

SPECIAL REPORT

Leading Alzheimer's group splinters over claims of misplaced priorities and lavish spending



SANDY HUFFAKER FOR STAT

Patients and caregivers engage in movement class at the Alzheimer's San Diego Center.

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The Alzheimer's Association, one of the country's most powerful disease advocacy groups, is rupturing amid an escalating dispute over its priorities: raising money for a future cure versus supporting patients and families struggling with the disease right now. Prominent chapters in Los Angeles, New York City, San Diego, and elsewhere have pulled out of the national association in recent months. The defectors accuse administrators of spending lavishly on salaries and travel, retaliating against breakaway chapters, and focusing too much on raising money for research and lobbying at the expense of [local programs](#), such as exercise classes and outings for Alzheimer's patients. The depths of the discord emerged in interviews by STAT with more than a dozen current and former association officials.

“Their message revolves to a large extent around fear: ‘This is such a terrible disease, and it has to be eliminated,’” said Christian Wells, president of the former chapter in Austin, Texas, which broke from the national association in January. “We prefer a message of hope: ‘There’s life with and beyond Alzheimer’s.’”

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The tensions among groups that collectively raise more than \$300 million a year comes at a time of rising concern about Alzheimer's, which affects more than 5 million Americans today and is expected to afflict more than 10 million by 2050. Its long, painful trajectory makes it the [most expensive](#) disease in America.

In response to the [growing number of patients](#) with dementia, the national Alzheimer's Association is moving to centralize and standardize its programs from coast to coast. It's requiring all local chapters to dissolve their boards of directors and transfer their assets to the national organization by July 1. All major decision-making will now come out of headquarters.

Such consolidation is necessary because “the disease is on a steep trajectory,” Stewart Putnam, chairman of the national board of directors, told STAT. “We feel very strongly that we need to enhance our performance.” Putnam pointed to the group's lobbying efforts in Washington, D.C., which helped secure a record \$350 million increase in federal funding for Alzheimer's research this year, as a sign of the national association's success. And leaders of chapters sticking with the national association said they are confident patients will be served well by the reorganization.

But local activists worry that the new structure will hamper their ability to respond to unique community needs.



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Patients and caregivers engage in a movement class at the Alzheimer's San Diego Center.

Magic shows and chocolate tastings

In San Diego, for instance, chapter leaders feared the centralization plan would force it to scrap the weekly Memories in the Making class, which brings dozens of patients and caregivers together to paint or exercise, then takes them on social outings — recently, to a chocolate tasting.

“It really is about building a sense of a local community, because people are so isolated,” said Mary Ball, the nonprofit’s executive director. “We make it possible for people to set aside the disease, if only for a while.”

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The Los Angeles chapter has a similar program that has taken patients to the farmer’s market and treated them to magic shows. “The national program staff made it very clear that this was ... outside the common program plan and they were not happy we had started it,” said Susan Galeas, the president and CEO.

In Austin, Wells said she worried a caregiver respite program would be cut; it trains volunteers to work with Alzheimer's patients so their families can get a break for a few hours each week. "Over time, the national organization has become less focused on grassroots, high-touch care — the priority of our leadership here," she said.

Chapters have been especially exasperated by the national association's decision to funnel phone calls from people seeking help to a 1-800 hotline in its Chicago headquarters, rather than handling them locally. They say families in crisis need to connect with local advocates who can help them navigate local resources — not a central bureaucracy.



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Mary Ball, president and CEO of Alzheimer's San Diego.

Questions about spending and salaries

When the Alzheimer's Association held a non-binding referendum on its new direction last fall, chapters were evenly split: 27 in favor, 27 against. The national board overwhelmingly approved the plan two weeks later.

Since then, chapters in San Diego, Los Angeles, Austin, New York City, northern New Jersey, and Orange County, Calif., have defected and are now contemplating forming a new national federation. Several other local leaders privately said they wanted to strike off on their own, but didn't have the financial wherewithal.

Other chapters, however, remain loyal. “We have a lot of faith in the national organization, and we believe it is uniquely positioned to offer families an opportunity to change the future of this illness,” said William Fisher, chief executive of the association’s chapter in Northern California and Northern Nevada. Altogether, 48 independent chapters remain on board.

It’s unclear how donors and volunteers will respond to the internal conflict that has split the association, which collected \$166 million in contributions and grants in 2015, according to its annual report. Local chapters separately raised nearly \$155 million from walks and other fundraisers last year — money that will now come under the national association’s control.

“When an organization goes through something like this, it’s a tricky journey because you risk damaging trust and losing your supporters along the way,” said Regina Birdsell, president of the Center for Nonprofit Management in Los Angeles.

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The defectors have raised questions not just about the organization’s priorities, but also about its spending.

The San Diego chapter last year [compiled data](#) from the Alzheimer’s Association’s tax forms from 2005 to 2013.

According to that analysis, national spending on travel quadrupled and executive salaries nearly tripled during the nine-year period. Total 2013 compensation for Harry Johns, the association’s chief executive officer, reached \$2.8 million — one of the highest salaries for a nonprofit executive in the nation.

Rent for an office on Chicago’s swank Magnificent Mile nearly tripled, the analysis found.

Meanwhile, grants to researchers declined to \$13 million a year from \$21 million, a drop of 38 percent.

“Our board was very disappointed and dismayed by these results,” said Ball, the San Diego chapter leader.

The national association disputes the analysis, saying it doesn’t account for all its research-related activities, including international conferences, a scientific journal, and a service that facilitates patient enrollment in clinical trials of new drugs. Putnam, the national board chair, also asserted the association was “the primary organization” pushing Congress to dramatically hike federal funding for research.

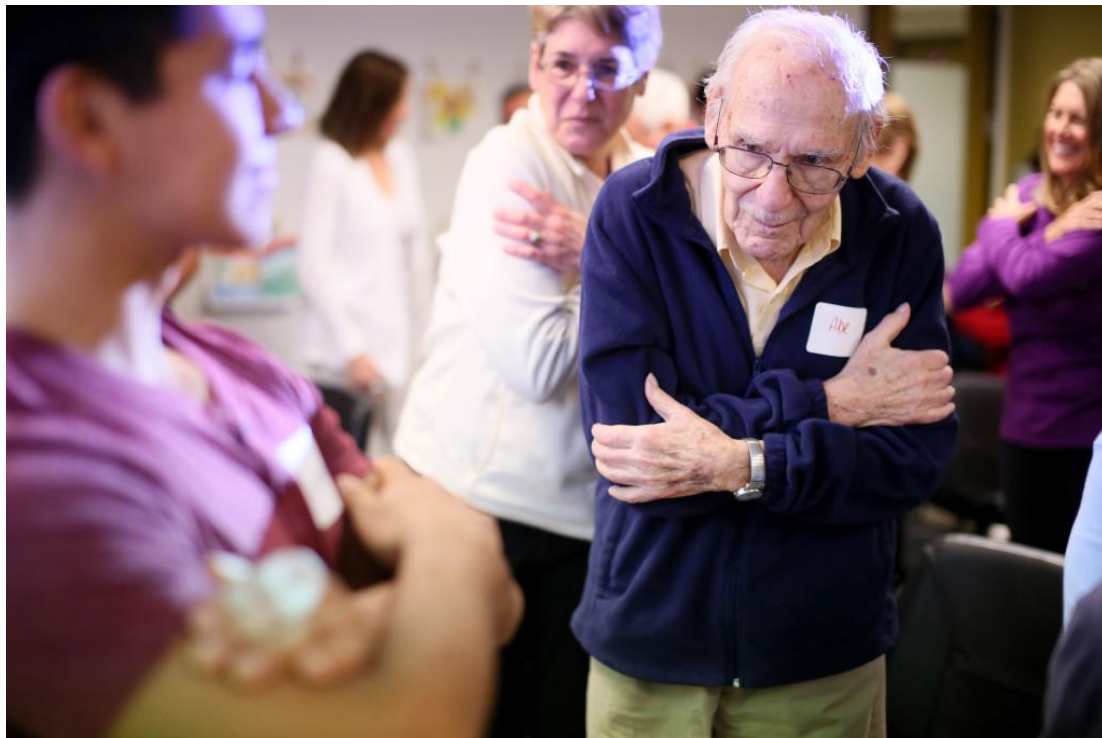
As for the emphasis on fundraising, Putnam said: “I’m not sure how any of the work happens without generating the resources to do it.”

He defended the chief executive’s salary as “reasonable” and in line with market demands.

Supporters at remaining chapters said they’re confident the national association will remain attentive to Alzheimer’s patients and families’ needs.

The organization has created a national task force to evaluate programs and decide which are worth replicating across the country. Top priorities include helping families coordinate care and training caregivers to handle erratic behavior. The goal is to “really have an impact” by identifying best practices, said Stacy Tew-Lovasz, executive director of the St. Louis chapter, which is sticking with the national group.

The task force is also drafting standards for delivering [dementia care](#) in nursing homes and other health-care settings, said James Wessler, who runs the association’s affiliate in Massachusetts and New Hampshire.



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Alzheimer’s patient Abe Horstain engages in movement activities at the Alzheimer’s San Diego Center.

Dueling fundraising walks

Since the split, some of the defectors have accused the national organization of vindictive behavior.

The newly independent San Diego chapter, for instance, scheduled a fundraising walk for next fall. The national organization then scheduled its own walk in the city, for a month earlier.

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All chapters that have broken away in recent months report that the national association has begun contacting their donors. Most say it has opened satellite offices in their areas. All have had their email systems and websites shut down and are facing demands that they return assets to the Chicago headquarters.

“They seem to think all the money we’ve raised is rightfully theirs,” said Galeas of Los Angeles.

“When we disaffiliated, we hoped that we would come to a quick and amicable resolution of any outstanding issues, but that hasn’t happened,” said John Nienstedt, chairman of the group now known as Alzheimer’s San Diego. “Instead, they’re being very aggressive.”

Asked about the national group’s tactics, Putnam said its mission called for it to have a presence “in all parts of the country.” The organization has a responsibility to protect itself and the funds supporters have contributed, he said.

Tension building for decades

The “care vs. cure” tension splitting the organization today has been bubbling below the surface for decades.

Bill Keane, a former hospital administrator and elder care consultant who served on the Alzheimer’s Association’s board for most of the 1990s, said “there was always a lot of friction” over whether to focus on caring for current patients or pouring resources into a future cure. Services for families “typically got the short end of the stick” compared to research, he said.

“We’d go to meetings and the discussions wouldn’t be about how we could help people,” said Alice Watkins, executive director of the North Carolina affiliate, which split from the

national group in 2009 in an earlier wave of defections. “It was more, ‘We’ve got to raise more money for the cause and get more people concerned about Alzheimer’s.’”

Chapters in Wisconsin, eastern Tennessee and Long Island, N.Y. all left the national association in that earlier wave, which was propelled by concerns over the group’s mission and spending priorities.

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During that time of tension, Dan Kuhn, who directed professional training at the Greater Illinois chapter for five years, pressed chief executive Johns about the intense focus on raising money to fund a cure. “What if there is no cure?” he recalls asking. “What do we do for millions of people in the meantime?”

The answer, he said, was that a cure would come — and that the association would help find it.

Kuhn left the Alzheimer’s Association in 2010 after it moved its professional education programs online. Several former association officials said they worried online training would replace more face-to-face programs under the new structure.

Putnam, the national board chair, dismissed the criticism of the association and said the group would continue to act in the best interest of patients and families across the United States. “The main emphasis of the national board,” he said, “is to take care of more people, not less.”

A previous version of this story misstated the title of Susan Galeas, president of the Alzheimer’s group in Los Angeles.

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