



Meeting Family Caregivers Where They Are

CAREGIVER ACTION NETWORK

Annual Report
July 1, 2016 – June 30, 2017

A LETTER FROM THE CHAIR AND CEO

Dear Friends of Caregiver Action Network –

CAN's FY17 Annual Report, "Meeting Family Caregivers Where They Are," demonstrates how CAN aided the 90 million caregivers across the country with our numerous programs and partnerships – many of which were new this year.

CAN was founded on the principle of caring for those who care. And after more than a quarter century, we are so pleased to be the nation's leading family caregiver organization. We wouldn't be here without the dedication of CAN's Board Members, our volunteers across the country, and our very committed staff. They make what we do possible.

Our increasing success enables us to reach more family caregivers than ever before. The quantity and quality of CAN's caregiver resources and information rose to an unmatched level in 2017:

- ✓ New webinars and instructional videos
- ✓ Needed supports for working family caregivers
- ✓ In-person Caregiver Lunch & Learn workshops which are giving real-life, practical information to real family caregivers across the country

We are truly "meeting family caregivers where they are." With everything we do, we never forget why we're here – for America's 90 million family caregivers. We work harder every day so that their lives can be just a bit easier. So they have somewhere to turn for advice, resources, and support. Most importantly, so they know they're not alone. Though 2017 was indeed a phenomenal year for CAN, the true measure of our success is in the lives that we touch every day.

Sincerely,



Wes Metheny
Chairman of the Board



John Schall
Chief Executive Officer

NEW NATIONAL TRAINING SESSIONS

FY17 saw Caregiver Action Network implement a program that has the potential to reach more family caregivers where they are than anything we have done in the past. Thanks to funding from the Patient-Centered Outcomes Research Institute (PCORI), CAN has the opportunity to go into communities around the country to engage with and teach family caregivers about Comparative Effectiveness Research (CER) and how to apply it in shared decision making. CAN will be holding seven workshops in different locations across to U.S. in FY17 and FY18.

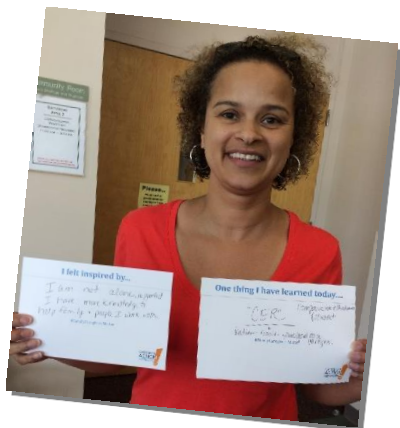
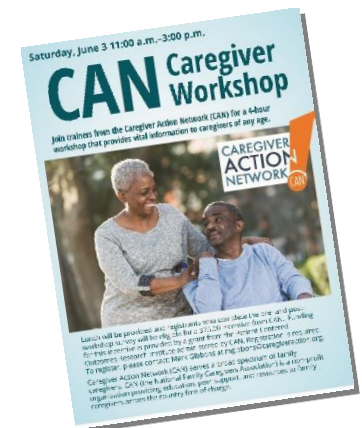


Each interactive workshop is comprised of four modules:



- ✓ **Module One** covers tools to prepare family caregivers for doctor office and E.R. visits, as well as gives examples of other tools like a Medication List and Patient File.
- ✓ **Module Two** covers patient and family-centered goals.
- ✓ **Module Three** explains what CER is and is accompanied by an activity where participants can roleplay a scenario of seeking out information on various interventions for their loved one's diagnosis.
- ✓ **Module Four** discusses how to apply CER to shared decision making.

Caregiver Lunch & Learn has already met with success. All participants complete pre- and post- workshop evaluation surveys. Post-survey results from our first session indicate that attendees had a better understanding of all four components after participating in the 4-hour training workshop. For example, participants' responses demonstrate very positive results to the following questions on a scale of 1 (strongly disagree) to 10 (strongly agree):



- 1) **I know what “patient-centered goals” are.** Increase from 4.7 in the pre-survey to 8.3 in the post-survey.
- 2) **I understand why “comparative effective research” is important and why it matters to me.** Increase from 3.9 in the pre-survey to 7.8 in the post-survey.
- 3) **I know what “shared decision-making” is and why it is important.** Increase from 6.2 in the pre-survey to 8.8 in the post-survey.

We train between 50 and 200 family caregivers at each event.

Caregiver Lunch & Learn will have enormous reach, and the potential to help real caregivers in the real world!

ASSISTING CAREGIVING EMPLOYEES

CAN created the Assisting Caregiving Employees (ACE) program to help employers assist their caregiving employees. ACE enables caregivers to quickly access caregiving tools and resources. It is a turnkey-ready, web-based program to provide working family caregivers with the tools and resources they need.

The ACE program includes a dedicated website for caregivers full of tips, a caregiver stress assessment, and a caregiving assessment for the organization, among other resources. ACE helps employers ensure that their employees remain productive and healthy, thus reducing employer costs.

Being aware of resources, and having a manager who is aware, reduces disruptions at work and home and makes for better outcomes for all.



- ➔ Your annual business cost can be as much as \$3,200 per caregiving employee *right now*
- ➔ Health benefits cost employers 8% more for caregiving employees
- ➔ *One out of five workers* are family caregivers
- ➔ Workers take *9.8 days off yearly* to manage their caregiving responsibilities
- ➔ It costs \$6.6 billion to replace caregiving employees who leave the workforce

ACE helps your employees stay healthy and remain productive.

Learn how you can support your caregiving employees and their supervisors.

WorkingFamilyCaregivers.org

INCREASING CAN'S REACH

Caregiver Action Network's work in FY17 was focused on reaching more family caregivers where they are, by providing resources that are easy to access from anywhere and meeting them in their communities.

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 individual caregivers.

CAN is now home to several different disease-specific videos and a series of caregiver instructional videos – many of which were new this year.

- ✓ Alzheimer's disease Videos: Caregivers talk about their day-to-day experiences caring for someone with Alzheimer's, its signs and symptoms, as well as the importance of addressing their own needs. Created with support from Allergan.
- ✓ Huntington's disease: Made with support from Teva Pharmaceuticals, these videos feature family members sharing their experiences dealing with Huntington's disease.
- ✓ Parkinson's disease: Spouses discuss the difficulties of caregiving for a loved one with Parkinson's disease. Also created with support from Teva Pharmaceuticals.
- ✓ COPD Videos: Two women describe taking on new responsibilities as their husbands age with COPD, and share how they find time for themselves. Created with support from Sunovion.
- ✓ Instructional Videos: This video series, created by Elder Stay At Home, teaches caregivers how to best perform care tasks at home.

What's important to family caregivers? Their loved ones! And that's why CAN remains wholeheartedly committed to reaching an ever-increasing number of America's family caregivers – so they may continue to care for those they love. It is an unrelenting challenge, but one CAN is ready to meet head-on!

REACH & ENGAGEMENT HIGHLIGHTS

Most Popular Web Resources

- Family Caregiver Toolbox
- Top 10 Tips for Family Caregivers
- Caregiver Statistics
- National Family Caregivers Month

E-newsletter

- Sent monthly to nearly 30,000 caregivers
- Open rates and click-thrus surpass nonprofit health sector benchmarks

Editorial and Media Coverage

- CAN is the go-to family caregiving resource for reporters and writers for major media outlets
- CAN was featured in more than 1,500 articles in 2017 alone with a potential reach of more than 438 million

Supporting Our Caregivers USA Today

- Over 2 million online impressions annually
- 750,000 print readers

Webinars

- Over 100,000 total views
 - Managing the Cost of Care
 - Understanding Medicare
 - Managing Your Loved One's Meds
 - How to Talk to Doctors

Twitter

- More than 1 million impressions last year
- Average of 2.9K impressions per day
- CAN's handle was tweeted more than 5,000 times last year

Facebook

- 1,510,750 Impressions in 2017
- Average total organic reach of 1,800 daily unique views

Videos

- Of CAN's 40+ videos, 55% of viewers watched the entire video

MORE PARTNERSHIPS

Much of CAN's strength comes in large part from partnering with many large companies and organizations across the country. In FY17, CAN created new partnerships and expanded existing partnerships to discover even more ways of meeting caregiver needs!

To reach millions more family caregivers, we forged new and important partnerships with companies and organizations across a wide spectrum – such as health providers, policymakers, insurance companies, and major manufacturers. A [List of CAN's Corporate Partners](#) can be found on page 13.

Here are some exemplary highlights of CAN's partnerships with major manufacturers, health care payers, and others:

- ✓ CAN joined with the Genworth Foundation throughout May 2017 for Older Americans Month. The goal of the campaign was to raise awareness of the contributions and value of older Americans, along with those of their family caregivers. The month-long campaign exceeded all expectations. It drove engagement among our social media audience, and resulted in thousands of shares, posts, and comments on both CAN and Genworth Foundation social media channels!
- ✓ Family caregivers need strength to be able to give care. In keeping with this year's NFC Month theme, **Take Care to Give Care**, CAN partnered with Abbott Nutrition to promote caregiver nutrition during all of NFC Month. Both CAN and Abbott posted messages daily on social media to help family caregivers remain strong and healthy through staying active and eating well. Abbott also developed a section within its website specifically for caregivers.

Supporting Our Caregivers

90 million Americans provide care to injured, aging adults, special needs children and individuals with chronic medical needs. **Montel Williams** has been one of them. His story and more on better supporting our nation's caregivers.

Take Care to Give Care

Caregivers, Don't Let Your Health Take a Backseat

By Zoe Alexander

Ensure ALWAYS BE YOU!

When it comes to caring for others, staying strong means taking care to give care.

The devotion caregivers show to the health and well-being of others is extraordinarily selfless and requires an incredible amount of energy. But in the process of focusing on those who need them, many caregivers put their own health second, either out of exhaustion or because of time constraints. Unfortunately, nutrition seems to be one of the first things to fall off the list of daily priorities.

One out of five caregivers surveyed by Abbott Nutrition said they have sacrificed their own physical health while caring for a loved one. That number is even higher in "high burden of care" roles. Abby Sauer, MPH, RD, Abbott Nutrition, says caregivers need to take care of themselves, so they're better able to care for others. "When caregivers' healthy eating habits take a backseat to the needs of a loved one, it places them at risk. It's important that they focus on proper nutrition, such as eating nutrient-dense foods that are high in protein, vitamins, and minerals, to help maintain optimal physical health."

The power of protein

Protein is macronutrient that is essential for building, repairing and maintaining body tissue. It is constantly being broken down and needs to be replenished. Powerful proteins can be found in foods like meat, poultry, fish, eggs, tofu, and legumes (dry beans and peas). High protein nutrition shakes, like Ensure® High Protein, can also provide an easy, nutritious on-the-go solution. To help increase energy and stamina, caregivers can also add protein-rich foods to their breakfast routine. Quick evening prep, like preparing beans or hard-boiling eggs, will make the morning run smoother.

Take care to give care

Caregivers should take to heart the advice they give to loved ones about proper diet and lifestyle. With balanced nutrition and attention to self care, they can have stronger immune systems and improved overall strength, and the resilience they need to help care for those who need them.

YOUR CARE MATTERS

It's National Family Caregiver Month, and Ensure® is partnering with Caregiver Action Network, the nation's leading caregiver organization, to provide caregivers with nutrition resources and to help them **Take Care to Give Care.**

We're also celebrating caregivers everywhere. For wellness tips and to send a thank-you e-card to a special caregiver, visit ensure.com/caregivers.

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Ensure ALWAYS BE YOU!

NATIONAL FAMILY CAREGIVERS MONTH NOVEMBER 2016

Caregiver Action Network is the organization that chooses the theme for National Family Caregivers Month each year and spearheads the celebration of NFC Month nationally.

National Family Caregivers Month – celebrated each November – is a time to recognize and honor family caregivers across the country.

Caregiver Action Network makes materials available for general use, including the theme, a media kit, posters, sample proclamations, etc.

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.

This year, CAN partnered with Abbott Nutrition to promote caregiver nutrition throughout NFC Month. Both CAN and Abbott posted messages daily on social media to help family caregivers remain strong and healthy through staying active and eating well.

Caregiver Action Network began promoting national recognition of family caregivers in 1994. President Clinton signed the first NFC Month Presidential Proclamation in 1997 and every president since has followed suit by issuing an annual proclamation recognizing and honoring family caregivers each November.

The theme for **National Family Caregivers Month 2016** was...

Take Care to Give Care

Take Care to Give Care

The theme for National Family Caregivers Month 2016 is

“Take Care to Give Care”

The first rule of taking care of others: *take care of yourself first*. Caregiving can be a rewarding experience, but it is also physically and emotionally demanding. The stress of dealing with caregiving responsibilities leads to a higher risk of health issues among the Nation’s 90 million family caregivers. So as a family caregiver, remember to pay attention to your own physical and mental wellness, and get proper rest and nutrition. Only by taking care of yourself can you be strong enough to take care of your loved one. You really do need to “*take care to give care!*”

- **Caregiving can be a stressful job.** Most family caregivers say they feel stressed providing care for a loved one. With all of their caregiving responsibilities – from managing medications to arranging doctor appointments to planning meals – caregivers too often put themselves last.
- **The stress of caregiving impacts your own health.** One out of five caregivers admit they have sacrificed their own physical health while caring for a loved one. Due to stress, family caregivers have a disproportionate number of health and emotional problems. They are twice as likely to suffer depression and are at increased risk for many other chronic conditions.
- **Proper nutrition helps promote good health.** Ensuring that you are getting proper nutrition is key to help maintain your strength, energy and stamina, as well as strengthening your immune system. Maintaining a healthy diet is one of the most powerful things you can do to take care of yourself and keep a positive attitude overall.
- **Ensuring good nutrition for your loved one helps make care easier.** As many as half of all older adults are at risk for malnutrition. Good nutrition can help maintain muscle health, support recovery, and reduce risk for re-hospitalization – which may help make your care of a loved one easier.
- **Remember: “Rest. Recharge. Respite.”** People think of respite as a luxury, but considering caregivers’ higher risk for health issues from chronic stress, those risks can be a lot costlier than some time away to recharge. The chance to take a breather, the opportunity to re-energize, is vital in order for you to be as good a caregiver tomorrow as you were today.

During **National Family Caregivers Month**,
we remind family caregivers that to be strong enough to care for your loved one, you must

Take Care to Give Care!

ADVOCATING FOR FAMILY CAREGIVERS

In 2014, CAN introduced the Congressional Leader Awards and was honored to recognize the following

2016 Caregiving Leaders in Congress



Rep. Steny Hoyer

Caregiver Action Network was pleased to honor Congressman Steny Hoyer as a Caregiving Leader in Congress in recognition of his leadership role in advancing policies that matter to family caregivers, people with disabilities, military families, and veterans.



Rep. Tom Reed

Caregiver Action Network was pleased to honor Congressman Tom Reed as a Caregiving Leader in Congress in recognition of his leadership in introducing the Credit for Caring Act to provide a tax credit for family caregivers.

AN EMPHASIS ON ADVOCACY

Another of CAN's main goals is to advocate for policies of interest to family caregivers. CAN embarked on three major new advocacy efforts in FY17:

- ✓ CAN Helped Establish a Congressional Caucus on Caregiving: The bipartisan, bicameral Assisting Caregivers Today (ACT) Caucus was launched in the U.S. Congress. This was an effort headed by AARP, CAN, and other interested organizations. The goal of the ACT Caucus is to bring greater visibility to the value of and need to support family caregivers, as well as the challenges and opportunities individuals of all ages face as they seek to live independently. The caucus aims to inform Members of Congress about these issues, elevate the conversation, forge an environment and context conducive to reaching bipartisan solutions, and help create a sense of urgency to act.
- ✓ CAN has also been advocating for passage of the RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act. This legislation directs the Secretary of Health and Human Services to create and sustain a National Family Caregiving Strategy with the goal of supporting family caregivers.



To further augment its leading role in advocacy on behalf of family caregivers, CAN created a new advocacy organization called Caregiver Voices United. CAN's CEO, John Schall, also serves as the President of Caregiver Voices United. Caregiver Voices United is a 501(c)4 nonprofit organization created to advocate for family caregivers who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age by:

- Supporting the passage of federal legislation that meets the needs and interests of family caregivers.
- Pursuing federal policy changes through administrative and regulatory channels to ensure the needs of family caregivers are appropriately addressed.
- Pursuing policy changes at the state level that better recognize the needs of family caregivers in respective states.
- Recognizing policymakers and other leaders who champion issues of importance to family caregivers.

ALWAYS IMPROVING EXISTING CAN PROGRAMS

At CAN, we are constantly working to update and improve our ongoing programs. Here are two examples of updates to two programs targeted to cancer caregivers and rare disease caregivers:

Cancer Caregivers

Even with all of the advances in medical science, few illnesses create as much anxiety and alarm for both the patient and the caregiver as cancer does. Because cancer care is often so complicated, CAN developed and launched the “Help for Cancer Caregivers” web tool at HelpForCancerCaregivers.org. In cooperation with Anthem, CancerCare, Johnson & Johnson, and Millennium: The Takeda Oncology Company, the website is constantly updated and made more user-friendly.

We are happy to report that 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

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. 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.

That is why CAN, working with Genzyme, developed the RareCaregivers.org website. 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.

Resources on RareCaregivers.org are now available *in five languages* as the website is currently being used in 91 countries worldwide!



CREATING THE VOICE 2016

On November 15, 2016, Caregiver Action Network hosted its fourth annual signature special event, *Creating the Voice: A Celebration of Family Caregiving*. Each year, CAN is pleased to honor visionaries who have created a voice for family caregivers across the nation. Funds raised at this event provide support for Caregiver Action Network's core program of family caregiver programs and enable CAN to provide education and resources to family caregivers free of charge.

Past honorees have included Senator Elizabeth Dole, *PBS NewsHour* Co-anchor and Managing Editor Judy Woodruff, Leeza Gibbons, Senator Bob Dole, and Alzheimer's advocate Meryl Comer.

This year we honored Emmy Award winning television host and MS advocate, Montel Williams, for his vital national leadership in honoring our nation's military veterans and for ensuring that those who served and their families receive the care they so fully deserve.



WITH APPRECIATION

FY17 Corporate and Foundation Support

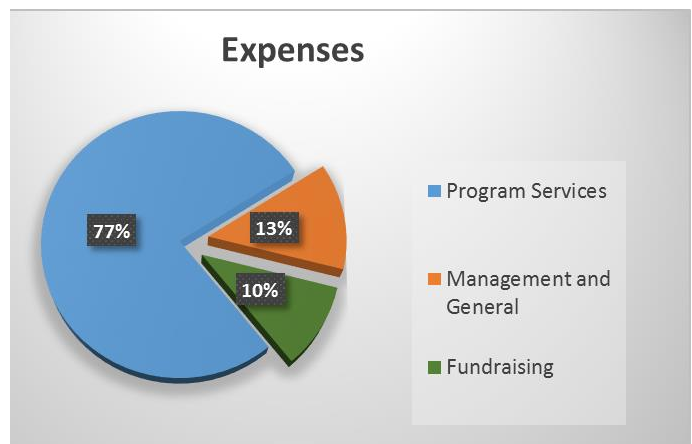
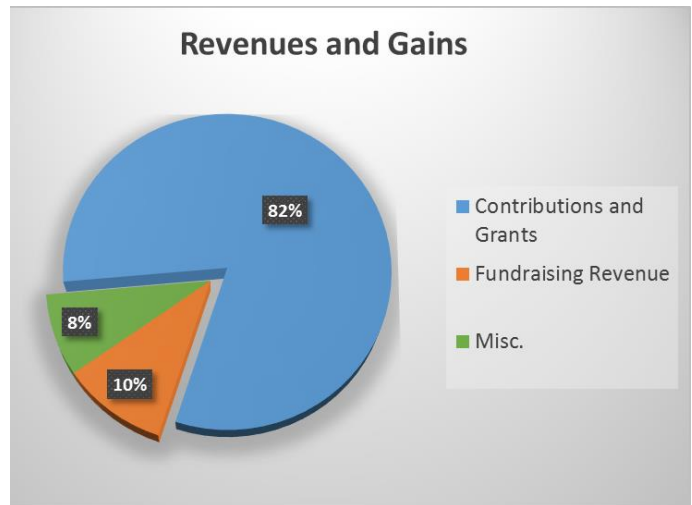
Abbott Laboratories	Great Call
Acorda Therapeutics	Johnson & Johnson
Alkermes, Inc.	Kimberly Clark
Allergan USA, Inc.	Merck & Co., Inc.
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AMGEN	Patient Centered Outcomes Research Institute
Astellas	Pfizer, Inc.
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ChemoCentryx	Sunovion
EMD Serono	Teva
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Sponsors of 2016 Creating the Voice: A Celebration of Family Caregiving

Bristol-Myers Squibb
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Sunovion
United Healthcare

FY17 FINANCIALS

Assets		
Current Assets		
Cash and Cash Equivalents		\$ 232,850
Accounts Receivable		289,223
Prepaid Expenses		<u>18,871</u>
Total Current Assets		<u>540,944</u>
Net Property and Equipment		<u>1,938</u>
Other Assets		
Intangible Assets, Net		28,119
Deposits and other assets		13,800
Total other Assets		<u>41,919</u>
Total Assets		<u>\$ 584,801</u>
Liabilities and Net Assets		
Current Liabilities		
Accounts Payable		4,290
Accrued Liabilities		33,128
Total Current Liabilities		<u>37,418</u>
Net Assets		
Unrestricted		547,383
Temporarily Restricted		-
Total Net Assets		<u>547,383</u>
Total Liabilities and Net Assets		<u>\$ 584,801</u>





CAREGIVER ACTION NETWORK

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Caregiver Action Network (CAN) is the nation's leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with special needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer's disease. CAN (the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.