older Caregivers Caring for Older Loved Ones?
Drs. Donna Wagner and Emiko Takagi of Towson University reviewed data from the new national caregiver survey, Caregiving in the U.S., to examine trends and key findings for caregivers of persons 50+, with an emphasis on the older caregivers themselves. They also made selected comparisons with the 1997 and 2004 NAC/AARP surveys. Although each survey consists of a unique sample, there are questions that are consistent across the three surveys and an operational definition of “caregiver” that is used in the screening to ensure that respondents are representative of the same caregiving population.

Some findings with interesting policy and program implications:

- The percentage of older caregivers caring for individuals 85+ has increased across all three surveys, from approximately one-quarter of care recipients to one-third;
- Parent care is the primary caregiving situation for mid-life caregivers- 70% of caregivers between the ages of 50 and 64;
- While caring for a spouse continues to be the most commonly reported care situation for caregivers 75+, the 2009 study suggests that a substantial number of people in this age group are involved in caring for a friend or neighbor (20%), a parent (20%) or a sibling (18%). This new finding is likely a factor of older adults relying on peers for the help they need;
- Yet, caregivers themselves who are 75+ are most likely to report that they have no help from relatives, friends or other informal source—no peer support.

For a detailed look at the survey results, please visit the Health Affairs Blog: [http://healthaffairs.org/blog/2010/02/16/informal-caregiving-by-and-for-older-adults/](http://healthaffairs.org/blog/2010/02/16/informal-caregiving-by-and-for-older-adults/)
The Guided Care Program for Families and Friends: New Support for Caregivers of Medically Complex Patients
A new program developed at the Johns Hopkins Bloomberg School of Public Health has been shown to support family caregivers of older adults with complex health needs. Guided Care is a proactive, comprehensive health care model for people with several chronic health conditions. The Guided Care Program for Families and Friends (GCPFF), a component of Guided Care, seeks to improve the well-being of the family and friends who help care for the chronically ill. This program was tested in a two-year, randomized controlled trial (RCT) involving 49 physicians, 904 older patients and 308 family members in eight locations in the Baltimore-Washington, D.C. area.

The program seeks to improve both patients’ health and the well-being of their families and friends. Guided Care is a type of “medical home” in which the patient’s care is closely coordinated by a specially trained registered nurse, working as a team with the patient’s physician. The caregiver support model includes five elements for caregivers that are managed by the nurse:

- An initial one-on-one caregiver assessment
- Education and referrals to community resources
- Ongoing caregiver “coaching” and support
- Six 90-minute group caregiver workshop sessions
- Unstructured monthly support group meetings

For more information, please visit: [http://www.GuidedCare.org/caregiver.asp](http://www.GuidedCare.org/caregiver.asp)

National Law Journal: Cities offer legal shield to caregivers facing workplace bias
Caregiver bias is becoming such a problem that cities are passing their own laws to prevent employees from being penalized at work because of their duties at home. The report found that at least 63 local governments in 22 states—including Chicago, Atlanta and Boston—have passed anti-discrimination laws that go beyond state and federal statutes in protecting caregivers at work. The laws surveyed in the report recognize parental status, familial status or family responsibilities as a protected class for purposes of employment—similar to sex, race, and religion. Most call for administrative redress, fines or injunctive relief. Many allow for monetary awards, some including punitive damages and attorney fees. For more information, contact: Tresa Baldas at: tbaldas@alm.com

Office on Women’s Health: Existing Supports for Single Parent Caregivers
The Office on Women’s Health has a new literature review on their website regarding existing supports for single parent caregivers that was prepared by the Alliance. This literature review develops a profile of the single parent caregiver, identifies gaps and services offered, and makes recommendations for further research and awareness to this specific population. To view the review, visit: [http://www.womenshealth.gov/aging/caregiving](http://www.womenshealth.gov/aging/caregiving)

Rosalynn Carter Institute for Caregiving
The Rosalynn Carter Institute (RCI) has partnered with the Cyber University of Korea. In this project, RCI and Cyber University of Korea will work together to develop new curricula that will be taught both in the United States and in South Korea. The curriculum will build on the experiences of teaching in the United States. Each course will integrate a cross-cultural perspective, so that the entire curriculum approaches “caregiving” as a global challenge. We believe this will be the first international curriculum in caregiving. For more information, visit: [http://seoul.usembassy.gov/rok_032210.html](http://seoul.usembassy.gov/rok_032210.html)
Resources, Events and Opportunities

2010 National Family Caregiving Awards Program
Deadline for applications is May 7, 2010. The request for applications is available online at: http://web.raffa.com/nac/caregiver_awards

Each award will carry a cash value of $20,000 that will be designated for use in the awardees’ caregiver program. The award categories are:

• Caregiver Education Awards: Three awards will be given in the category of caregiver education. These awards will go to organizations that have developed exemplary training programs to educate caregivers on topics such as: assisting with activities of daily living, financial planning, time management, and caring for older adults with dementia.

• Caregiver Support Awards: Four awards will be given in the category of caregiver support. These awards will go to organizations that provide family caregiver support programs such as respite, counseling, or corporate eldercare in a truly innovative way.

• Older Caregivers Caring for Adult Children with Disabilities: Two awards will be given to non-profit organizations that have established an innovative and effective program to meet the needs of older persons caring for their adult children with disabilities. Potential programs could include counseling to plan for the future needs after the parent dies or innovative support programs to address the immediate needs of the older caregiver.

In addition, two special recognition awards will also be presented to award recipients that have already met the other criteria in the award category in which they have applied. One is the Alzheimer’s Recognition Award, which will be given to one of the above award recipients that innovatively support family caregivers of those with Alzheimer’s disease. The other is a Cultural Diversity Recognition Award, which will be given to one of the above award recipients that innovatively support family caregivers of diverse older adults.

The awards will be presented at a luncheon ceremony held at the National Association of Area Agencies on Aging (n4a) 35th Annual Conference and Tradeshow, which will take place in St. Louis, Missouri on July 20. Travel and hotel costs for an awardees’ representative to attend this event will be paid for by the National Family Caregiving Awards program. For additional information, contact Kathleen Cameron at: kathleen56@caregiving.org

Care for the Family Caregiver: A Place to Start
This wonderful resource has been updated by Emblem Health and the National Alliance for Caregiving. Family Caregiving presents considerable challenges-physical, emotional and economic. There is no reason to suffer in silence. If you take away one thing from this booklet it’s should be the fact that it’s always OK to seek and ask for help. Getting help can enable you to become a better caregiver. This booklet is designed to give family caregivers an overview of the basic aspects and issues involved with caregiving. It specifically looks at the following topics:
The caregiving journey, told through family caregiver stories;
The basics of family caregiving;
Caregiving tips;
Caregiver training;
Caring for yourself;
Legal and financial issues to consider;
Where to turn for help

To view this entire booklet, visit: www.caregiving.org on our homepage and also on our Resources Tab.

Campaign for Better Care
A new campaign aiming to focus health reform implementation on improving, coordinating care for vulnerable older adults launched on April 8, 2010. One of the new Campaign’s key goals is to build a consumer movement of and for older adults and individuals with multiple chronic conditions, who are counting on health reform to provide the patient-centered, comprehensive and coordinated care they need.

The Campaign’s policy agenda aims to ensure that the reformed health care system provides the comprehensive, coordinated, patient-and family-centered care that older adults and individuals with multiple health problems need. It will advocate for better ways of delivering care including effective care coordination, transition management, medication reconciliation, and support for patients and their family caregivers, and care that is culturally and linguistically appropriate. For more information, visit: www.CampaignForBetterCare.org

National Association of Councils on Developmental Disabilities
The 2010 Annual conference is taking place September 27-28 at the Renaissance Orlando in Florida. This year’s conference will celebrate State Councils on Developmental Disabilities progress they have made in advancing inclusion and integration of people with Disabilities and their families through: systems change, capacity building, and advocacy. For more information, visit: http://www.nacdd.org/site/home.aspx

If you would like to share information about the creation of your caregiving coalition or other information about your coalition’s activities, please email Jordan Green: Jordan@caregiving.org