



NATIONAL FAMILY CAREGIVERS ASSOCIATION

*A year of*  
growth  
and  
change

Fiscal 2010 Annual Report

JULY 2009 – JUNE 2010

# Table of Contents

1	Letter From the Chairman of the Board and CEO
2	Board of Directors
3	Honorary Board and Staff
4	Vision, Mission, and Values
5	Overview
6	Report on Programs
7	Education
9	Building Community
10	Advocacy
11	NFC Month
12	Growth and Change at NFCA
14	Summary
15	Financials for 2010

# Letter From the Chairman of the Board and CEO



Family caregiving as an issue that affects virtually all of us and that has huge ramifications for healthcare delivery and public policy reached the “tipping point” during fiscal year 2010. You need look no further than the passage of the Patient Protection and Affordable Care Act (Affordable Care Act) — its commitment to patient-centered care and the major changes it’s bringing to the treatment of chronic conditions — to know this is true.

As the year dawned, there was no way to know that this would happen, but the NFCA board and staff have seen our issues moving ever closer to capturing the attention of the public and government for some time now. Several years ago, we began planning both to build our capacity to move the tipping point over the edge and also to expand awareness of NFCA as a key player in supporting family caregivers and moving policy. That planning and forethought have helped us immeasurably in the past year by allowing us to grow and positioning us for even stronger growth in the coming year and beyond. Three factors made this happen:

1. The addition of two employees, a COO and an executive assistant, following on the heels of hiring a director of marketing and development at the very end of fiscal 2009.
2. The establishment of a Corporate Leadership Council based squarely on a value proposition crafted for each individual member.
3. A truly engaged board committed to its own expansion and achievements.

The following pages report on our activities and achievements during fiscal year 2010, none of which would exist without the commitment of our members, volunteers, staff, and you. Thank you for helping to advance our mission to empower family caregivers and to remove the barriers to good health and quality of life for all family caregivers.

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

**Jonathan (Jon) Shanfield, Treasurer**

Vice President  
Chevy Chase Bank, FSB  
Bethesda, MD

## DIRECTORS

**Eric Berger, Director**

Senior Vice President, Public Policy and Communications  
DaVita, Inc.  
Washington, DC

**Hal Chapel, Director**

CEO and Co-Founder  
Lotsa Helping Hands  
Sudbury, MA

**Suzanne Mintz, President and CEO**

National Family Caregivers Association  
Kensington, MD

**Elizabeth Pearson**

President, Managing Attorney  
Pearson & Bernard PSC  
Covington, KY

**Eve Stern**

Co-CEO and President  
SNAPforSeniors  
Seattle, WA

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

[http://www.thefamilycaregiver.org/about\\_nfca/board\\_and\\_staff.cfm](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 NewsHour 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

**David Schulbaum**, Director of Marketing and Development

**Judy Barlas**, Member Relations Specialist

**Elizabeth Fernandez**, Administrative Specialist

**Mark Gibbons**, Executive Assistant

## PART-TIME STAFF

**Deborah Halpern**, Director of Communications

**Stephen McMahon**, Grant Writer and Director of Programs

**Sandy Rogers**, Newsletter Managing Editor

**Brooks Kenny**, Strategic Advisor, Corporate Relations

# Vision, Mission, and Values

## Vision

*NFCA envisions an American 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*

# Overview

Fiscal 2010 was a transformative year for NFCA. We added two new staff members: a chief operating officer and an executive assistant. In the process, we transformed the way we operate and view our future. Our newfound capacity and skill sets can be seen in everything from our internal operations to our external visibility. We developed new programs, built new partnerships, and participated in the public debate more than ever before.

Among our biggest accomplishments are:

- Influencing the substance and passage of the Patient Protection and Affordable Care Act of 2010 and the Caregiver and Veterans Health Services Act of 2009
- Development and hosting of a new educational webinar for family caregivers: *Safe & Sound: How to Prevent Medication Mishaps*
- Development of a new delivery mechanism for our highly touted educational program, *Communicating Effectively with Healthcare Professionals*, so it can be readily accessible to employed family caregivers
- Development of a new member benefit: The Family Caregiver Tool Kit and Savings Book
- The evolution of *TAKE CARE!* from an all-print publication to one that is now available electronically
- Strategic planning for a new volunteer service (still to be named) that will bring hands-on practical help to hundreds, if not thousands, of caregiving families across the country

# Report on Programs

NFCA programs fall into three broad categories: Education, Building Community, and Advocacy. Some of our initiatives don't fit neatly under just one. A prime example of this is National Family Caregivers Month, which, by its very nature, defies categorization.

- **Education**
- **Building Community**
- **Advocacy**
- **NFC Month**

On the following pages we highlight our activities and accomplishments in these areas.



# Education

## *Communicating Effectively with Healthcare Professionals (CE)*

This longstanding NFCA program, which was initially begun in 2001 with a grant from the Jacob and Valeria Langeloth Foundation and then saw nationwide growth when it became designated as a Program of National Significance under the National Family Caregiver Support Program, continued to expand in new ways in fiscal 2010.

Surveys show that 60 percent of family caregivers are employed and that American business loses between \$17 billion and \$34 billion annually due to employees' caregiving responsibilities. With a new grant from the Langeloth Foundation, NFCA is creating a version of *Communicating Effectively with Healthcare Professionals* specifically targeted toward employed family caregivers.

This new version of CE is an on-demand webinar comprised of three segments. These can be viewed consecutively at one time or spread out if that better meets a busy working caregiver's schedule. The on-demand format permits a company to have access to the webinar for a two-week period of time. The webinar will be available with an accompanying PowerPoint, tool kit, and video scenarios illustrating communication techniques taught during the webinar. At year's end, NFCA was finalizing the materials and developing our marketing effort for the new program.

## *Safe & Sound: How to Prevent Medication Mishaps*

NFCA created a new educational webinar for NFC Month 2009: *Safe & Sound: How to Prevent Medication Mishaps*. The program aired November 17, 2009, to an audience of 348. As with NFCA's 2008 nationwide transmission of our *Communicating Effectively* webinar, *Safe & Sound* was completely free.

**The WHO of Medication Safety**

A medication safety team includes professionals plus you and your loved one.

- Prescriber** - These professionals write prescriptions.
- Dentist** - These professionals write prescriptions.
- Pharmacist** - They inform you about your medications and how to take them.
- Hospital Nurse** - They help you understand your medications and how to take them.
- Discharge planner** - They help you understand your medications and how to take them.

**Safe & Sound: How to Prevent Medication Mishaps**

**A Family Caregiver Healthcare Education Program**

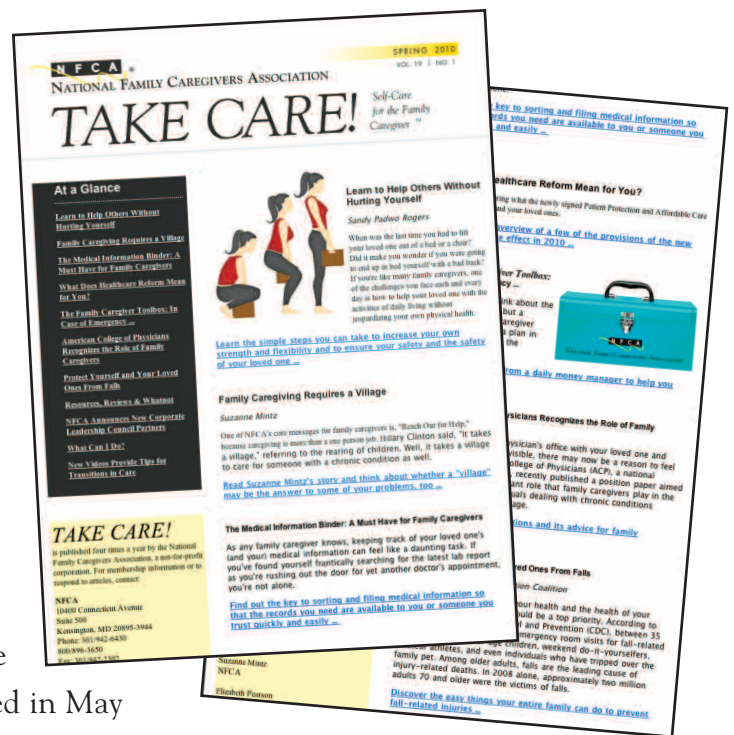
**A Who What Where Why When Tool Kit**

© National Family Caregivers Association www.thefamilycaregiver.org 800/896-3650

# Education *continued*

An advisory board of pharmacists, doctors, and nurses helped inform the choice of content. Pre- and post-program evaluations showed it had a statistically significant impact on family caregivers' confidence and level of knowledge. An additional survey three months later showed that family caregivers were inclined to put what they learned into practice. *Safe & Sound* was made possible by a grant from Novartis Pharmaceuticals Corporation.\*

**TAKE CARE!**, NFCA's highly regarded quarterly newsletter, was first published in 1992, thereby predating the formation of NFCA by one year. Early issues had to be typeset; there were no ubiquitous computer programs for creating and editing documents. Indeed, personal computers were not yet standard issue for every office worker in America. Fast forward 18 years and **TAKE CARE!** is now available as an electronic newsletter. Although the print version is still available to those family caregivers who choose to pay a small annual fee (\$10), the majority of NFCA's members have chosen to receive the new electronic version. Reaction to the first electronic issue, which debuted in May 2010, was very positive. Readers like its interactivity and the ability to go deeper into a subject through the links embedded within the articles.



\* Additional funding by Intel Digital Health Group, Eisai Inc., Home Instead Senior Care, National Association of Chain Drug Stores Foundation, Pharmaceutical Research and Manufacturers Association, Genworth Financial, Health Services for Children with Special Needs Inc., and AmeriGroup Foundation.

# Building Community

Family caregivers who reach out to NFCA continue to have the opportunity to connect with other family caregivers in multiple ways:

- Sharing their stories through the National Family Caregiver Story Project and reading those sent in by other family caregivers
- Participating in online forums
- Connecting with a member of NFCA's volunteer network, the Caregiver Community Action Network (CCAN), comprised solely of past and present family caregivers, either in person or by phone

The media makes extensive use of the Family Caregiver Story Project when seeking people to interview for particular stories. The fact that the stories can be sorted by diagnosis, geography, relationship, and more makes it very easy for members of the media to use. Family caregivers visit the site to enter their own stories, read about others in similar situations, and, at times, to locate a pen pal.

The online forums are very popular and get more visits than any other part of the Web site. Forum posts were viewed more than one million times over the course of the year. Many visitors have bookmarked the forum page, allowing them to go directly there without visiting the home page first.

In fiscal 2010, NFCA began planning for an addition to the CCAN network. This new national initiative, scheduled to be announced during fiscal 2011, will allow those who are neither former nor current family caregivers to participate in a program that will assist family caregivers and their care recipients on a local basis.

# Advocacy

During the first half of fiscal 2010, NFCA's advocacy activities were focused on ensuring that system delivery reform efforts proposed in the Patient Protection and Affordable Care Act were truly patient and family centered, and that the legislation specifically acknowledged the role family caregivers play in the delivery of chronic illness care. Working through coalitions including the Partnership to Fight Chronic Disease, Independence at Home, and several others initiated by the National Partnership for Women and Families, NFCA was able to raise the profile of family caregiver concerns to a wide variety of organizations and to obtain their support for our message, thereby significantly expanding the organization's influence.

NFCA focused on those features of the proposed reform bill that we believed would have the most impact for family caregivers and their loved ones: care coordination and transitions in care, home-based care for Medicare's most expensive beneficiaries, and the movement of our healthcare delivery system from its current procedure-focused, fee-for-service model to one that is more attentive to the needs of the chronically ill.

With the passage of the Affordable Care Act in the second half of the fiscal year, NFCA's focus turned to understanding the aspects of the new law that were meaningful to family caregivers and working to see that these areas of the bill are supported in the implementation process. NFCA identified 15 specific sections within the Affordable Care Act that mention family caregivers. Believing that some issues are so important that they need to be supported by a collaboration between the three national family caregiver organizations (NFCA, the National Alliance for Caregiving, and the Family Caregiver Alliance), rather than by one organization alone, NFCA proposed joint actions by the "family caregiver advocacy organizations." These include: educating the professional family caregiver community, the administration, members of Congress, the media, and family caregivers themselves about the 15 sections of the Affordable Care Act that specifically mention family caregivers and how they will, or will not, impact the day-to-day aspects of the life of a family caregiver. Efforts are currently under way to implement these ideas.

Although not part of the Affordable Care Act, NFCA also focused on the meaningful use provision of the 2009 American Recovery and Reinvestment Act (ARRA). ARRA will provide funding starting in 2011 for the development of electronic health records in hospitals and doctors' offices around the country. When the first rule for this initiative was issued in June, it contained a number of provisions that will benefit patients and family caregivers and facilitate better care coordination and communication between providers and caregiving families.

# National Family Caregivers Month

National Family Caregivers (NFC) Month 2009 was acknowledged with a proclamation from the White House, as it has been since 1997. The theme for the month was the fourth of NFCA's key messages: Speak Up for Your Rights. This message was delivered through multiple mediums, most obviously NFCA's Web site and publications. More than 50 other organizations shared the message with their constituents. In addition, stories appeared in newspapers and magazines, as well as on the radio.



**For yourself  
For your loved one  
For all family caregivers**

**November 2009  
National Family  
Caregivers Month**

Learn more at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

**10 TIPS FOR FAMILY CAREGIVERS**

- Caregiving is a job and respite is your earned right. **Reward yourself** with respite breaks often.
- Watch out** for signs of depression, and don't delay in getting professional help when you need it.
- When people offer to help, **accept the offer** and suggest specific things that they can do.
- Educate yourself** about your loved one's condition and how to communicate effectively with doctors.
- There's a difference between caring and doing. **Be open** to technologies and ideas that promote your loved one's independence.
- Trust your instincts.** Most of the time they'll lead you in the right direction.
- Caregivers often do a lot of lifting, pushing, and pulling. **Be good to your back.**
- Grieve for your losses, and then allow yourself to **dream new dreams.**
- Seek support** from other caregivers. There is great strength in knowing you are not alone.
- Stand up for your rights** as a caregiver and a citizen.

As noted earlier, NFCA hosted our second annual webinar for family caregivers and, with the support of Eisai Inc., continued the Caregiver Community Action Network (CCAN) Ambassadors' program for a fourth year. NFCA's volunteer corps delivered 35,000 bags of educational materials to family caregivers across the country. Working through hospitals and local non-profits and businesses, CCAN members were able to educate the community about the needs of family caregivers while simultaneously providing supportive and helpful information to family caregivers.

**Sponsored by**

**N F C A** \* NATIONAL FAMILY CAREGIVERS ASSOCIATION

**FOUNDING PARTNER** Intel Health

**FAMILY PARTNER** Eisai

**CARING PARTNERS** Forest Laboratories, Inc. | NOVARTIS | Home Instead

**FRIENDS** AMERIGROUP Foundation | Genworth Financial | Health Services for Children with Special Needs, Inc. | National Association of Chain Drug Stores Foundation | Pharmaceutical Research and Manufacturers Association

# Growth and Change

## **Additional Staff**

Fiscal 2010 was in many ways one of the most significant in NFCA's history. Days before the start of this year, NFCA hired a director of marketing and development; shortly thereafter, a chief operating officer was hired. This addition of two senior staff members has enabled NFCA to move beyond our entrepreneurial beginnings and enter a more mature stage of organizational development. An executive assistant was also hired during the fiscal year, bringing the total NFCA staff during fiscal 2010 to seven, a growth of nearly 50 percent. That is a big leap at any time; given the current economic climate, it is a huge accomplishment.

## **Broader Public Presence**

Additional staff brings new energy, new ideas, and new capabilities, including greater participation on boards and committees and attendance at public forums.

NFCA's president and CEO, Suzanne Mintz, raised the profile of NFCA through her leadership position on numerous boards and committees, including:

- National Health Council Board of Directors
- National Transitions of Care Coalition Advisory Task Force
- National Patient Safety Foundation Governing Board
- Partnership to Fight Chronic Disease Advisory Board
- Joint Commission Patient and Family Committee

Ms. Mintz also spoke at a number of noteworthy meetings and conferences, including:

- World Healthcare Congress Conference on Hospital Readmissions
- Collaborative Family Healthcare Association Annual Conference
- American Society on Aging/National Council on the Aging Joint Conference

She testified before the Subcommittee on Health of the House Committee on Veterans' Affairs on the needs of family caregivers of wounded warriors.

Lisa Winstel, COO, became NFCA's representative to Novartis' Power of Partnering advocacy group initiative and sanofi-aventis' AF STAT educational initiative.

# Growth and Change *continued*

## NFCA Online and in the News

During fiscal 2010, NFCA saw significant traffic to our Web site.

Monthly averages included:

- 269,454 visitors
- 20,128 new visitors
- 23,324 unique visits

Media coverage was extensive, too. During FY2010, NFCA appeared in 646 news stories with a potential viewership of 152,874,297 (as reported by Nielson NetRatings). Media coverage included both national and regional publications, as well as the Internet, radio and TV.

**The Washington Post**

**CNN**

**The New York Times**

**The Philadelphia Inquirer**

**Forbes**

**PARADE**

**Woman'sDay**

**The Dallas Morning News**



## Corporate Leadership Council

In fiscal 2010, NFCA put in place a Corporate Leadership Council (CLC), a program that had been planned in the past but not executed.

The CLC met once via phone and then in person during National Family Caregivers Month, in November 2009. Twelve companies were represented and the meeting, which featured a presentation by the

Institute for Alternative Futures as well as an interactive dialogue between NFCA staff, board, and Council members, was a huge success.

## Founding Partner

Allsup • Intel's Digital Health Group

## Family Partners

Eisai Inc. • Forest Laboratories, Inc. • Home Instead • The Johnson & Johnson Caregiver Initiative • Losta Helping Hands • Novartis

## Friends

Abbott Labs • AGIS • Elan Wyeth • NACDS Foundation • Pfizer • PhRMA • Purdue Pharma • sanofi-aventis

## Supporters

PBE Tranquility • Right at Home • TEVA Neuroscience

# Summary

Fiscal 2010 truly was a very significant year in the life of NFCA. We were able to improve the efficiency of our operations, expand our public presence, develop new fundraising mechanisms, attract new funders, and move our mission forward. The most significant happenings included:

- The addition of two new staff members: a chief operating officer and an executive assistant.
- The development of two new programs to be introduced in fiscal 2011: the Family Caregiver Tool Kit and Planner and the expansion of NFCA's Caregiver Community Action Network.
- The recognition by policymakers of the role that family caregivers play in the provision of chronic illness care in America by including family caregivers as active participants in various elements of the Patient Protection and Affordable Care Act.

The staff and board of the National Family Caregivers Association wish to thank all of the individuals, companies, organizations, and foundations that enabled us to help so many family caregivers during fiscal 2010. We are pleased that so many family caregivers reached out to NFCA, giving us the opportunity to help them help themselves.



# Financials – FY 2010

Fiscal 2010 financials will be posted upon the completion of our audit.