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Support Still Strong for ALS Awareness

By Daniel Smith



Caitlin Januszewski of Orinda was doused by Matt Chaney's son, Brian, during last year's Ice Bucket Challenge. Photo provided

over 100 to the Orinda Country Club venue. Brian Griggs, the evening's event chair, revealed that ALS "has an unfortunate place in the (Orinda Country Club)." In the last decade, OCC has lost five members to the disease. An astronomical figure considering the number of cases is about 3 per 100,000.

Three guests living with ALS were joined by an entourage of supporters. Among them was Lafayette resident Matt Chaney. Griggs, in addition to his duties as event chair, was also there for Chaney. The two are old friends. Both coached little league before Chaney's diagnosis in 2001. It was Chaney's decision to join The ALS Association that inspired Griggs to get involved.

Chaney has received wider support from Lafayette as well. The Lafayette City Council last year gladly rose to the Ice Bucket Challenge when Chaney challenged them. Chaney, reciprocating the show of solidarity, took the frigid dousing alongside them. "I love living in Lafayette," said Chaney.

Detractors of the Ice Bucket Challenge were skeptical whether the social media sensation could muster significant money, but attendees from The ALS Association Golden West Chapter were quick to point out that the intake of money had been good. Quite good. Over \$200 million was raised worldwide for ALS charities. The ALS Association, which is entirely dependent on donations, received \$115 million of that. By comparison, the organization received only \$18.1 million during the entirety of 2013. Of the 3 million people who donated, 2.5 million were doing so for the first time. The Golden West Chapter members were anything but reserved in sharing how they have spent the Ice Bucket Challenge money.

The ALS Association donated \$77 million to research. They awarded \$1.5 million to Cytokinetics, a South San Francisco biopharmaceutical company. Robert Blum, CEO and president of Cytokinetics, made a momentous announcement before a rapt audience at Life Vines: Thanks in part to this grant, his company has just launched late-stage clinical trials for their developmental new drug, Tirasemtiv. The drug offers a new hope for ALS patients whose only current FDA approved treatment is Riluzole, which can cost patients \$1,200 a month while only extending their lives by mere months.

The ALS Association feels it's important to expedite drug research into the late-stage trials, bringing potential life-prolonging medicine to desperate ALS patients who usually only live two to

Remember the ALS Ice Bucket Challenge last summer? Your Facebook feed was probably filled with videos of friends and celebrities pledging their support in the battle against ALS (amyotrophic lateral sclerosis), then pouring a bucket of ice water over their heads. In doing so they earned the privilege of calling out others to do the same. On and on it went, each time more elaborate, or with bigger buckets or bigger names.

Critics accused the social media trend of encouraging more self-applause than activism or philanthropy. They speculated that the ALS awareness generated was wider than it was deep and prognosticated fading public interest.

If the Live Vines Wine Tasting and Auction on July 16 was any indication, both interest and financial support remain strong. The public fundraiser brought in \$38,000 for The ALS Association Golden West Chapter, a top rated nonprofit, and drew a thoroughly engaged crowd of

five years past diagnosis. Besides, argues Golden West Chapter CEO and President Fred Fisher, "the cure for ALS isn't going to be found in a lab, it will be found in a patient living with ALS."

Another \$23 million has gone toward patient and community services. This money helps fund ALS Association Certified Centers of Excellence. These are multidisciplinary treatment centers that act as "one stop shops" where patients can receive all of their doctors, specialists, equipment, and medicine in one location. Simple concept, massive benefits. According to The ALS Association, these certified centers can significantly extend life expectancy.

Despite real progress, the biggest buzz of the evening still concerned the Ice Bucket Challenge and the revelation that The ALS Association is already underway on an ambitious public relations campaign to revive it for a second summer beginning in August. When asked how many seasons the challenge might last, members were unanimous in their response: "Every summer until a cure." Expect to see that slogan soon.

Of course, the association is sensitive to environmental realities. Fisher offered this drought-conscious advice: "It's important for people to understand that it's called the ALS Ice Bucket Challenge, even if you pour a bucket of straw over your head."

The ALS Association Golden West Chapter will be hosting their bike-riding fundraiser Napa Valley Ride to Defeat ALS on Sept. 26 and their East Bay Walk to Defeat ALS on Oct. 24. More information can be found online at: www.alsagoldenwest.org.

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[back](#)

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