

We CAN and We Did



Annual Report

July 1, 2012 – June 30 2013

*On January 1, 2013
National Family Caregivers Association
became
Caregiver Action Network*

A Letter from the Chair



Dear Friends of the Caregiver Action Network:

It is my great pleasure to introduce you to the new “Caregiver Action Network” – the successor to the National Family Caregivers Association.

Family caregiving is at the heart of all we do as an organization. Recently, it became apparent that family caregiving is also an important component of America’s overall health care system. This realization inspired the Board of Directors to undertake an extensive process to re-examine family caregiving in the context of America’s changing health care environment.

At the end of this process, the Board realized that to adequately address the importance of family caregivers in health care today, the organization needed to make some profound changes.

The results of these changes are what the Board proudly presents to you in this Annual Report. We are particularly pleased to note the appointment of John Schall as Caregiver Action Network’s new Chief Executive Officer. John brings a vision, sense of dynamism and keen grasp of health care – and particularly family caregiving – that has revitalized CAN and will enable us to tackle the complex challenges facing health care and family caregivers.

As always, I wish to thank my fellow Board members, our volunteers and our staff. Without them, all that you see in these pages would not have been possible.

Most of all, we wish to honor the millions of family caregivers throughout this country. You are a network of caring and compassion and it is for you that we continue to work.

Sincerely,

ANDREA COHEN

Board Chair

A Letter from the CEO



Dear Friends of the Caregiver Action Network:

Let me start by saying what a great privilege it is to have been selected as the CEO of the Caregiver Action Network. It is an exciting and challenging opportunity.

Like so many people, I suddenly became a family caregiver myself – so I know firsthand how family caregivers need all the help they can get when they take on the responsibility of caring for a loved one.

I have spent my career in public policy, with a strong emphasis on health care, and it is astonishing the pace of change that America is seeing. More and more it is becoming apparent just how central family caregiving is to those changes.

What I hope to do in the years ahead is not only help family caregivers in their important and life-affirming work, but also to raise awareness in political, government and business circles of just how central that work has become and will continue to be.

I will redouble our efforts to bring family caregivers the best tools and resources available *to help caregivers care for their loved ones*. And because family caregivers have their own individual needs and challenges, I will also redouble our efforts to provide resources *to help caregivers care for themselves*.

In just one year we have already made many important changes. You will see those changes in the pages of this Annual Report titled *We CAN and We Did!* We needed organizational changes to meet the evolving needs of millions of caregivers across the country. We needed to change and we did.

There is much challenging work to do, but I am excited and energized by the opportunities. Working with the Board of Directors, the staff, and all of our volunteers and contributors, I know that CAN will grow even stronger as the nation's leading family caregiver organization.

Sincerely,

A handwritten signature in black ink that reads "John Schall". The signature is fluid and cursive.

John A. Schall

Chief Executive Officer

A New Vision

Fiscal 2013 was the year of greatest change in this organization since its founding in 1992.

For too long the needs of family caregivers were viewed as something separate from the other aspects of the health care system. But at a time when 2 out of every 5 adults are caregivers to a friend or relative, family caregivers are not just *part* of our health care system, they are at the *nexus* of it. Family caregivers are now more than ever the backbone of our nation's long-term care system.

We saw that time and circumstances had changed. And therefore we changed as an organization.

We changed how we view family caregivers, and because of that we changed how we reach out to them.

We changed what kind of support we offer family caregivers, and we changed the way we deliver it.

We changed our vision to one that emphasizes not just the administrative and financial needs of family caregivers in their relationship to the care recipient, but to a focus on the family caregiver as a person with physical and emotional needs in their own right.

Yes, we made a lot of organizational changes in 2013.

We changed what we are and how we think of ourselves.

We changed what we do and how we do it. We changed our vision, our message, we even changed our name.

We stepped back, took a look at ourselves, put everything on the table, and out of those changes, on January 1, 2013, the National Family Caregivers Association was transformed and became



A New CEO and a New Look



In June 2012, the Board of Directors hired John Schall to serve as the new CEO of Caregiver Action Network (CAN).

John Schall is an experienced public policy expert with a keen understanding of the rapidly changing dynamics in American health care. He shared the Board's vision of family caregiving not as something separate and distinct from health care generally, but as the nexus of an interconnected array of networks, coming together collaboratively to care for the elderly, the disabled and the chronically ill, but doing so while balancing efficiency, economy, and compassion.

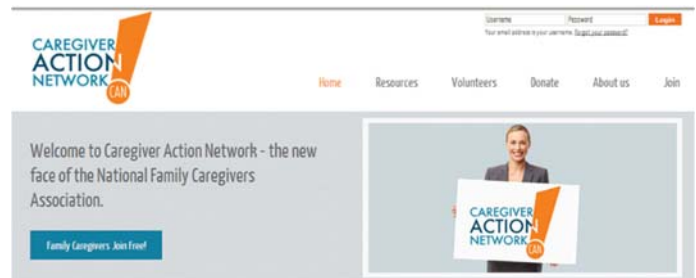
John understands these related but sometimes competing aspects of health care, and how family caregiving is the pivot around which so much of it turns. Seeing this, and acting on the insight inherent in our new name of Caregiver Action Network, John began to remake our organization by...

- ✓ **Creating a new vision and new goals.** CAN is not just a new name, it is a new vision of what our role is in supporting family caregivers. No longer are we just a great resource for information. Now we are an active partner in a network of family caregivers, and we have set ourselves new goals and benchmarks to making that partnership real and forward looking.
- ✓ **Rebranding.** Our new name reflects our new goals and our new vision. So CAN took on a new look to match its new thinking. We have adopted a new logo, a new color scheme, and a new distinctive visual style for all of our materials. The new look maintains a link with our past, but it point us in a new direction, too – outward looking and interconnected.
- ✓ **Creating Facebook page and Twitter feed.** CAN updated and heightened its social media presence, making us accessible to all family caregivers from the most technophobic to the most technophile.
- ✓ **Transforming the organizational culture.** This included making necessary staff changes and streamlining operations, as well as substantially diversifying CAN's income stream with: a new business line of "fee for service" survey work; PSA sponsorships; publication royalties; and a new special event.
- ✓ **Recruiting new corporate partners.** CAN added several new members to its Corporate Leadership Council – companies who financially support CAN's non-profit work.

A New Website

New thinking means a new website. For CAN, the goal was to turn our website into something that would be more proactive, interactive, and better adapted to serving the increasingly diverse nature of family caregivers. Something that would not treat all caregivers alike, and would address the widely different circumstances in which family caregivers often find themselves.

CaregiverAction.org reflects this approach, beginning with a dynamic and visually appealing home page. Most importantly, the home page targets four different types of caregivers.



Under each of these four profiles, caregivers find materials and information tailored to his or her specific needs.



CaregiverAction.org



✓ I just realized I'm a family caregiver.



✓ I have been a family caregiver for years.



✓ I live far away and I'm on the caregiving team.



✓ I have a job and I'm the caregiver for my loved one.

The website links family caregivers to other family caregivers through:

- ✓ The Online Forum
- ✓ Caregiving Stories
- ✓ Peer Volunteers

The site also now provides links to a variety of new CAN resources, including,

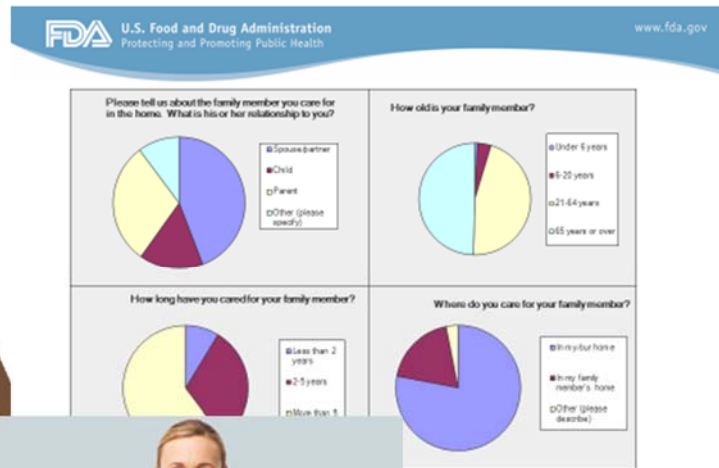
- ✓ Alzheimer's Caregiver Video Series
- ✓ The "Plugged-in" Caregivers micro-site
- ✓ ...and much more

New Data!

In 2013, CAN conducted various research projects to take different snapshots of the family caregiving population, sharpening our understanding of the specific needs and experiences of family caregivers. During the year, CAN:

- Released a survey conducted in partnership with United Healthcare/XL Health of “Caregivers of Medicare Special Needs Beneficiaries.”
- Released a field survey, conducted on behalf of the Food and Drug Administration and published in the AAMI Journal, on the use of medical equipment in the home by family caregivers.
- Conducted a proof-of-concept survey of caregivers for a client.
- Recruited caregivers for Help for Cancer Caregivers research.
- Participated in the release of the Family Caregivers Online Survey from the Pew Research Center.

CAN plans both to continue and to expand its efforts to obtain new data that will help to more sharply define the composition and the nature of the family caregiving network so that we can better meet its needs.



Building a New E-Network!

Central to maintaining CAN's role as the hub of America's family caregiving network was the need to upgrade our communications effort – both modernizing it and expanding it to reach our wider and increasingly diverse audience. In FY13,

- ✓ CAN's newsletter, TAKE CARE! went 100% electronic. Although e-newsletters had been the practice for some time, CAN no longer delivered a quarterly "snail mail" TAKE CARE! at considerable costs savings.
- ✓ CAN expanded its use of strategic topic-specific e-blasts.

These efforts generated enormously positive results. CAN's e-newsletter open rate (averaging 16%) and click through rate (averaging 4%) are comparatively very high – reflecting our very engaged audience. TAKE CARE! open rates exceeded the benchmark rates for e-mail newsletters across all non-profit sectors (as well as the health sector) and surpassed the click through rate for health sector e-mail newsletters, according to an eNonprofit Benchmark Study published in April 2013.

In addition, CAN created both a Facebook page and a Twitter feed to better reach out to family caregivers. These pages not only widen who we reach, they also increase interactivity between CAN and family caregivers and even between caregivers themselves.

More Media!

While CAN reached family caregivers through the internet and social media, the fact is that many family caregivers continue to receive messages through traditional media.

- ✓ In March, CAN spearheaded "Supporting our Caregivers" – an 18 page supplement in USA TODAY. This was the largest supplement ever produced by Media Planet and reached 18 million readers.
- ✓ CAN ran 3 different public service announcements in New York City's Times Square over a ten week period.



Alzheimer's Video Series



No two family caregiving experiences are alike. The problems and burdens that come with caring for a disabled child are vastly different than those that come with caring for an elderly parent or a wounded war veteran.

Acting on that key insight, CAN began developing materials that address the specific needs and concerns of different types of family caregivers. CAN identified different family caregiver communities and developed resources specifically tailored to assist them.

Among the first of these new targeted resources was the creation of the Alzheimer's Caregiver's Video Series.

Produced with support from Forest Laboratories, released in January 2013, and prominently displayed on the CAN website, the Alzheimer's Caregivers Video Series offers brief 2 to 3 minute videos that combine practical information, helpful tips and vignettes of the personal stories of Alzheimer's family caregivers.

The series includes one introductory video and four categories with five videos each:

- ✓ Discovering Alzheimer's disease – Knowing its signs, symptoms and progression.
- ✓ Life as a Caregiver – A personal story of what the experience was like for one family caregiver.
- ✓ Caregiver Tactics – The best methods for staying connected to the Alzheimer's patient.
- ✓ Finding Support – Emphasizing the importance of your loved one's needs as well as your own.

The series of 21 videos has been extraordinarily successful, with 6,500 views in its first three months.



Help For Cancer Caregivers

Having taken the first step to address the specialized needs of family caregivers of loved ones with Alzheimer's with its Alzheimer's Video Series, CAN applied the same principle to family caregivers of loved ones with cancer. CAN partnered with WellPoint, Michigan State University, Indiana University and Cancer Care, to jointly develop the "Help for Cancer Caregivers" web tool www.HelpforCancerCaregivers.org

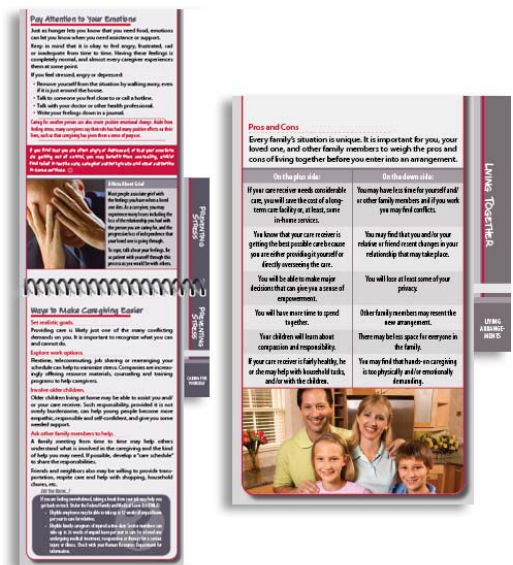
"Help for Cancer Caregivers" drills down into the specific resources and support networks available to family caregivers of cancer patients. Special emphasis is given to the emotional toll that caregiving takes on the family caregiver and on ways to cope with stress, seeking assistance and to developing a caregiving plan, among much else.

Military Family Caregivers

From amputees to the victims of traumatic brain injury, the injuries suffered by soldiers returning from foreign battlefields in recent years are unlike those confronted by almost any other generation of family caregivers. This is further compounded by the emotional toll families must endure as they try to cope with the effects of Post-traumatic Stress Disorder (PTSD).

These stresses can tear families apart and leave nothing but heartache in their wake. Research into this area is still new, but CAN is working to assure that all of the resources – financial, medical and emotional – that exist in this specialized area of caregiving are made available to Family Caregivers of Veterans.

That is why CAN wrote the "QuickSeries Flipbook" for Military Family Caregivers. The flipbook is a compact, handy reference guide to the resources available for helping to ensure that the caregiver and the care recipient are living the best lives possible, with an emphasis on daily life, living arrangements and government assistance.



Plugged In: Technology Guide



Family caregiving can be an enormously stressful, time consuming and expensive effort. Family caregivers are devoted and deeply involved in the care of their loved ones. However, they often do not grasp the enormous assets that they have at their disposal and how technology can be their ally in reducing their burdens.

CAN brings these resources to family caregivers. To assist caregivers we created the “[Plugged-in Caregiving: Technology for Family Caregivers](#)” micro-site. Designed to help the family caregiver sort through the new and perhaps daunting world of high-tech products and services in a way that makes sense, the site will help the caregiver to discover:

- What’s available to the caregiver that perhaps they didn’t know existed.
- Where to start if the caregiver is looking for technologies.
- The new technologies coming in the future.

Accessible through the CAN main website at [CaregiverAction.org](#) and featuring technologies available at minimal or even no cost, the “[Plugged-in Caregiving](#)” micro-site can help caregivers with tasks as simple as managing medications to handling complex emergencies – such as utilizing GPS if an Alzheimer’s care recipient should go missing.

This has been a wildly successful feature, used by approximately 11,500 caregivers in just its first 6 months.



Creating the Voice

With the “silver tsunami” upon us and medical advances making it possible to live longer with chronic conditions and disabilities, family caregiving has reached the proverbial tipping point. There is now so much more support for family caregivers that CAN seized the opportunity to celebrate the voices of family caregivers who have played a pivotal role in making this possible.

On September 20, 2012 from 6:00 – 8:00 p.m. in the recently renovated historic Warne Ballroom of the Cosmos Club (2121 Massachusetts Ave., NW, Washington, DC) CAN (then still known as NFCA) hosted its first annual awards reception, ***Creating the Voice: A Celebration of Family Caregiving***.

The highlight of the evening was the first annual presentation of CAN’s “Hands-On Help” Award – honoring those who give family caregiving its voice. CAN bestows this award on individuals and institutions who have used their voice to support family caregivers and caregiving issues.

The 2013 Hands-on Help Award recipients were:

- Veterans Affairs Caregiver Support Program – accepted by Deborah Amdur, Chief Consultant Care Management and Social Work Services, VA on behalf of VA Secretary, General Eric Shinseki
- ReACT – accepted by Dr. Jack Waters, VP for External Medical Affairs, Pfizer & Mr. Drew Holzapfel, Global Marketing Lead, Pfizer’s Alzheimer’s Program

The awards were presented by the new CEO of Caregiver Action Network, John Schall, who also presented an additional achievement award to The National Family Caregiver Association’s original co-founder and President, Suzanne Mintz.



National Family Caregivers Month!

CAN is the organization that spearheads National Family Caregivers Month each year in November. In 2012 we chose as the month's theme: "Family Caregivers Matter."

Since 1994, November has been National Caregivers Month, and with the ranks of family caregivers growing every year, CAN firmly believes in the need for a sharp and persistent focus on the role of family caregiving in American health care.

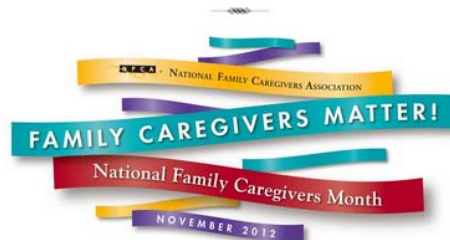
At a time when family caregivers are providing an estimated \$450 billion worth of unpaid care each year, CAN takes the opportunity at National Family Caregivers Month to enhance public understanding through tools such as:

- ✓ The National Family Caregivers Month Media Kit.
- ✓ Blogs targeted to different parts of the family caregiving network.
- ✓ An increased media campaign and outreach to government, business, and civic associations.

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 the rapidly rising number of Americans who are caregivers. All that they are doing for family and friends is a constant reminder to the nation that "Family Caregivers Matter!"

NFCA Caregiving Statistics

National Family Caregivers Month Press Kit 2012



Family Caregivers Matter!

The theme for National Family Caregivers Month 2012 is "Family Caregivers Matter!"

Family caregivers are the unacknowledged backbone of the nation's long-term care system. They provide daily assistance to manage health care and personal care, while enabling their loved ones to stay in the community longer.

Family caregivers matter in so many important ways:

- **Family caregivers matter to their loved ones**, spending an average of 20 hours per week providing care – and many caring for their loved ones around the clock.
- **Family caregivers matter in making sure that medications are taken and that doctor appointments are kept.** More often than not, family caregivers are the managers of their loved one's medication regimen, seeing to it that medicines are taken on time and that different medicines prescribed by different doctors are properly reconciled.
- **Family caregivers matter in reducing health care costs and avoiding hospital readmissions.** Family caregivers provide the lion's share of care and support for those with chronic care needs – approximately \$450 billion of unpaid care each year.
- **Family caregivers matter to each other.** Family caregivers so often feel isolated and alone. Just knowing that there are 65 million other family caregivers they can reach out to who are going through many of the same challenges can be a source of great consolation.

Family caregivers are the only people who are consistently present with their loved ones across all care settings. Everyone else can and does change. People with chronic conditions may have multiple doctors. Nurses change shifts in hospitals. Even pharmacists change locations. But family caregivers are there as full partners with their loved ones through it all.

That's why National Family Caregivers Month is the ideal time to recognize that family caregivers really do matter!

[Comments \(0\)](#)

PRESS KIT CONTENTS

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"Family Caregivers Matter" on Facebook
Reflections by Suzanne Mintz
A Special Thank You...
A Picture of Higher Burden Caregiving
A Picture of Higher Burden Caregiving - Infographic



Corporate and Foundation Support

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Financials as of 6/30/2013!

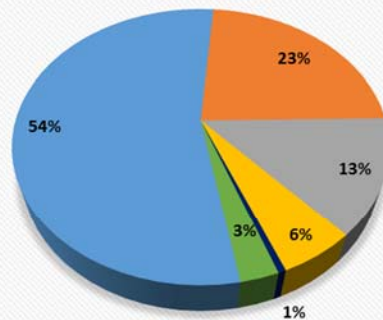
ASSETS

Current Assets	
Checking/Savings	23,538.59
Accounts Receivable	61,500.00
Other Current Assets	159.98
Total Current Assets	85,198.57
Other Assets	26,135.75
TOTAL ASSETS	111,334.32

LIABILITIES & EQUITY

Liabilities	
Current Liabilities	
Accounts Payable	13,987.77
Credit Cards	3,954.99
Other Current Liabilities	68,436.55
Total Current Liabilities	86,379.31
Long Term Liabilities	4,865.20
Total Liabilities	91,244.51
Equity	20,089.81
TOTAL LIABILITIES & EQUITY	111,334.32

Revenues and Gains



Expenses

