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Dear Friends,

Family caregivers, who have been largely absent in our cultural dialogue and environment, are now becoming more visible. They are featuring more prominently in movies, the media and in the public square of ideas—a huge difference from just a few years ago.

More visibility, more opportunities to help
We’re learning that caregivers are performing more complex care and medical tasks at home, that more young people are providing care to a family member, and that caregivers across diverse communities and cultures need more relevant support and resources.

These insights are driving important changes in policy, health care and human services. In fact, California has taken an unprecedented step by addressing caregiver impacts, concerns, and needs as part of its Master Plan for Aging. This is a bold and future-focused effort by the country’s most populous state—one that we hope will serve as a model to others.

As an organization that’s been a champion and advocate of family caregivers for more than 40 years, we couldn’t be happier with this growing recognition for the role.

In this time of growing need, we’re there for family caregivers
During the fiscal year 2021-2022, FCA continued to meet family caregivers where they are, with the right resources at the right time.

We assisted more than 3,000 caregivers in the San Francisco Bay Area with direct services such as counseling, personalized care plans, training, respite and support groups. Through online and telephonic support, we helped many more across the country and now serve family caregivers in all 50 states. In collaboration with our partners, we expanded online platforms, tools and data-driven technologies to better serve caregivers along their caregiving journey.

These successes were made possible through the skilled and dedicated work of our incredible team, and because of the commitment and generosity of our partners, funders and donors.

Thank you for joining us in creating a stronger, brighter future for family caregivers. We couldn’t do this work without you!

Sincerely,

Kathleen Kelly
Executive Director, Family Caregiver Alliance

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Our Impact

As the go-to resource for caregivers of adults with physical and cognitive impairments, we occupy the unique role of serving caregivers both locally and at the regional and national levels.

In 2021-2022, we assisted family caregivers in the San Francisco Bay Area’s six counties* with one-on-one support, referrals to community resources and other enhanced services. For caregivers outside the Bay Area, we provided extensive online resources, expert guidance and customized support.

*Alameda, Contra Costa, Marin, San Francisco, San Mateo, and Santa Clara

SAN FRANCISCO BAY AREA
FCA serves as the Caregiver Resource Center for the Bay Area, one of 11 California Caregiver Resources Centers across the state. This year we provided 3,104 local caregivers with support services.

6,728 hours of assessment, counseling, case management, training & other support activities
578 personalized assessments & care plans
2,274 hours of support group assistance to 129 clients
31,323 hours of respite services to 406 clients
404 hours of training to 59 clients
513 hours of individual therapeutic counseling to 110 clients

NATIONAL
FCA established The National Center on Caregiving in 2001 to advance policies and programs for family caregivers in every state. Our website, caregiver.org, acts as a key hub for sharing resources and information with caregivers everywhere.

1.75M website visitors from the US & 200+ countries
2.1M sessions
50 states in which we have supported family caregivers
3.1M pageviews
Expanding Access Through Virtual Programs

In response to public health protocols early in the pandemic, FCA quickly pivoted to a remote support model, launching an expanded suite of classes and events for family caregivers that augmented our existing online and telephonic resources.

Since then, we’ve continued to adapt our programming to meet caregiver needs—including an enhanced focus on young caregivers and those from diverse communities. Here are some highlights from 2021-2022.

1,665 ONLINE PARTICIPANTS

- 12 online classes ▶️ 211 attendees
- 10 online webinars ▶️ 860 participants

7 SUPPORT GROUPS HOSTING 129 CAREGIVERS

“...it’s difficult to manage all aspects of life while being a primary caregiver. The resources and expert information available from FCA has eased a lot of anxiety and unknowns, which has made me a better caregiver.”

-Family Caregiver, northern California
Resiliency

Enhancing Awareness Among Family Caregivers

In mid-2021, after 15 months of pandemic caregiving, family caregivers’ health and well-being were cratering. Many faced an unrelenting horizon of continued isolation, infection prevention, and health care challenges for themselves and their care recipients.

We knew that to help more caregivers, we had to reach more caregivers—including those who had not yet heard of FCA. Here are some ways we engaged new and existing caregiver clients over the last year.

BRAND REFRESH
We modernized our logo, refreshed our brand and launched an all-new website.

ANIMATED VIDEOS
We released an explainer video of CareNav™, plus a series of animated videos highlighting Caregiver.org in English, Spanish, Chinese, Tagalog and Vietnamese.

10 NEW INFOGRAPHICS
Based on our most popular fact sheets — all translated into 4 languages.

NEW & TRANSLATED FACT SHEETS ON A RANGE OF CAREGIVING TOPICS
- 71 translations
- 8 new fact sheets
- 3 updated fact sheets

22 WEBINARS, VIDEOS AND SHORT INFO VIDEOS
Added to our YouTube channel.

883 MEDIA MENTIONS

26,523 SUBSCRIBERS
Across 4 e-newsletters.

56,149 SUBSCRIBERS & FOLLOWERS
Across our social media platforms.

MORE RESOURCES FOR DIVERSE COMMUNITIES

To meet the increased need of family caregivers from diverse communities, we redoubled our efforts to make resources and information available in multiple languages.

- All-new classes and events in Chinese, Spanish and Tagalog
- A new Spanish language e-newsletter
- Dozens of fact sheets and videos translated to Spanish, Chinese, Tagalog, Vietnamese and Korean.
Expanding CareNav™ to Improve Services Throughout California

CareNav™ was developed by FCA as the first social-care record system for family caregivers. In addition to providing key caregiver information and support, CareNav data contributes to annual reporting and evaluation by the California Caregiver Resource Center system, in partnership with UC Davis.

Over 2019-2020, CareNav™ was deployed and integrated across all 11 California Caregiver Resources Centers (CRCs) as part of a state-funded expansion of services for California’s 4.5 million family caregivers.

Never before have social service organizations been able to access so much aggregate data in real-time across such a large caregiving population—or across an entire state. By year-end 2021, the platform was already delivering valuable data insights at the individual and population levels, enabling CRCs to improve service recommendations and delivery, identify and mitigate risk for caregivers and better support them—especially those from vulnerable communities.

See the 2021 report Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile for an in-depth analysis of the CRC expansion project and top findings.

2,414 intakes and calls for information & assistance

What is CareNav?
CareNav is a free, secure online tool that uses information provided by caregivers to customize a user-friendly dashboard loaded with personalized caregiving resources.

“I cannot believe what a difference FCA has made in my life and in the lives of my family members.”
—Family Caregiver, San Francisco County, CA
Launching the Nation's First Database for Dementia Caregiving Best Practices

Family caregivers of those living with dementia are twice as likely as other caregivers to report adverse effects of caregiving on their physical and emotional health, financial situation and personal relationships.

To improve accessibility of services for these caregivers, FCA partnered with Benjamin Rose Institute on Aging to create Best Practice Caregiving (BPC), a groundbreaking online resource. Three years in the making, the site launched in January 2020.

Now, for the first time, health care and community service organizations, providers, funders and policy makers have a comprehensive, one-stop resource to learn about, compare and adopt top dementia caregiver programs that are implementation-ready and proven to improve caregivers' lives.

WHAT IS BEST PRACTICE CAREGIVING?
Best Practice Caregiving is an online database of 44 evidence-based dementia caregiver programs. It’s searchable, free and easy-to-use.
To learn more, visit the BPC site.

BEST PRACTICE CAREGIVING SITE ACTIVITY

38,868 users
54,305 sessions
181,943 page views
147,236 Twitter impressions
40,274 LinkedIn impressions
9,805 reached on Facebook

A BPC SITE FOR FAMILY CAREGIVERS IS NEXT:
Inspired by BPC’s successful launch, partner organizations are developing a site targeted to individual family caregivers. It’s slated to launch in 2023.
Serving More Caregivers Through Partnerships

In addition to assisting family caregivers directly with resources and support, FCA works with partners to strengthen caregiver assistance at the local, regional and national levels through collaborative programs and initiatives.

In partnership with organizations such as state Area Agencies on Aging, universities and nursing schools, health systems, state health departments and dozens of other government agencies, foundations and peer organizations, we’re extending our reach to improve the lives of family caregivers and the people who receive their care. Here’s a look at some of our key partnership initiatives in 2021-2022.

Caregivers Count Conference, an annual event for friend and family caregivers in the Bay Area covering a wide range of caregiving topics.

Panelist Veronica Bedon of AARP joined a discussion following a screening of the Spanish-language documentary “Enid & Mami,” which offers a glimpse into the humor, honor and hardship of being a family caregiver.

I have profound gratitude for FCA—the services I received are exactly what I needed, at the right time, and promptly provided. Contacting FCA was one of the best decisions I’ve made during the [caregiving] process.

–Family Caregiver, Alameda County, CA

Stanford University’s Parkinson’s Caregiver Support Group Leader Denise Dagan joined a panel discussion following a special screening of the documentary “SPARK: Robin Williams and his Battle with Lewy Body Dementia,” in partnership with the Brain Support Network.

Pictured: Denise Dagan
Leveraging Research to Better Serve Present and Future Caregivers

Improving support and services for family caregivers requires a deep understanding of their lived experience, including their needs, caregiving tasks, family situations, challenges and more. That’s why FCA has a long history of collecting caregiver voices and perspectives—through thousands of intake conversations and interactive events, panels and classes, as well as more formalized research projects featuring listening sessions, focus groups, surveys and interviews.

As a pioneer of data-led research in the caregiving space, we track not only the needs and challenges of individual caregivers but also the caregiving trends at both the community and regional levels. As an advocate for all caregivers, we bring the voice of the caregiver to the table to design programs, craft policy and embark on partnerships that will advance the caregiver cause at local, state and national levels.

PARKINSON’S DISEASE & LEWY BODY DEMETIAS
In this NIH-funded project, FCA is part of a research team assessing digital delivery of support services to family caregivers of adults with Parkinson’s and Lewy Body Dementias across 24 service sites nationwide.

FAMILY CAREGIVER SUPPORT
FCA is facilitating listening sessions, caregiver interviews and other forums to generate insights, data and recommendations that inform caregiving reports by local government agencies.

CARENAV™
UC Davis researchers are examining assessment and service usage data pulled from CareNav to evaluate the California Caregiver Resource Center system.

LOOKING AHEAD:
FCA recently partnered with the USC Family Caregiver Support Center to launch the California Coalition on Family Caregivers. This broad coalition of caregivers and organizations will amplify the voice of family caregivers in the state capitol and in local communities as we work towards a vision of supporting caregiving families throughout the state.
The mission of Family Caregiver Alliance is to improve the quality of life for family caregivers and the people who receive their care.

OUR PROJECT PARTNERS IN 2022

- Alzheimer’s Association
- AARP
- Benjamin Rose Institute on Aging
- Betty Irene Moore School of Nursing at UC Davis
- Brain Support Network
- California Caregiver Resource Centers
- Community Tech Network
- The Gerontological Society of America
- The Hummingbird Project
- Kimochi
- Lewy Body Dementia Association
- Memory and Aging Center, University of California, San Francisco
- Mission Hospice
- Openhouse
- Tight Knit
- Healthy Brain Initiative | Santa Clara County Public Health Department
- Self-Help for the Elderly
- SteppingStone

To learn more about our work and services, visit caregiver.org.

See our funding partners on our website.