



# National Alliance for Caregiving

A National Resource for Caregivers

## The Caregiving Connection The e-newsletter for Caregiving Coalitions

### March 2006

For those of you who were able to take part in our most recent conference call, sponsored by the Centers for Medicare and Medicaid Services, on January 18, 2006, we are pleased that you could join us and thank you for your participation.

For those unable to participate, we will recap the highlights of the call in this issue. We had an opportunity during the call to interview Igal Jellinek, who has successfully launched a caregiving coalition in New York City—and you know what they say about being able to make it in New York City! He has some useful advice for other coalitions and we want to share that with you.

We also want to share with you some very important initial statements on caregiving that came out of the White House Conference on Aging. The head of the Alliance, Gail Hunt, continues to serve on the Policy Committee for the WHCoA. During the call she summarized the Implementation Strategies related to caregiving that had been developed and prioritized by the delegates and reported on during the final day of the conference. The strategies represent the real work of the conference. They actually create pathways for implementing the Resolutions which are the goals for the next ten years.

We also want to tell you about a new caregiving awards program and direct you to a brand new website, [www.asaging.org/caregiver](http://www.asaging.org/caregiver), which has the details. You can link to it from our website, [www.caregiving.org](http://www.caregiving.org) by clicking on the description of the awards program. The awards website gives you the information you need in order to participate in our newly launched MetLife National Family Caregiving Awards Program. And we hope you will apply. The announcement is included here—but the details are on the website.

Finally, we have included a notice of a new program that could assist many individuals who lack prescription drug insurance and are not Medicare eligible with access to medications.

Our next phone call for the coalitions is scheduled for April 26 at 1 pm EST. We plan to have another successful coalition leader who will share the experience of starting a coalition and be ready to take your questions as well as ours. We'll remind you of this again.

### **INTERVIEW WITH IGAL JELLINEK, NEW YORK CITY CAREGIVING COALITION—HIGHLIGHTS**

We asked Igal to set the stage for us by describing his “day job” as head of a major aging services agency. He explained that the agency he directs, the Council of Senior Centers and Services of New York City, has been in place since 1979, includes 265 organizations, and serves 300,000 older adults. Its work focuses on three primary areas: advocacy, training and management support, and new initiatives. Direct services include case management, housing, and meals on wheels. The budget is \$1.2 million, 80 % of it private funding.

When asked about his history of working within a coalition, he said, “The only way to survive is as a coalition.” He went on to describe the starting point for him in the creation of this coalition as a combination of personal experience within his own family plus the realization that caregiving issues touch everyone and can serve as the catalyst to bring folks together.

How did he become interested in setting up a caregiving coalition? “Gail called!” Gail Hunt described for him the advocacy handbook under development by the Alliance and asked for an opportunity to test it in New York City. He agreed to do this through a coalition but did not want to do it on a “one shot” basis. He wanted to develop a structure for a collaborative long-term arrangement.

He began by sending letters to hospitals, nursing homes, and HMOs. This led to a natural alliance with HIP, the Health Insurance Plan of New York, an HMO. Gregory Johnson, the Director of caregiving programs at HIP, became a strong supporter, even offering meeting space and lunches for the group. Altogether 33 groups were invited and were interested though not all could participate. Included were the AAA, a university, the United Hospital Fund and other organizations.

There have been 5 meetings beginning in December 2004. The first was a focus group, used as a basis for a retreat that followed—using the advocacy guide and the services of Brian Duke, the Alliance’s trainer from Philadelphia and part of Philadelphia’s successful caregiving coalition. The coalition has had an additional 3 meetings on its own. Through the course of the meetings, a strong core group has developed—including the UHF, HIP, a government agency, a foundation, and an elder law attorney. The Alzheimer’s Association has also played a key role. It was decided early on to span all age groups of caregivers and care recipients—but to begin with a focus on aging.

The coalition has had a fabulous opportunity quite recently. The husband of one of the key members retired recently and was looking for a stimulating opportunity. Having had a successful career in the private sector and as the director of a large not-for-profit, he will be taking on the role of volunteer director of the coalition. He will shortly begin working on goals, objectives, and an action plan for the group.

Igal, whose agency will provide office space, said that his agency's role is that of an incubator, and will, at some point, spin this off. He expects that it could stand alone eventually. His goal is to witness its evolution.

How does New York City's experience translate into advice for other coalitions? Igal mentioned the need for patience, the need to look for opportunities for support that may not always be in the form of money, and the need for good luck. He also talked about the need for key actors in the group who are committed to the cause and have the perseverance to move forward. Another element: "The talent that abounds in all communities in this new wave of retirees—this is an untapped resource of truly valuable volunteers everywhere."

He also talked about the importance of timing. He was approached by someone else about a year before Gail contacted him. There was an interest but it was not the right time or the right set of circumstances. His advice to other emerging coalitions: don't give up—keep going back until the time is right.

He described the importance of the technical assistance offered by Gail and Brian Duke. The advocacy training was very valuable itself and the retreat enabled the core group to bond.

Other questions and answers:

- What are the benefits for him? Doing the right thing and trying to respond to a need.
- What about funding? Right now the coalition is in a developmental stage—once a plan is decided upon, then funding can be pursued.
- How about conflicts within the group? He hasn't seen that—"strong leadership reduces conflicts."
- Are there caregivers involved? Almost everyone in the room was a caregiver, including key members of the coalition.
- What motivates a supporting organization such as HIP? Its commitment to integrated wellness and an interest in caregiving.

**NOTE:** There will be an advocacy session led by Gail Hunt and Brian Duke, as well as Rick Greene from the Administration on Aging, at the ASA/NCOA Conference on Saturday, March 18, 2 to 4 pm, in Anaheim, CA—you, too, can take advantage of this resource for your coalition if you are attending the ASA/NCOA conference.

We plan to train caregiving coalitions, via webcast, using the advocacy guide. We will be looking for 3-4 coalitions for the pilot test. Watch the listserv for the announcement and plan to be a pilot site.

## **WHITE HOUSE CONFERENCE ON AGING AND CAREGIVING**

During the call, Gail Hunt briefly described the White House Conference on Aging and its role in charting the course in aging for the next ten years. Of the 75 resolutions presented to the 1200 delegates, 50 were voted the most important. Delegates then worked in small groups to reach agreement on the most significant strategies for implementing those resolutions. When the top strategies were presented, there were a number on caregiving:

### **WHCoA CAREGIVING STRATEGIES**

Delegates at the 2005 White House Conference on Aging developed many implementation strategies around caregiving and then gave their strongest support to the following. They may well serve as a foundation for local planning or state-level advocacy.

## **NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM (PART OF THE OLDER AMERICANS ACT)**

- Expand the program across the life span to cover caregivers of people of all ages
- Double the funding to \$324 million
- Define “family caregivers” to include friends and neighbors
- Expand the definition of “grandparents” caring for grandkids to include all types of relatives caring for dependent children
- Permanently authorize the Aging & Disability Resource Centers (ADRCs) to be supportive of family caregivers

## **A NATIONAL STRATEGY TO SUPPORT CAREGIVERS**

- Develop a national strategy for supporting family caregivers and ensuring that they have “fair working conditions,” including offering a range of financial and other incentives to encourage caregiving, such tax credits, affordable healthcare and early Medicare buy-in, public disability insurance, Social Security credits for time off work spent caregiving, and respite care equivalent to a two-week vacation.
- Promote services and resources for long-distance caregivers

## **A NATIONAL LONG-TERM CARE POLICY**

- Establish a national long-term care policy with the following key features:
  - A comprehensive consumer education program and incentives to plan ahead

A partnership that involves the private sector and all other stakeholders  
A comprehensive needs assessment for LTC consumers  
Information services that respect consumer choice  
An extensive network of support services for family caregivers

- For the sick and seriously disabled, offer a comprehensive package of coordinated long-term care services to enable the person to live independently as long as possible; these services include extensive caregiver support, housing, transportation, nutrition, medical care, etc.

## **SENIOR CENTERS**

- Create a distinct title in the Older Americans Act for multi-purpose senior centers which serve family caregivers along with older people.

## **CONGREGATE AND HOME-DELIVERED MEALS**

- Expand congregate and home-delivered meals and nutrition education, screening, assessment and counseling to family caregivers, where appropriate

## **KINSHIP CARE**

- Encourage state school boards and departments of education and human services to allow a relative caregiver without legal custody or guardianship to submit an affidavit to enroll child in school and to consent to medical treatment on his or her behalf.
- Ensure that government programs, including navigator programs, offer an array of services, such as legal, housing, healthcare, education, advocacy, counseling and respite.
- Culturally and socio-economically sensitive outreach and education directed at caregivers, as well as schools and the public
- Provide for adequate funding for “grand” families, including:
  - Title IVE foster care and for subsidized guardianship
  - Housing: support HUD, NAHASDA, and Legacy
  - Reauthorization of Indian Healthcare Improvement Act

Note: If you are interested in reviewing all of the highlighted implementation strategies presented to the delegates on the last day of the WHCoA: go to the website [www.whcoa.gov](http://www.whcoa.gov); scroll down to the 4<sup>th</sup> bullet, WHCoA Speakers and Presentations; under Speakers’ Remarks, scroll down to Wednesday, December 14, 2005; click on Implementation Strategy Highlight Report.

The draft WHCoA report will go to the governors in March and the final report will be released in June.

## MetLife NATIONAL FAMILY CAREGIVING AWARDS PROGRAM

The National Alliance for Caregiving and MetLife Foundation are pleased to announce a new national awards program focused on family caregiving. The goal of this program is to improve the quality of life of family caregivers by recognizing and supporting the efforts of not-for-profit community groups that work with them. The awards will recognize the work of community agencies and other organizations that support family caregivers as a significant part of their mission.

**The Award Categories** It is anticipated that there will be two awards in each of these three categories:

- Caregiver Education Awards will go to groups that have developed exemplary training programs to educate caregivers on topics such as: assisting with ADL needs, financial planning, time management, and others.
- Technology Awards will go to organizations that have developed and implemented innovative technology to support family caregivers or have adapted existing technology in a unique way to support the needs of family caregivers.
- Caregiver Support Awards will go to organizations that provide family caregiver support programs such as respite, counseling, or corporate eldercare in a truly innovative way.

### Details

- One award in each category will go to an organization working in a community with a population of 100,000 or less.
- The other award in each category will go to an organization working in a community with a population of 100,000 or greater.
- Each award will carry a cash value of \$25,000 that will be designated for use in the awardee's caregiver support program.

**NOTE: A special Alzheimer's Award (one of the six) will be given to an organization in either a large or small community that innovatively supports family caregivers of those with Alzheimer's disease—and meets the other criteria in the category in which they apply.**

The awards will be presented at a gala awards ceremony in November 2006 (National Family Caregiver Month) in Washington, DC.

**Applications for the awards can be submitted on a special website: [www.asaging.org/caregiver](http://www.asaging.org/caregiver). Go there directly or through a link on the website of the National Alliance for Caregiving—[www.caregiving.org](http://www.caregiving.org)— and learn more.**

## **Help the Uninsured Get a Quick Start on Rx Savings**

With the new quick start savings card from Together Rx Access, individuals who lack prescription drug coverage and are not eligible for Medicare don't have to wait to start saving on the medicines they need.

Individuals and families can determine if they qualify for the quick start savings card by calling 1-800-250-2839. If eligible, the card can be used at the pharmacy counter that day.

Most cardholders save 25% to 40% on their brand-name medicines with the free-to-get and free-to-use Card. The program includes more than 275 brand-name medicines and products, prescribed to treat diabetes, hypertension, high cholesterol, allergy, asthma, arthritis, and depression, and other common conditions. Savings on a range of generic medicines are also available.

Email Amy Niles at [amyniles@aol.com](mailto:amyniles@aol.com) to request a supply of quick start cards that you can distribute to those who may be eligible.

For more information about the program, go to [www.TogetherRxAccess.com](http://www.TogetherRxAccess.com).