

THE SPLIT

Split

Two nonprofits, now separate, continue to fight Alzheimer's

HEALTH REBUILDING AFTER

By Courtney Perkes

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For three decades, the Alzheimer's Association Orange County chapter was the go-to name for dementia support here. But after a split a year and a half ago, the nonprofit was left with little besides its brand.

The chapter, which is part of the national Alzheimer's Association, has started over by hiring new staff, re-establishing support groups and recently moving to a permanent office.

"The priority is the same," said Anne Grey, executive director of the Alzheimer's Association Orange County chapter. "While we work really hard to raise money to fund research with an end goal of treatment and a cure, providing support and education programs are really the hallmarks of the Alzheimer's Association. Letting people know we're here and we do provide these services is always job one."

In December 2015, the nonprofit, then operating as the local Alzheimer's Association chapter, announced that it was breaking away from the national organization to create Alzheimer's Orange County. Alzheimer's Orange County kept its Irvine headquarters, phone number and all but two of 33 employees and one board member.

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— *Jim McAleer, CEO of Alzheimer's Orange County in Irvine*

PAUL RODRIGUEZ — STAFF PHOTOGRAPHER



“For me, while the split was very devastating as anything like that is, ... we get to look at everything with fresh eyes.”

— Anne Grey, executive director of the Alzheimer’s Association Orange County chapter, in the association’s new offices in Orange

SAM GANGWER — STAFF PHOTOGRAPHER

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The group, which left in order to retain local control of funds, changed its signature color from purple to blue and expanded into direct patient care through adult day programs.

While there’s been some confusion about the two nonprofits, which both offer 24/7 help lines and hold annual fundraising walks, observers say there’s plenty of need to go around because of the county’s rapidly aging population.

“Both are in some ways in periods of new beginnings, but both are really vital to the county,” said Joshua Grill, an Alzheimer’s researcher at UC Irvine. “We’re incredibly lucky to have very strong organizations devoted to families and providing service and advocating for research, where this quite frankly is a bigger problem than in almost any other part of the country.”

Old name, new group

On the same day that Alzheimer’s Orange County announced its independence, the national association said it would create a new chapter to continue its work in Orange County.

Two months later, in February 2016, the Alzheimer’s Association re-established the chapter in temporary office space in Costa Mesa.

The chapter retained two employees, including Susannah Morales, program and education manager. Last month, the scaled-down group reached full staffing with 13 employees.

“For me, while the split was very devastating as anything like that is, what has been really neat about going from that two to 13, is we get to look at everything with fresh eyes,” Morales said. “While I stayed here and we’re smaller now, we still have that same mission that I believe wholeheartedly in.”

Grey, who was hired last summer, said when her grandfather, a retired air traffic controller, battled Alzheimer’s in the 1990s, her family had no idea about the available resources.

“If we’d known about the Alzheimer’s Association, it probably would’ve been an easier path for us,” Grey said. “We just didn’t know you could make a phone call and have your question answered.”

In March, the group moved into permanent offices in Orange. Board member Paul Wexler, who chose to remain with the association, said he’s pleased with the progress that’s been made so far.

“Our association has been involved in Orange County for over 30 years, so we wanted to maintain that activity moving forward,” said Wexler, who also sits on the national board.

The association is working to rebuild its budget and fundraising. Last year’s Walk to End Alzheimer’s raised \$353,000 and the goal for this year’s event is \$535,000.

“We have projected to be on track to where we were prior by this time next year,” Grey said. “When something splits, there is a dip for both organizations until the paths become very clear and people know this is where my passion lies and where I’d like to direct my support. For people who want research to find a cure and support the organization with the strongest global impact in Alzheimer’s, that’s us.”

Joanna Richardson-Jones, CEO of the Alzheimer’s Family Center in Huntington Beach, said she refers families to the local Alzheimer’s Association because she supports the national initiative. She also criticized Alzheimer’s Orange County for breaking away and providing day programs open to seniors without memory impairment.

“I believe that given time and marketing dollars the old national Alzheimer’s Association can be great again,” Richardson-Jones said. “It’s not going to be very easy because they have almost something like a resistance by the other organization.”

Jim McAleer, CEO of Alzheimer’s Orange County, who began leading what was then the national chapter in 2004, said most adult day care programs serve a high percentage of dementia patients.

He and Grey said they each refer to the other organization and say the success of the other benefits the community.

“If ours doesn’t resonate with you, you’ve got other places to go,” McAleer said. “And if they don’t have what you need, maybe we do.”

New name, expanded mission

Alzheimer’s Orange County is the third name for the grassroots nonprofit that started in 1982 when a group of caregivers founded the Alzheimer’s Disease and Related Disorders Association of Orange County Inc. In 1984, the group joined the national Alzheimer’s Association.

But McAleer’s group decided to change course in late 2015 after the Chicago-based parent association said it would merge 54 independent chapters into one in order to have a unified strategy for attacking the brain disease. Orange County, along with five other large chapters across the U.S., left to maintain local control of their budgets and programs.

Cutting ties gave Alzheimer's Orange County the freedom to offer direct patient services at two adult day care centers. Before the disaffiliation, the group raised about \$5 million a year but sent 40 percent to Chicago. Now all funds stay here. The group continues to fund Alzheimer's research, with an emphasis on clinical trials, and offer support groups and caregiving classes.

"In a year and a half, we've taken quite a lot of steps of growth that have been really wonderful," McAleer said. "Our point of existence has always been direct service."

Last year, Alzheimer's Orange County took over operations of South County Adult Day Services in Laguna Woods. In April, the group announced a merger with Acacia Adult Day Services of Garden Grove.

"More are going to be needed as seniors continue to rapidly increase and age into needing medically supervised day care," said Holly Hagler, CEO of SeniorServ, a nonprofit based in Anaheim. "We're very happy, particularly, to see nonprofits are increasing their scope in this arena."

McAleer said those programs have bolstered revenue because of insurance contracts and donor enthusiasm for providing scholarships for the care, which allow seniors to remain at home because their caregivers can work or get a break.

In 2014, 11.7 percent of Orange County residents over 65 were treated for dementia, a figure higher than the state and national averages, according to a 2016 report funded by the county's Health Care Agency. An estimated 84,000 residents have Alzheimer's or dementia, and 34,000 people care for a loved one.

"We're quick to be grateful for both organizations and mention both in the same sentence and help people understand their multiple sources to get education or support services," Grill of UCI said. "I think we're all watching as these two organizations evolve locally and I suspect will more and more carve out unique roles that I think will synergize."



The staff of Alzheimer's Association Orange County chapter in the association's new offices in Orange. Sitting, from left, are Gina Moran, volunteer; Susannah Morales, program and education manager; Anne Grey, executive director; Deborah O' Connor, programs director; Jennifer Mower, director of development; Emily Hilker, walk manager. Standing, from left, are Jody Willis, program and education assistant; Daniel Gaytan, public policy manager; Jessica Houston, community engagement specialist; Larissa Haiker, program and education specialist; Kenzie Durham, mass marketing manager; Julia Dres, communications manager; and Alex Zeroski, development coordinator.

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