

Reaching More Caregivers Than Ever Before

Annual Report

July 1, 2013 – June 30, 2014

A Letter from the Chair & CEO



Dear Friends of the Caregiver Action Network –

In 2014 we at Caregiver Action Network (CAN) continued our efforts to reach out to the nation’s 90 million family caregivers and provide them with a wealth of resources and support. Our aim, as always, is to find those caregivers wherever they are and whatever their circumstances to let them know that they are appreciated and most of all, that they are not alone.

We understand that no two caregiving experiences are alike, and so we made it our goal this year to begin to tailor the resources we offer to the particular needs of individual caregivers. The best examples of this are CAN’s new “Caring for Rare Disease Caregivers” website (www.RareCaregivers.org) and our “Help for Cancer Caregivers” web tool (www.HelpforCancerCaregivers.org). Both were designed to focus on the needs and problems confronting specific members of the family caregiving network.

We wish to thank CAN’s Board Members, our volunteers and staff. Without them, all that you see in these pages would not have been possible.

And most of all, we honor family caregivers throughout the country. You are a network of love and support to the millions of Americans who suffer from old age, chronic illness and disabilities. We at CAN remain committed to supporting one of this nation’s most vital resources – the family 90 million caregivers who are at the heart of all we do.

Sincerely,

A handwritten signature in black ink that reads "Jon Shanfield".

Jon Shanfield

Chairman of the Board

A handwritten signature in black ink that reads "John A. Schall".

John A. Schall

Chief Executive Officer

Reaching Millions More

After a year of tremendous organizational changes in FY13, Caregiver Action Network's focus in FY14 was on reaching more caregivers than ever before.

There are 90 million family caregivers in America – 2 out of every 5 adults are caregivers to a friend or relative. And recognizing that no two family caregiving experiences are alike, we not only greatly expanded our efforts to reach out to family caregivers generally, we also targeted our resources to meet the specific needs of the individual caregiver.

That is why Caregiver Action Network made depth as well as breadth our overarching goal in FY14. We reached out to a wider array of family caregivers. At the same time, we also went further in-depth – providing information and resources targeted to caregivers based on their specific needs and circumstances. In short, we brought more family caregivers more deeply into a wider network of practical advice, support and encouragement.

These efforts earned CAN increasing recognition. We were especially proud to receive a Guidestar Exchange Silver Participant rating by Guidestar, the prestigious ratings agency of charitable organizations. CAN was cited especially for “Strong leadership and an ability to engage the corporate sector in understanding caregiving.” Guidestar went on to say that CAN, “Does the best work at reaching family caregivers directly across the nation.”

But we don't intend to sit on our laurels. Our aim is to continue to expand the family caregiving network while focusing more deeply on the specific needs of every part of that network. To add both “breadth and depth” in order to assure better care for patients and a better quality of life for the 90 million Americans who care for them. It is an ongoing challenge, but in FY14 we made great strides and proved once again that – working together – we CAN!



Public and Media Outreach

One of the CAN's goals is to increase awareness of family caregiving issues in the general public, government, media circles and with family caregivers themselves.

Getting the word out is critical to improving the quality of life for family caregivers and their care recipients. But this can be a challenge when so many people don't self-identify as a family caregiver, even though they are handling caregiving responsibilities.

So, in FY14, CAN greatly expanded its efforts to raise the profile of family caregiving. We did so with a combination of media appearances, Public Service Announcements and general education efforts.

Among these:

- ✓ CAN reached over 35 million viewers with a nationally televised Public Service Announcement. Produced in cooperation with United Healthcare, the announcement was released in both English and Spanish and had a total ad value of more than \$2 million.
- ✓ CAN Chief Executive Officer John Schall appeared on COMCAST Newsmakers. The interview was periodically re-played over a month on the Headline News Network. It was seen in six states and the District of Columbia.
- ✓ CAN participated in over a hundred media interviews with leading news services, including the Washington Post, the New York Times, CBS News, and others.
- ✓ CAN partnered with United Healthcare, AARP, Walgreen's, Target, Walmart/Sam's Club and others for "National Medicare Education Week."
- ✓ CEO John Schall made dozens of presentations across the country, including the American Society on Aging Conference in San Diego and other conferences.

Greater Depth



We also continued to focus on caregivers themselves by more deeply examining the needs of family caregivers not just as a whole, but as a network of individuals with problems specific to their own particular circumstances.

This builds on CAN's successful effort in FY13 to tailor resources on our overall website CaregiverAction.org to four caregiving profiles:

- ✓ The first-time family caregiver
- ✓ The experienced family caregiver
- ✓ The long distance caregiver
- ✓ The working family caregiver

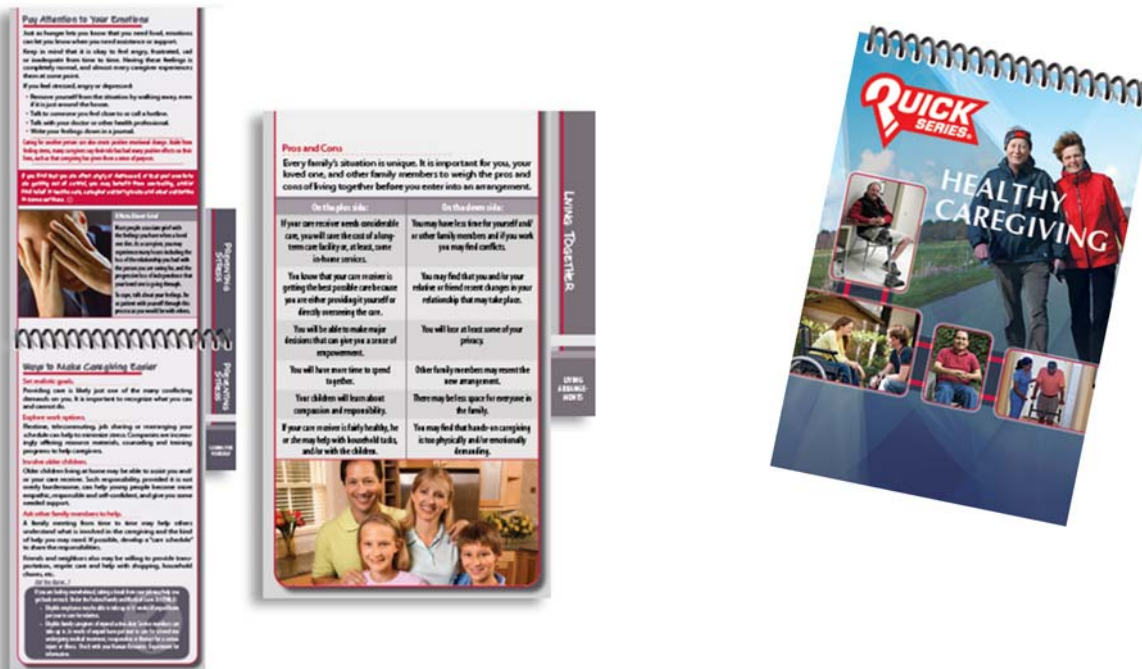
In FY14, we took this to the next level by creating new websites and resources targeted to specific caregiving situations like veterans, cancer and rare disease.

Military Caregivers!

In FY14, our spotlight turned especially to those who care for the men and women who have served their country on foreign battlefields. In particular:

- ✓ CAN joined with the Elizabeth Dole Foundation on a RAND study of Military Caregiving. CAN subsequently participated in a press conference on military caregiving and was represented at a White House event on the same issue.
- ✓ CEO John Schall was proud to participate in the Gary Sinise Foundation summit on the care of severely wounded veterans in Los Angeles. Hosted by actor and veteran's activist Gary Sinise, the summit was an opportunity for CAN to offer advice to military family caregivers and reach out to them as we improve the quality of life and care both for the caregiver and the patient.
- ✓ CAN's "Quickseries Flipbook" for Military Caregivers was distributed widely. This co-branded effort with the Department of Defense and Veterans Administration has reached tens of thousands with CAN's caregiving content. The "healthy caregiving" flipbook has many of the resources of our website condensed into a pocket-sized laminated booklet.

CAN recognizes that caregiving of wounded combat veterans presents challenges unlike those confronted by almost any other family caregivers. The stresses that such caregivers endure can tear families apart, but CAN continues to work to assure that all the resources – financial, medical and emotional – that exist in this specialized area of caregiving will be available to family caregivers of veterans.



Cancer Caregivers

Just as the needs of the veteran's caregiver are unique, perhaps no other form of caregiving requires such a range of resources and knowledge as caregiving for an oncology patient does. Even with all of the advances in medical science, few illnesses create as much anxiety and alarm for both the patient and the caregiver. Cancer manifests itself in so many ways and with such a complex array of pathologies and treatments that it is almost literally true that no two cancer cases are alike.

That is why CAN developed and launched, in cooperation with CancerCare, Johnson & Johnson, Michigan State University, Indiana University, Millennium: The Takeda Oncology Company, Onyx Pharmaceuticals, and Wellpoint, a new "Help for Cancer Caregivers" web tool

HelpForCancerCaregivers.org

The site offers articles and tip sheets on a range of topics, including:

- ✓ Taking Care of You
- ✓ Getting Help
- ✓ Coping with Caregiving
- ✓ Working Together
- ✓ Making a Caregiving Plan
- ✓ Making Things Happen
- ✓ Caregiver Stress
- ✓ Caregiver Overload

Initial studies of the *Help for Cancer Caregivers* web tool demonstrate that receiving the right information at the right time lessens distress throughout the caregiving experience. Data consistently shows that caregivers who experience less stress are more capable of providing care for the cancer patient.



Rare Disease Caregivers



Caregiving is, under the best of circumstances, an often disorienting and challenging experience. But when a caregiver's loved one has a rare disease, the family caregiver can often feel overwhelmed.

There are an estimated 30 million Americans who suffer from some form of rare disease. Caregivers in the rare disease community face some exceptional hurdles. Rare disease caregivers often face a higher burden of very intense caregiving activities. They often are the ones actually educating medical providers and others about the rare disease itself. And they have smaller communities to rely on for support. Not surprisingly, rare disease caregivers regularly report unmet needs related to social support, self-care and connections across diagnoses.

So CAN, working with Genzyme and a special international task force of rare disease caregivers, developed the "Caring for Rare Disease Caregivers" website RareCaregivers.org.

As with much of CAN's work, the focus of the site is not just on helping the family caregiver deal with the unique medical issues that often arise when caring for a loved one with a rare illness. Its main purpose is to improve the quality of life of the caregiver, recognizing that especially in cases of rare illnesses, the quality of the caregiver's life is directly related to the quality of care for the patient.

The new website RareCaregivers.org was launched on February 28 - World Rare Disease Day – with many resources available in four languages.



Patient and Family Engagement

As part of its mission, CAN has sought to distill and publicize the best practices in integrating family caregivers as a vital element in the national health care system. The data on this is clear: The more engaged patients and their family caregivers are in their own care, the better health care outcomes that will result.

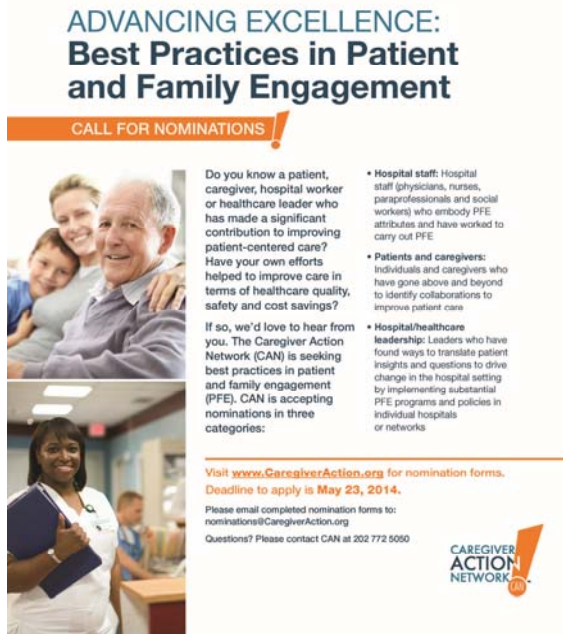
So in FY14, working with Weber Shandwick and the federal Centers for Medicare and Medicaid Services, CAN inaugurated the *Advancing Excellence: Best Practices in Patient and Family Engagement* Recognition Program.

Beginning in April, CAN asked doctors, nurses, hospital administrators and, most importantly, patients and family caregivers to nominate the best examples of how patients and caregivers have contributed to, and become part of, excellence in quality caregiving. This open nomination process has resulted in dozens of high quality submissions from around the country.

Nominations will be reviewed and scored by a Review Committee of 13 outside expert evaluators, taking into account such factors as program adaptability and replicability, program impact on vulnerable populations and measurable statistics demonstrating the program's effectiveness.

The results of the project will provide both family caregivers and health care professionals with crucial insights and data on the best techniques for fully integrating the patient and family caregiver into the caregiving experience.

CAN looks forward to publishing the results in the fall of 2014 to publicize best practices that can be replicated across the country.



**ADVANCING EXCELLENCE:
Best Practices in Patient
and Family Engagement**

CALL FOR NOMINATIONS!

Do you know a patient, caregiver, hospital worker or healthcare leader who has made a significant contribution to improving patient-centered care? Have your own efforts helped to improve care in terms of healthcare quality, safety and cost savings?

If so, we'd love to hear from you. The Caregiver Action Network (CAN) is seeking best practices in patient and family engagement (PFE). CAN is accepting nominations in three categories:

- **Hospital staff:** Hospital staff (physicians, nurses, paraprofessionals and social workers) who embody PFE attributes and have worked to carry out PFE.
- **Patients and caregivers:** Individuals and caregivers who have gone above and beyond to identify collaborations to improve patient care.
- **Hospital/healthcare leadership:** Leaders who have found ways to translate patient insights and questions to drive change in the hospital setting by implementing substantial PFE programs and policies in individual hospitals or networks.

Visit www.CaregiverAction.org for nomination forms. Deadline to apply is **May 23, 2014**.

Please email completed nomination forms to: nominations@CaregiverAction.org

Questions? Please contact CAN at 202 772 5050

CAREGIVER ACTION NETWORK

Creating the Voice



For the second year in a row, CAN was pleased to host “*Creating the Voice - A Celebration of Family Caregiving.*” As with the previous year’s event, the reception on September 23, 2013 proved to be the highlight of the national family caregiving year.

Held in Washington, DC, “*Creating the Voice*” is an evening to honor family caregiving. This event brought together CAN sponsors, supporters and family caregivers for an evening to celebrate those who have given a voice to the nation’s caregivers.

The 2013 recipients of the Hands-on Help Awards were:



Senator Elizabeth Dole established Caring for Military Families, The Elizabeth Dole Foundation, to raise public awareness about the enormous tasks facing caregivers for service members wounded in the wars in Iraq and Afghanistan. Dole, a former Transportation secretary, Labor secretary, and president of the American Red Cross who served in the Senate from 2003 to 2009. Dole knows more than a little about military caregiving. Her husband—former Senator Bob Dole, who lost the use of his right arm after being wounded in Italy during World War II—spent 11 months at Walter Reed National Military Medical Center in Bethesda, Md., after developing a hematoma in his leg in 2010.

The Caregiver Action Network was pleased to honor Senator Elizabeth Dole for her role in creating a voice for families caring for veterans wounded in the wars in Iraq and Afghanistan, for her distinguished career of public service and her exemplary dedication in creating Caring for Military Families.



Leeza Gibbons is one of the best-known and most well-loved pop-culture icons on the air and at the top of her game. She’s also a wife, mother, businesswoman, New York Times bestselling author of TAKE 2, and champion for family caregivers. Recognized as a social entrepreneur, Leeza has become one of the leading voices for issues facing family caregivers. After her family’s experience with her mother’s and grandmother’s Alzheimer’s disease, Leeza took action. With her training as a journalist united with her compassion and business savvy she created the Leeza Gibbons Memory Foundation, a 501 (c)(3); and its signature programs, Leeza’s Place and Leeza’s Care Connection, which offer free services for family caregivers.

The Caregiver Action Network was pleased to honor Leeza Gibbons for her role in creating a voice for family caregivers, for her decade of leadership and service to family caregivers and for creating community gathering places where family caregivers come together and develop skills that help them become stronger and more resilient when facing the demands of caregiving.

National Family Caregivers Month



CAN coordinates National Family Caregivers Month each November as a time to thank, support, educate and empower family caregivers. Celebrating Family Caregivers during NFC month enables all of us to:

- ✓ Raise awareness of family caregiver issues
- ✓ Celebrate the efforts of family caregivers
- ✓ Educate family caregivers about self-identification
- ✓ Increase support for family caregivers

In 2013, CAN highlighted NFC Month garnered greater public and media attention:

- ✓ A 38% increase in the use of CAN's National Caregivers Month Media Kit
- ✓ A 42% increase in the number of unique views on CAN's National Caregivers Month web page

In addition, the on-line media kit received literally hundreds of "related links," not including the numerous Facebook and Twitter messages about National Family Caregivers Month. All of this was supplemented by dozens of media interviews and in-person events.

At a time when family caregivers are providing an estimated \$450 billion worth of unpaid care each year, and when more and more Americans are caring for a loved one who is sick or disabled, there must be an intensified focus on this fast growing and essential part of the nation's healthcare network.

CAN is proud to continue the tradition of National Family Caregivers Month and is dedicated to shining an ever brighter spotlight on the burdens, responsibilities and achievements of those Americans without whom – "**Now More than Ever**" – the critical role of family caregiving would not be possible.

NFC Month 2013

Home CAN Join CAN for FREE Family Caregiver Forum Create a Community Caregiving Tools

FAMILY CAREGIVERS - NOW MORE THAN EVER!

The theme for National Family Caregivers Month 2013 is
"Family Caregivers - Now More Than Ever!"

Each year, more and more Americans are caring for a loved one with a chronic condition, disability, or the frailties of old age. There are as many as 90 million family caregivers in the U.S. today.

- **Two out of every 5 adults are family caregivers.** 39% of all adult Americans are caring for a loved one who is sick or disabled – up from 30% in 2010.
- **Alzheimer's is driving the numbers up.** More than 15 million family caregivers are providing care to more than 5 million loved ones with Alzheimer's disease.
- **But it's not just the elderly who need caregiving.** The number of parents caring for children with special needs is increasing, too, due to the rise in cases of many childhood conditions.
- **Wounded veterans require family caregivers, too.** As many as 1 million Americans are caring in their homes for service members from the Iraq and Afghanistan wars who are suffering from traumatic brain injury, post-traumatic stress disorder, or other wounds and illnesses.
- **And it's not just women doing the caregiving.** Men are now almost as likely to say they are family caregivers as women are (37% of men; 40% of women). And 36% of younger Americans between ages 18 and 29 are family caregivers as well, including 1 million young people who care for loved ones with Alzheimer's.
- **Family caregiving is serious work.** Almost half of family caregivers perform complex medical/nursing tasks for their loved ones – such as managing multiple medications, providing wound care, and operating specialized medical equipment.
- **Family caregivers are the backbone of the Nation's long-term care system.** Family caregivers provide \$450 billion worth of unpaid care each year. That's more than total Medicaid funding, and twice as much as homecare and nursing home services combined.

With the ranks of family caregivers growing every year – tens of millions strong – we recognize the importance to the Nation of the role that family caregivers play

Now More Than Ever!

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Caregiver Action Network | Plugged-In Caregiving | Financial Planning for Family Caregivers

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Financials!

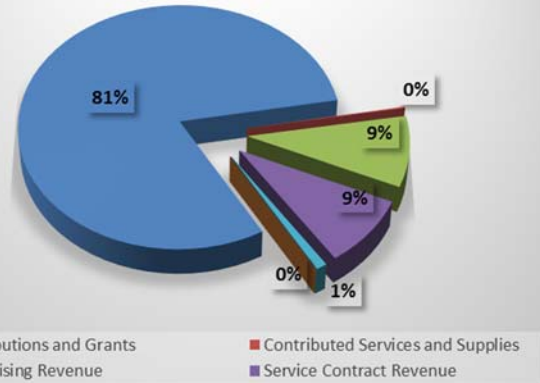
Assets

Current Assets	
Cash and Equivalents	\$ 267,348
Accounts Receivable	51,805
Prepaid Expenses	<u>2,000</u>
Total Current Assets	<u>321,153</u>
Net Property and Equipment	<u>1,783</u>
Other Assets	
Intangible assets	43,948
Total Other Assets	<u>43,948</u>
Total Assets	<u>\$ 366,884</u>

Liabilities and Net Assets

Current Liabilities	
Note Payable	\$ 15,066
Accounts Payable	787
Accrued Vacation	<u>15,681</u>
Total Current Liabilities	<u>31,534</u>
Long Term Liabilities	
Note Payable - long term portion	44,168
Total Long Term Liabilities	<u>44,168</u>
Net Assets	
Unrestricted	291,182
Temporarily Restricted	<u>-</u>
Total Net Assets	<u>291,182</u>
Total Liabilities and Net Assets	<u>\$ 322,716</u>

Revenues and Gains



Expenses

