

DATE: June 26, 2023

FROM: Barb Leetch, Region VIII Alzheimer's Coordinator

TO: Region VIII VP, Federation Presidents and Alzheimer's Coordinators

SUBJ: NARFE Region VIII Alzheimer's Association Report for May 2023

As of the end of May, the NARFE fundraising total was \$15,741,860. This amount includes the Longest Day totals and the Walk to End Alzheimer's for 2022. The total amount includes the money raised (\$78,610) from the NARFE teams participating in the 2022 Walk to End Alzheimer's and the donations received (\$2,625) from the Longest Day in 2022. Also, planned gifts received in FY 2023 in the amount of \$767,749 were posted. The planned gifts amount will be updated monthly as more gifts are received throughout the year. During the month of May, our members raised a total of \$30,966, down \$99,645 from donations received in May 2022. The amount raised by Region VIII in FY 2023 is \$15,439 which is up \$1,957 from the same reporting period in FY 2022. Below is the breakout by Federation for both reporting periods:

	FY 2023	FY 2022	Difference	
California	\$12,373	\$10,999	\$ 1,374	
Hawaii	\$ 2,209	\$ 1,642	\$ 567	
Nevada	\$ 2,290	\$ 2,481	-\$ 191	
Total	\$16,872	\$15,122	\$ 1,750	

The new fundraising goal is \$16 million by December 31, 2025.

Fiscal Year 2023 covers the period July 1, 2022, through June 30, 2023.

The Longest Day was on June 21, 2023. The Longest Day is the day with the most light – the summer solstice. On this day, people from across the world fought the darkness of Alzheimer's through a fundraising activity of their choice. You can still register at alz.org/tld. I am fundraising for this event. You are welcome to join my team and donate at alz.org/tld – team name is NARFE CA Federation. Fundraising is through July 31, 2023

Walk to End Alzheimer's. The NARFE Goal for the 2023 Walks is \$100,000. To date, \$21,923 has been raised. Teams can now register for the walk this year at

<u>alz.org/narfewalks</u>. The Walk is the largest fundraiser for Alzheimer's care, support, and research. The name "NARFE" should be included in the team's name. You will be making a difference! The place and date for the 2023 Walks in Region VIII are shown below.

Walk Location	2023 Walk Date		
Aptos, CA	9/23/2023		
Bakersfield, CA	10/21/2023		
Chico, CA	10/14/2023		
Escondido, CA	9/23/2023		
Eureka, CA	10/14/2023		
Fresno, CA	10/21/2023		
Hermosa Beach, CA	10/7/2023		
Huntington Beach, CA	11/4/2023		
Imperial County, CA	11/19/2023		
Irvine, CA	10/21/2023		
Long Beach, CA	10/28/2023		
Los Angeles, CA	10/28/2023		
Merced, CA	10/7/2023		
Modesto, CA	9/9/2023		
Monterey, CA	10/7/2023		
Orcutt, CA	9/30/2023		
Oxnard, CA	9/23/2023		
Palm Desert, CA	11/4/2023		
Rancho Cucamonga, CA	10/14/2023		
Rancho Mission Viejo	9/30/2023		
Redding, CA	9/23/2023		
Ridgecrest, CA	10/28/2023		
Rohnert Park, CA	10/7/2023		
Sacramento, CA	9/30/2023		
San Diego, CA	10/7/2023		
San Fernando Valley, CA	10/22/2023		
San Francisco, CA	11/4/2023		
San Jose, CA	10/14/2023		
San Luis Obispo, CA	11/4/2023		
San Ramon, CA (East Bay Area)	10/28/2023		
Santa Barbara, CA	10/14/2023		
Santa Monica, CA	10/22/2023		
Stockton, CA	10/14/2023		
Suisun City, CA	10/21/2023		
Temecula Valley, CA	10/7/2023		
Valencia, CA	10/7/2023		
Visalia, CA	8/20/2023		

West Lake Village, CA	10/21/2023		
Yountville, CA (Napa)	9/9/2023		
Yuba City, CA	9/9/2023		
Kahului, HI	10/21/2023		
Kapa'a, HI	8/26/2023		
Hilo, HI	9/23/2023		
Honolulu, HI	11/4/2023		
Las Vegas, NV	10/28/2023		
Sparks, NV	10/14/2023		

CNN Health — June 9, 2023

An advisory panel for the US Food and Drug Administration voted unanimously Friday that the Alzheimer's drug lecanemab shows "clinical benefit" for the treatment of the disease, paving the way for the medication to be considered for full FDA approval.

A decision from the FDA is expected by July 6.

Lecanemab, a monoclonal antibody sold under the brand name Leqembi, is one of the first dementia drugs that appears to slow the progression of cognitive decline. The drug is not a cure but works by binding to amyloid beta, a hallmark of Alzheimer's disease.

In January, the FDA granted accelerated approval of Leqembi for people with mild cognitive impairment or mild dementia, even though there were some safety concerns due to the treatment's association with certain serious adverse events, including brain swelling and bleeding.

The accelerated approval program allows for earlier approval of medications that treat serious conditions and "fill an unmet medical need" while researchers continue studying the drug to confirm, verify and describe its clinical benefit. If those additional studies show a benefit, the FDA can grant traditional full approval for the drug. But if the confirmatory studies do not show benefits, the drug could be taken off the market.

If lecanemab receives traditional FDA approval, the federal Centers for Medicare and Medicaid Services has said it will provide broader coverage – meaning Medicare patients could get greater access to the treatment. However, the coverage will come with some qualifications.

"If the FDA grants traditional approval CMS is prepared to ensure anyone with Medicare Part B who meets the criteria is covered," CMS Administrator Chiquita Brooks-LaSure said in a statement this month.

Medicare will cover the approved drugs when a physician and clinical team participate in the collection of evidence about how these drugs work in the real world, also known as a registry, CMS said. Providers will be able to submit the evidence through a CMS-facilitated portal.

Patient groups and the pharmaceutical industry, however, have voiced concerns about the use of a registry, saying it will create a barrier to treatment.

FDA-approved Alzheimer's drugs will be covered by Medicare, with some limitations, CMS says.

"We are in full agreement with the FDA Advisory Committee that Leqembi provides clinical benefit and that this benefit outweighs the risks. Now all eyes turn to CMS," Dr. Joanne Pike, president and CEO of the Alzheimer's Association, said in a statement Friday. "Medicare is supposed to be a rock-solid guarantee for Americans, and it is time for CMS to step up and provide Medicare access on the day of an FDA traditional approval. Americans living with Alzheimer's disease deserve access to FDA-approved therapies without barriers, just like people with cancer, heart disease and HIV/AIDS."

The committee's support for lecanemab serves as an "important milestone" on its pursuit for possible full FDA approval, experts say.

"The support vote for Lecanemab is an important milestone for every patient living with Alzheimer's disease, every family with a loved one who is affected by Alzheimer's disease, and indeed every person at-risk for developing Alzheimer's disease in the future," Dr. James Galvin, chief of cognitive neurology and director of the Comprehensive Center for Brain Health at UHealth - The University of Miami Health System, said in an email Friday. He was not involved in the FDA committee's meeting. "It has been nearly two decades since the last Alzheimer's treatment received full FDA approval, and never before has a disease-modifying medication received full FDA approval," he wrote. "This vote today almost assuredly will be followed by two momentous decisions – full FDA approval and agreement by CMS to cover treatment in some form. This is a critical issue to assure that all patients from all social and economic backgrounds have access to medication."

Please remember that Chapter dues CAN NOT be used for donations to the Alzheimer's Association. Even if the Chapter is closing, they cannot donate the funds to NARFE-Alzheimer's Research.

Donations collected from NARFE members should be sent to the Federation Alzheimer's Coordinator for submission to the Alzheimer's Association and not be held for another month.

Thank you so much for all your support to make it possible to improve the lives of so many others!

Regards,

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NARFE/ALZHEIMER'S RESEARCH		BY REGION AND FEDERATION		
CONTRIBUTIONS				
JULY 1, 2022 THROUGH MAY 31, 2023		PER ALZHEIMER'S ASSOCIATION		
NARFE HQ	\$0.00	FY 2023 PGA FIGUR	RES	
ANONYMOUS CASH	\$0.00			
REGION I	\$8,887.75	REGION VI	\$24,589.29	
Connecticut	\$1,140.50	Arkansas	\$5,793.00	
Maine	\$386.25	Louisiana	\$4,491.00	
Massachusetts	\$1,258.00	Oklahoma	\$3,618.29	
New Hampshire	\$4,100.00	Panama	\$0.00	
New York	\$1,903.00	Texas	\$10,687.00	
Rhode Island	\$100.00			
Vermont	\$0.00	REGION VII	\$9,617.26	
		Arizona	\$3,239.00	
REGION II	\$20,665.55	Colorado	\$5,290.50	
Delaware	\$1,340.00	New Mexico	\$693.76	
Dist. of Columbia	\$316.00	Utah	\$150.00	
Maryland	\$8,782.21	Wyoming	\$244.00	
New Jersey	\$2,730.86			
Pennsylvania	\$7,496.48	REGION VIII	\$16,871.50	
		California	\$12,372.50	
REGION III	\$22,777.61	Hawaii	\$2,209.00	
Alabama	\$2,671.50	Nevada	\$2,290.00	
Florida	\$2,881.63	Philippines	\$0.00	
Georgia	\$11,013.68			
Mississippi	\$4,402.04	INTERNATIONAL FEDERATION \$100.00		\$100.00
Puerto Rico/	\$335.00			
Virgin Islands		REGION IX	\$24,180.33	
South Carolina	\$1,473.76	Alaska	\$0.00	
		Idaho	\$5,448.88	
REGION IV	\$21,347.51	Montana	\$605.00	
Illinois	\$6,684.40	Oregon	\$11,209.90	
Indiana	\$4,035.61	Washington	\$6,916.55	
Michigan	\$2,640.00			
Ohio	\$4,380.50	REGION X	\$79,196.89	
Wisconsin	\$3,607.00	Kentucky	\$5,281.60	
(11000110111	70,007.100	North Carolina	\$4,791.00	
REGION V	\$44,942.98	Tennessee	\$4,566.50	
lowa	\$7,336.61	Virginia	\$52,488.13	
Kansas	\$11,910.55	West Virginia	\$12,069.66	
Minnesota	\$5,064.00		,,,	
Missouri	\$3,527.00	July 1. 2022 through	July 1, 2022 through May 31, 2023	
Nebraska	\$1,617.20	, -,		
North Dakota	\$4,645.15	TOTAL	\$273,176.67	
South Dakota	\$10,842.47		A. Williams (Un-Offici	al Report)
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