



DATE: October 2, 2024

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 August 2024

As of the end of August, the NARFE fundraising total was \$16,308,608. During the month of August, our members raised a total of \$15,492, **up** \$1,728 from donations received in August 2023. The amount raised by Region VIII in FY 2025 is \$1,419 which is **down** \$1,717 from the same reporting period in FY 2024. Below is the breakout by Federation for both reporting periods:

	FY 2025	FY 2024	Difference
California	\$ 1,379	\$ 2,835	-\$ 1,456
Hawaii	\$ 40	\$ 195	-\$ 155
Nevada	\$	\$ 100	-\$ 100
Total	\$ 1,419	\$ 3,130	-\$ 1,717

Fiscal Year 2025 covers the period July 1, 2024, through June 30, 2025.

The new NARFE Alzheimer’s Fundraising Goal is \$17 million by December 31, 2026.

The Longest Day 2024. The Longest Day was on June 20, 2024, and is the day with the most light – the summer solstice. Donations for this event are now closed.

Walk to End Alzheimer’s. The NARFE Goal for the 2024 Walks is \$100,000. To date, \$52,164 has been raised. Teams and team members can now register for the walk at alz.org/narfewalks. The Walk is the largest fundraiser for Alzheimer’s care, support, and research. The name “NARFE” should be included in the team’s name. NARFE will be listed as one of the sponsors on the Alzheimer’s Walk banner. Please consider joining one of the following registered walk teams: California – Bakersfield, San Diego and Solano County; Hawaii – Oahu.

Breaking News: Email from Alzheimer’s Association President and CEO Joanne Pike, DrPH on 10/2/24.

I’m excited to share that two of the Alzheimer’s Association’s top bipartisan legislative priorities were signed into law by the president: the NAPA Reauthorization Act and the Alzheimer’s Accountability and Investment Act.

Together, these bipartisan bills renew our nation's commitment to the fight against Alzheimer's and other dementia. They will continue the critical work of the National Plan to Address Alzheimer's Disease to support Alzheimer's research and improve the delivery of clinical care and services for people impacted by Alzheimer's.

The initial laws have had a transformative impact on our nation's ability to meet the challenges of Alzheimer's and dementia, and we are confident the new legislation will support continued progress.

- The **NAPA Reauthorization Act** reauthorizes the National Alzheimer's Project Act (NAPA) by extending the strategic National Plan and emphasizing the importance of healthy aging and risk reduction. Prior to NAPA, there was no comprehensive plan to address Alzheimer's. In 2010, for every dollar the federal government spent on the cost of Alzheimer's care, it invested less than a penny on research for the disease. NAPA fundamentally changed the way the nation addresses Alzheimer's and all other dementia.
- The **Alzheimer's Accountability and Investment Act** builds on the original Alzheimer's Accountability Act, which was first enacted in 2014. This bipartisan legislation ensures Congress will continue to hear directly from scientists at the National Institutes of Health on the Alzheimer's and dementia research funding needed to achieve the goals in the National Plan.

Reauthorization of these bills comes as a result of tireless commitment from our grassroots volunteer advocates, leadership from bipartisan champions in Congress, and relentless work from our public policy staff.

We are at a critical moment in time in Alzheimer's and dementia. As we celebrate the progress we have made, we are also looking ahead to prepare for a changing Alzheimer's and dementia landscape. These bills are a critical step forward toward a future in which everyone in all communities has access to prevention, early detection, treatment, care, and one day, cures.

Thank you for all that you do to support this important work.

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Medical Tests for Diagnosing Alzheimer's

Source: Alzheimer's Association, Alzheimer's and Dementia E-News on 9/11/24

There is no single test that can determine if a person is living with Alzheimer's or another dementia. Physicians use diagnostic tools combined with medical history and other information, including neurological exams, cognitive and functional assessments, brain imaging (MRI, CT, PET) and cerebrospinal fluid or blood tests to make an accurate diagnosis.

Medical history

During the medical workup, the health care provider will review the person's medical history, including psychiatric history and history of cognitive and behavioral changes. He or she will want to know about any current and past medical problems and concerns, as well as any medications the person is taking. The doctor will also ask about key medical conditions affecting other family members, including whether they may have had Alzheimer's and other dementia.

Physical exam and diagnostic tests

During a medical workup, the physician will likely:

- Ask about diet, nutrition and use of alcohol.
- Review all medications. (Bring a list or the containers of all medicines currently being taken, including over-the-counter drugs and supplements.)
- Check blood pressure, temperature and pulse.
- Listen to the heart and lungs.
- Perform other procedures to assess overall health.
- Collect blood or urine samples for laboratory testing.

Information from a physical exam and laboratory tests can help identify health issues that can cause symptoms of dementia. Common causes of dementia-like symptoms are depression, untreated sleep apnea, delirium, side effects of medications, thyroid problems, certain vitamin deficiencies and excessive alcohol consumption. Unlike Alzheimer's and other dementias, these conditions often may be reversed with treatment.

If the diagnosis is Alzheimer's or another dementia, you or your loved one are not alone. Join our free online community [ALZConnected](#) to share questions, experiences and practical tips on message boards and in live chat rooms.

Be prepared for the doctor to ask:

What kind of symptoms have you noticed?

- When did they begin?
- How often do they happen?
- Have they gotten worse?

The doctor may also ask a family member to provide input about changes in your thinking skills and behavior.

Neurological exam

During a neurological exam, the physician will closely evaluate the person for problems that may signal brain disorders other than Alzheimer's. The doctor will look for signs of stroke, Parkinson's disease, brain tumors, buildup of fluid in the brain, and other conditions that may impair memory or thinking.

The physician will test the following: reflexes; coordination, muscle tone and strength; eye movement; speech; and sensation.

The neurological exam may also include a **brain imaging** study.

If the evaluation does not indicate Alzheimer's or another dementia, but the symptoms continue to get worse over time, your doctor may need to order more tests, or you may wish to get a second opinion.

Home screening tests for dementia

A number of dementia screening tests have been marketed directly to consumers. None of these tests have been scientifically proven to be accurate. Furthermore, the tests can have false-positive results, meaning that individuals can have results saying they have dementia when in fact they do not. This is extremely unlikely to happen if the individual visits a physician to seek care and potential diagnosis. For these and other reasons, the Alzheimer's Association believes **that home screening tests cannot and should not be used as a substitute for a thorough examination by a skilled doctor.** The whole process of assessment and diagnosis should be carried out within the context of an ongoing relationship with a responsible and qualified health care professional.

Cognitive, functional and behavioral tests

Cognitive, functional and behavioral tests evaluate memory, thinking and simple problem-solving abilities, and may quickly assess changes in behaviors and symptoms. Some tests are brief, while others can be more time intensive and complex. More comprehensive cognitive, functional and behavioral tests are often given by a neuropsychologist to evaluate executive function, judgment, attention and language.

Such tests may give an overall sense of whether a person is experiencing cognitive symptoms that affect activities of daily living and function and is aware of these symptoms; knows the date, time and where he or she is; and can remember a short list of words, follow instructions and perform simple calculations.

Examples of cognitive, functional and behavioral tests include: Ascertain Dementia 8 (AD8); Functional Activities Questionnaire (FAQ); Mini-Cog; Mini-Mental State Exam (MMSE); Montreal Cognitive Assessment (MoCA); and Neuropsychiatric Inventory Questionnaire (NPI-Q).

Computerized cognitive tests and devices

A growing area of research is the development of medical devices and technologies to help physicians evaluate cognition and function. Among these are medical devices or digital technologies including computerized testing software; these have several advantages, including giving tests exactly the same way each time.

Digital computerized assessments are designed to measure an individual's performance on a variety of cognitive or functional tasks and may be appropriate for administration in randomized clinical trials or clinical settings, when lengthier standard assessments are not practical.

The U.S. Food and Drug Administration (FDA) has granted permission for several digital cognitive testing tools to be marketed: Automated Neuropsychological Assessment Metrics (ANAM); Cambridge Neuropsychological Test Automated Battery (CANTAB Mobile®); CognICA; Cognigram; and Cognivue.

The FDA has also granted permission for a medical device called Cognision to be marketed. This device is a headset with electrodes that are affixed to the scalp to measure electrical activity in the brain responsible for cognitive function.

Depression screen and mood assessment

In addition to assessing mental status, the doctor will evaluate a person's sense of well-being to detect depression or other mood disorders that can cause memory problems, loss of interest in life and other symptoms that can overlap with dementia.

Genetic testing

Researchers have identified certain genes that increase the risk of developing Alzheimer's and other rare "deterministic" genes that directly cause Alzheimer's. Although genetic tests are available for some of these genes, health professionals do not currently recommend routine genetic testing for Alzheimer's disease.

Risk genes: While there is a blood test for APOE-e4, the strongest risk gene for Alzheimer's, this test is mainly used in clinical trials to identify people at higher risk of developing Alzheimer's. Carrying this gene mutation only indicates a greater risk; it does not indicate whether a person will develop Alzheimer's or whether a person has Alzheimer's. Genetic testing for APOE-e4 is controversial and should only be undertaken after discussion with a physician or genetic counselor.

Deterministic genes: Testing also is available for genes that cause autosomal dominant Alzheimer's disease (ADAD) or "familial Alzheimer's," a rare form of Alzheimer's that accounts for 1 percent or less of all cases. ADAD runs strongly in families and tends to begin earlier in life, sometimes as early as one's 30s. Many people in these families do not wish to know their genetic status, but some get tested to learn whether they will eventually develop the disease. Some ADAD families have joined clinical studies to help researchers better understand Alzheimer's.

Brain imaging

A standard medical workup for Alzheimer's disease often includes **structural imaging** with magnetic resonance imaging (MRI) or computed tomography (CT). These tests are primarily used to rule out other conditions that may cause symptoms similar to Alzheimer's but require different treatment. Structural imaging can reveal tumors, evidence of small or large strokes, damage from severe head trauma, or a buildup of fluid in the brain.

In some circumstances, a doctor may use brain imaging tools to find out if the individual has high levels of beta-amyloid, a hallmark of Alzheimer's; normal levels would suggest Alzheimer's is not the cause of dementia.

Imaging technologies have revolutionized our understanding of the structure and function of the living brain. Researchers are studying other brain imaging techniques so they can better diagnose and track the progress of Alzheimer's.

Cerebrospinal fluid (CSF) tests

CSF is a clear fluid that bathes and cushions the brain and spinal cord. Adults have about 1 pint of CSF, which physicians can sample through a minimally invasive procedure called a lumbar puncture, or spinal tap. Research suggests that Alzheimer's disease in early stages may cause changes in CSF levels of multiple markers such as tau and beta-amyloid, two markers that form abnormal brain deposits strongly linked to Alzheimer's. Another potential marker is neurofilament light (NfL), an increased level of which has been found in neurodegenerative diseases such as Alzheimer's.

One challenge researchers face is that analysis of biomarker levels in the same sample can often vary significantly from institution to institution and across different testing platforms. Great strides have been made in standardizing the measurement of these markers in research and clinical care. CSF tests are currently used by dementia specialists to aid in the diagnosis of Alzheimer's, and research continues to develop and standardize new markers that will aid in diagnosis and detection of other dementias.

There are a few new CSF tests — Lumipulse® and Elecsys® — that have received FDA approval. These diagnostic tools can be used by clinicians to detect beta-amyloid and tau markers in CSF, which can be predictive of amyloid changes in the brain.

The Alzheimer's Association convened a multidisciplinary workgroup and **published appropriate use criteria** to guide the safe and optimal use of the lumbar puncture procedure and CSF testing for Alzheimer's disease.

Blood tests

Researchers are investigating whether consistent and measurable changes in blood levels of specific markers may be reliably associated with Alzheimer's-related changes. These markers may include tau, beta-amyloid or other biomarkers they could be measured before and after symptoms appear.

An urgent need exists for simple, inexpensive, non-invasive and easily available diagnostic tools such as blood tests to diagnose the disease. These testing technologies would support drug development by helping to identify and follow treatment effectiveness in clinical trial participants and to increase the possibility of early detection, diagnosis and intervention. A blood test would also enable interpretation and understanding of the progression of Alzheimer's in larger and more diverse populations.

Today, blood tests are already improving the design of clinical trials, and they are being used in some specialty care centers. In the future, they are very likely to revolutionize the diagnostic process for Alzheimer's and all other dementia. The use of these tests in trials and at the doctor's office must be done in a careful and controlled way because much more research is still needed before they can be routinely used in the clinic, as researchers are still working toward creating standardized and validated tests that will deliver reliable results for all individuals.

There are a few blood tests currently on the market that can be ordered by health care providers to aid in the diagnosis of memory complaints. These tests do not yet have FDA approval. At this time, it is recommended that blood tests only be used by specialty care doctors who are seeing patients with memory complaints. They are not recommended for individuals who do not have any cognitive or memory symptoms.

The currently available tests may predict the presence of amyloid changes in the brain or the presence of neurodegenerative disease or neuronal damage. These blood tests cannot be used as a stand-alone test to diagnose Alzheimer's or any other dementia; they will be used as part of a diagnostic workup with other exams.

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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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