



NATIONAL FAMILY CAREGIVERS ASSOCIATION

Respect
and
Resourcefulness

Fiscal 2011 Annual Report

JULY 2010 – JUNE 2011

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Letter From the Chairman of the Board and CEO

Dear Friends of the National Family Caregiver's Association:

Periodically, NFCA's board takes a look back to determine if what we've accomplished in the past has truly helped the organization work toward meeting our mission. It is an analytical view and the first step in the process of setting strategic goals for the future. Fiscal 2011 was such a year.



We've titled this annual report *Respect and Resourcefulness* to herald the new value statements NFCA put in place in fiscal 2011 as the first step in setting strategic goals for the future and a new brand image for NFCA. We took a hard look at the services we provide and the services that are offered by other family caregiver organizations and for-profit companies to get a clear view of what we excel at and what family caregiver needs are not currently being met by either NFCA or others. It was clear that no one was tackling the difficult challenge of providing hands-on help to family caregivers.

Fiscal 2011 was a big year for healthcare policy initiatives. With passage of the Patient Protection and Affordable Care Act (ACA), advocacy efforts turned toward making sure that the regulations that would guide the implementation of the ACA would be patient and family friendly, and NFCA committed itself to explaining to family caregivers how the ACA impacted them. We were asked to make a presentation to the Institute of Medicine on the role of family caregivers in chronic illness care. This presentation helped a work group looking at how the public health service could better support those with chronic conditions. NFCA's name has become synonymous with authenticity in understanding and addressing family caregiver issues. Calls for our input increased, as did requests for our involvement with coalitions.

Both within and beyond the family caregiving community, respect for NFCA has grown and we have had to be resourceful in managing the work that comes from an enhanced reputation. We could not have done it all without the commitment of our board of directors, volunteers, and staff, and we are grateful for all of the effort and enthusiasm these individuals bring to their work.

Sincerely,

Jim Paglia
Chairman

Suzanne Mintz
President and CEO

NFCA Board of Directors

OFFICERS

Jim Paglia, Chairperson

CEO/President (Owner)
In's & Out's, Inc.
Chesterton, IN

Andrea Cohen, Secretary

Co-Founder and CEO
HouseWorks
Boston, MA

Elizabeth Pearson, Treasurer

President, Managing Attorney
Pearson & Bernard PSC
Covington, KY

DIRECTORS

Eric Berger, Director

CEO
Home Health Advocacy Coalition
Washington, DC

Hal Chapel, Director

CEO and Co-Founder
Lotsa Helping Hands
Sudbury, MA

Cheri Lattimer, Director

President
CMI
Little Rock, AR

Suzanne Mintz, President and CEO

National Family Caregivers Association
Kensington, MD

Dean Stephens, Director

President/COO
Healthline Networks, Inc.
San Francisco, CA

Click here for additional information about the members of NFCA's board:

http://www.thefamilycaregiver.org/about_nfca/board_and_staff.cfm

Honorary Board and Staff

HONORARY BOARD MEMBERS

In addition to our voting board, NFCA's honorary board includes:

Senator Charles Grassley (R-IA)

Senator Barbara Mikulski (D-MD)

Irene Pollin, MSW – Founder/Chairman
Sister to Sister: The Women's Heart Health Foundation

Senator Olympia Snowe (R-ME)

Judy Woodruff – Senior Correspondent for “The News Hour with Jim Lehrer”

Dana Reeve – (Deceased) Honorary Board Member 2000 - 2006

SPECIAL ADVISOR

Cynthia (Cindy) Fowler, NFCA Co-Founder
Vice President, Graves Fowler Creative
Sacramento, CA

FULL-TIME STAFF

Suzanne Mintz, President and CEO

Lisa Winstel, Chief Operating Officer

Christal Willingham, Director of Finance and Program Administration

Judy Barlas, Member Relations Specialist

Elizabeth Fernandez, Administrative Specialist

Mark Gibbons, Executive Assistant

CONTRACTORS

Joni Blymire, Graphic Designer

Sandy Rogers, Newsletter Managing Editor

Vision, Mission, and Values

Vision

NFCA envisions an America in which family caregivers lead full and productive lives, free from depression, pain, isolation, and financial distress.

Mission

NFCA empowers family caregivers to act on behalf of themselves and their loved ones, and to remove barriers to health and well-being.

Values

- *Authenticity*
- *Community*
- *Empowerment*
- *Advocacy*

In fiscal 2011, NFCA began a process to determine how best to position the organization to enable us to make significant strides toward meeting our mission in the years ahead. Although this strategic process is still under way, the board has agreed on a restated set of values to underpin the organization's work.

The board realized that NFCA's longstanding values of Authenticity, Community, Empowerment, and Advocacy are about the character and work that NFCA does. Although these are still extremely important, it was necessary to redefine our values in terms of what we hope will happen for family caregivers.

Before year's end, the board voted on just two words to capture all that we want for family caregivers: *Respect and Resourcefulness*. These words represent what the organization will work toward in helping family caregivers individually and collectively. They will set the tone for all of our future work.

Report on Programs

Family Caregiver Educational Webinars

The National Association of Chain Drug Stores (NACDS) Foundation granted funds to NFCA to create on-demand* versions of the organization's two proven health education programs; and Allsup supported the development of a new educational program on financial planning for family caregivers:

- **Communicating Effectively With Healthcare Professionals**
“Communicating Effectively” discusses how to be prepared for doctors’ office visits and how to present yourself in ways that garner the respect of medical professionals. It teaches a family caregiver how to create a patient file, what to do in the ER, and more.
- **Safe & Sound: How to Prevent Medication Mishaps**
“Safe & Sound” focuses on the Who, What, Where, When, and Why of medication management to show family caregivers how to increase their loved ones’ adherence to medical treatment, and to prevent medication errors or unnecessary visits to the ER.
- **Financial Planning Options for Caregivers**
Allsup, with NFCA’s assistance, created a webinar and tool kit to help family caregivers understand the best ways to deal with their parents’ finances. This live event was held on February 24, 2011. At year’s end, work was under way to provide this program in on-demand format.

**The flexibility afforded by on-demand programming allows employees to take advantage of these valuable programs at times that are convenient to them. As a trial run before broader distribution, Easter Seals and sanofi-aventis have agreed to provide the on-demand version of “Communicating Effectively” to their employees. The program will be available for their viewing at the beginning of fiscal 2012.*

Education

VA Family Caregiver Program

NFCA worked on the implementation of the family caregiver components of the *Caregivers and Veterans Omnibus Health Services Act of 2010*. The new law provides the family caregivers of veterans of the Iraq and Afghanistan wars with training, counseling, supportive services, and a living stipend. It also provides healthcare to the caregivers of injured veterans.

NFCA worked on two projects related to the implementation of the new law:

- A new Web site for family caregivers: www.caregiver.va.gov. The site gives family caregivers access to a toolbox of information, resources, connections to other caregivers, and a support line. NFCA provided some content for the site and reviewed information developed by others to ensure the information would resonate with a family caregiver audience.

Broad-based education and training curriculum:

- The family caregiver training curriculum teaches caregivers how to obtain community resources such as legal assistance, financial support, housing assistance, home-delivered meals, and spiritual support. In addition, caregivers are taught skills such as time management techniques, medication management, communication skills with the medical staff and the veteran, and ways to take better care of themselves. NFCA wrote two of the modules: advocacy and caregiver self-care. In addition, we assisted with recruitment of family caregivers for the program.

Tool Kit

- NFCA introduced, with corporate partner Eisai, a new print 2011 Calendar and Educational Tool Kit for members. Thirty-five thousand copies were mailed out directly to NFCA members. The tool kit contained “how to” information drawn from NFCA’s *Education and Empowerment Series* as well as a 2011 calendar caregivers could use to keep track of medical visits and related information.

Education *continued*

Newsletter

TAKE CARE!

Fiscal 2011 was the first full year for the electronic version of *TAKE CARE!* The online format provides us with data, including what types of articles are of the most interest to our members, and it enables us to receive actual feedback from readers. The print version of the newsletter is still available at the nominal rate of \$10.00 per year.

Some of the topics covered in fiscal 2011 were:

- Making Decisions During a Crisis
- Where Do You Hold Your Tension?
- Budgeting 101: Simple Steps to Take Control
- Identifying the Out-of-Pocket Costs of Caregiving
- Tax Tips for Family Caregivers
- Faith Communities Can Help Family Caregivers
- The Face of Family Caregiving in America
- The New Healthcare Law: A Broad Overview of Its Family Caregiver-Friendly Components
- Understanding Social Security Disability: Does Your Loved One Qualify?



E-Letter

As with the electronic newsletter, our monthly e-letter provides hyperlinks so that readers can learn more about a particular topic; and, of course, it allows for more timely information than *TAKE CARE!* (which is published quarterly). The e-letter alerts family caregivers to articles of interest, connects them to resources, and provides information about what is happening at the federal level that will impact them. The monthly e-letter is distributed to 16,000 individuals, the majority of whom are family caregivers.

Partnerships and Publications

In the spring and summer of 2011, NFCA partnered with the Cancer Support Community (CSC) and other organizations to develop a free booklet for long-distance cancer caregivers. The 40-page booklet provides information on how to care for a loved one with cancer from afar at different stages of the disease, relationships, and practical matters. It is available through the Cancer Support Community.

Education *continued*

NFCA Reach

It is one thing to create programs and educational materials; it is another thing for people to learn about them. During fiscal 2011, NFCA had a strong reach via our Web site and the media. NFCA's Web site averages 26,000 unique visitors per month with 82,000 page views. In an average month, visitors download nearly 12,000 documents from NFCA. Each month, 3,500 people log into the Family Caregiver Forum, with another 3,500 visitors viewing the forum. Altogether, on a typical day there are 1,500 message views.

In order to gauge our reach, NFCA employs a media monitoring service to track media exposure. During fiscal 2011, NFCA earned an average potential viewership per month of 85,535,858. The organization was specifically mentioned or featured in an average of 58 articles or media stories per month, and NFCA has appeared in an average of 52 media markets each month, sometimes appearing in as many as 91 markets in one month. *USA Today*, *The New York Times* and the *Huffington Post*, among others, had stories mentioning NFCA.

Building Community

Feeling isolated is one of the most frequently mentioned stressors for family caregivers. NFCA continued to help caregivers share their stories with others, find pen pals, discuss their concerns, and connect with NFCA volunteers.

Story Project

Many family caregivers are hesitant to speak up or share their feelings for fear of being misunderstood and/or admonished. However, speaking up is one of the best ways to reduce feelings of isolation and to relieve pent-up emotions. It is also a great way to learn from others and introduce shared ideas that can make life easier for families. *The National Family Caregiver Story Project* offers family caregivers a platform to both share their stories and to read other family caregiving experiences through this Web site. This year we were able to collect stories that spoke of caregivers' difficulties in navigating the healthcare system.

http://www.thefamilycaregiver.org/connecting_caregivers/the_caregiver_story_project.cfm

Building Community *continued*

Caregiver Community Action Network (CCAN)

The purpose of CCAN is to bring NFCA closer to family caregivers by giving them access to other family caregivers (current or past) closer to home. CCAN added five new members in fiscal 2011 for a total of 116 representatives in 41 states. CCAN volunteers participated in a number of important activities and helped more than 2,000 family caregivers meet their individual needs.

Bonnie Danowski from Arizona spoke at the National Respite Coalition Conference in Washington, D.C., and, at year's end, she and fellow Scottsdale-based CCAN member Lois von Halle were busy helping to plan the 2012 conference, which will be held in Phoenix.

Policy/Advocacy

Impacting Public Policy: Affordable Care Act (ACA)

Shortly after passage of the *Affordable Care Act* of 2010, NFCA did a search to determine where family caregivers were mentioned and found 15 sections that included referrals to family caregivers. The ensuing document creates context for understanding these provisions and has been distributed widely. It has also served as the basis for a number of presentations to various audiences, including family caregivers, professionals working with family caregivers, government agencies, and businesses. To read the document, click [here](#). In addition, NFCA published a number of articles explaining the ACA to family caregivers. These articles were published in NFCA's newsletter *TAKE CARE!* and can be viewed at: http://nfca.typepad.com/takecare_summer_2010/family-caregiver-mentions-in-the-affordable-care-act.html

Promoting Support for Family Caregivers

Throughout fiscal 2011, NFCA's influence was apparent as representatives of the organization attended briefings at the White House, spoke to the media, and worked with several coalitions as the "caregiver watchdog" to ensure that the caregiver's voice was heard with respect to the implementation of Centers for Medicare & Medicaid Services (CMS) regulations. Coalitions included the Partnership to Fight Chronic Disease, the Partnership for Women and Families, the National Transitions of Care Coalition, the Future of Nursing, and Leaders Engaged in Alzheimer's Disease.

Policy/Advocacy *continued*

Family Caregiver Finances Project

While advocacy groups and researchers alike have suggested different ways to ease the financial burden of caregiving, there haven't been any careful studies or comparative analyses to determine the most fruitful ways to address this pervasive problem.

In fiscal 2011, NFCA, in partnership with the National Multiple Sclerosis Society, the National Alliance for Caregiving, Easter Seals, and the health policy journal *Health Affairs*, agreed to explore this topic. While *Health Affairs* can't guarantee that an article based on the research will be published, such an article will be given serious consideration. *Health Affairs* will host a forum to present the findings of the comparative analysis to policymakers and advocates.

Susan Dentzer, editor-in-chief of *Health Affairs*, will be the host of the first forum on the financial problems faced by family caregivers. Although a firm date for the publication of an article and the forum has not been set, the target date is November 2012.

Special Projects – Research

In fiscal 2011, NFCA embarked on several research projects, including one to survey our members and another to understand the impact of Alzheimer's disease on family caregivers.

Market Research Survey of NFCA Members

- With support from our Corporate Leadership Council partner Allsup, NFCA surveyed online members to better understand their needs, their thoughts, and what potential new services from NFCA they would find helpful.

As the fiscal year ended, NFCA received some of the preliminary data, which provided us with some very interesting insights, including:

Special Projects – Research

continued

NFCA’s members are “high-burden” family caregivers, meaning they are providing care to loved ones with multiple needs who require help with a significant number of both the incidental activities of daily living (IADLs) — medication management, transportation, shopping and cooking — as well as the functional activities of daily living (ADLs) — transferring, toileting, dressing, and feeding. They are a microcosm of the population of family caregivers and they are the ones who need the most help and support.

What is most gratifying about the survey results so far is that it appears that NFCA members have absorbed our message to “Protect Your Health.” They note that their number two concern is the impact of caregiving on their own health. Given that the majority of family caregivers think about their own health as an afterthought at best, it is good news indeed that NFCA members recognize the importance of this message. In addition, NFCA was recognized as our survey respondents’ most trusted source for caregiving information.

A Profile of NFCA Members

On average, NFCA family caregivers:

- Care for loved ones across the life span
 - 42% care for a parent
 - 36% care for a spouse
 - 14% care for a child
- 69% are in their middle years – age 45 – 64
- 48% are employed full or part time
- 65% have household incomes under \$60,000
- 33% care for loved ones whose conditions severely limit their ability to care for themselves, such as Alzheimer’s, Parkinson’s disease, muscular dystrophy, or spinal cord or brain injury, etc.

Alzheimer’s Disease Caregiver Survey

With funding from Forest Laboratories, NFCA conducted a survey on the communication problems experienced by Alzheimer’s family caregivers as their loved ones’ cognitive abilities deteriorate. The survey found that what family caregivers fear most, after health and physical decline in their loved ones, is their loved ones’ progressive inability to communicate day-to-day needs and concerns. The complete results of the survey will be made public in the fall.

National Family Caregivers Month

NFC Month: 10th Anniversary of the Enactment of the National Family Caregiver Support Program (NFCSP)

“No matter how good community-based programs are, no matter how family friendly our healthcare system becomes, and no matter if there is meaningful financial assistance available, on a day-to-day basis, caregivers still need help when taking care of the details of life.”

~ Assistant Secretary for Aging Kathy Greenlee at the celebration of the 10th anniversary of the passage of the National Family Caregiver Support Program

The Administration on Aging (AoA) hosted a public event to celebrate the passage of the NFCSP legislation in 2000. NFCA was a key partner in planning the program and worked with AoA to design the celebratory event. More than half a million family caregivers from all across the country have since received respite; resource information; help in accessing services, support and training; and, at times, specialized assistance.

The event included a speaker from the White House and an award was given to Jeanette Takamora, the assistant secretary of aging who helped design the legislation and get it passed. NFCA's president and CEO participated in a panel of family caregiver leaders, all of whom had been involved in supporting the legislation.



Future Goals

Rebranding NFCA

As noted earlier, NFCA's board and staff began the hard work of looking at the organization with fresh eyes to develop a strategic direction that clearly meets the needs of family caregivers now and in the foreseeable future, and that builds a reputation for the organization that sets us apart from others working in the "caregiver space." This rebranding work will be completed in fiscal 2012 and will culminate in the creation of a new name, a new look, and a new Web site.

Thematic Goals for Fiscal 2012

Create Resourceful Caregivers

Serve an increasing number of family caregivers an expanding, rich amount of practical help, support and information.

Reduce Caregiver Stress

Improve the quality of life for family caregivers by reducing their day-to-day stress and financial distress.

Create Respect for Family Caregivers

Advance the case for family caregiver recognition and support.

Create Capable Caregivers

Build family caregiver confidence and capability through the dissemination of educational programs that demonstrate a positive impact on the lives of family caregivers.

New Board Members and Corporate Partners

NFCA added two new board members in fiscal 2011: Dean Stephens and Cheri Lattimer



***About Dean Stephens:
President and COO, Healthline***

Dean Stephens is president and COO of Healthline, an online portal for health information. Its taxonomy-based search engine makes Healthline an extremely user-friendly portal that has attracted clients such as: Merck, Tenet Health Systems, PacifiCare, and, most recently, Yahoo. Prior to Healthline, Dean spent 13 years at Deloitte Consulting, where he was the partner in charge of the customer relationship management service line for Deloitte's world-renowned healthcare practice. Dean has degrees from Dartmouth College and the University of Washington.

About Cheri A. Lattimer, RN, BSN: President & CEO, CMI

Cheri Lattimer is the president and CEO of CMI, an innovative consulting and management company providing outsourcing and advisory services to the care management and healthcare industries. She serves as the executive director of the Case Management Society of America, the executive director of the Case Management Foundation, and the coalition director for the National Transitions of Care Coalition. She serves on several national boards and committees, URAC, Roundtable on Critical Care Policy, and participates on several of the Society of Hospital Medicine advisory committees: Diabetes, Hospital Collaborative Care and Better Outcomes for Older Adults Through Safe Transitions.



Corporate Leadership Council (CLC)

The NFCA's Corporate Leadership Council met in Washington, D.C., on November 17, 2010, and again on June 21, 2011, at the request of members. The purpose of these meetings is to provide members with a deeper understanding of family caregiving issues of interest to NFCA and CLC members, and to brainstorm solutions. Member companies are diverse and come from a number of different industries, all of which have an interest in family caregivers, including: pharmaceuticals, home care, pharmacy, education, patient advocacy and more. To view a complete list of NFCA Corporate Leadership Council members, click [here](#).

Financials – FY 2011

Fiscal 2011 financials will be posted upon the completion of our audit.