First Hawaii Site Recognized and Selected to be Part of National Alzheimer's Network (ALZ-NET) to support Evidence-Based Care of Alzheimer's Disease in US Honolulu, 2025





Hawaii Memory Disorders Center & Alzheimer's Research Unit is proud to be selected along with Mayo Clinic, Harvard, Stanford, Cornell, NYU as part of Alzheimer's Network for Treatment and Diagnostics (ALZNET), an integrated network of global experts collecting real-world data that

(Pictured: Hawaii's Memory Specialists & Researchers) can be used by researchers to advance innovative research and improve clinical care to improve detection, diagnosis, and access to treatments. It aims to support evidence-based diagnosis, treatment and quality care. ALZ-NET is approved by the Centers for Medicare and Medicaid Services (CMS) as a Coverage with Evidence Development (CED) study and used as a pathway to Medicare coverage for anti-amyloid Alzheimer's therapies that have received traditional (full) FDA approval. The ALZ-NET infrastructure, data, and its network of experts is used as a backbone for innovative research. It collects quality data to support a variety of research needs, such as exploratory research as well as regulatory-required reporting using real-world data. ALZ-NET seeks to reduce the burden of clinical assessment, monitoring, and care planning while streamlining the collection of real-world data to support clinical care.

<u>List of US Sites</u> <u>Global Sites</u>



"Our Hawaii patients, caregivers, families, neurologists & researchers at HI Memory Ctr are honored to be recognized and selected to be the first Hawaii site to be part of this global AD

network" Kore Kai Liow, MD, Neurologist & Principal Investigator, <u>Hawaii Memory Disorders</u>
<u>Center</u> & <u>Alzheimer's Research Unit</u>, Clinical

Professor of Medicine (Neurology), Graduate Faculty, Clinical & Translational Research,

University of Hawai`i John Burns School of Medicine.



**Nationally Designated Site 6239** 



ALZHEIMER'S \\\ \\ ASSOCIATION'

### Winter 2025

# **ALZ-NET Newsletter**



# **ALZ-NET Sites**

82 Active Sites (Purple) 140 Sites in Start-Up (Dark Gray) 1322 Patients Registered

As of: January 27, 2024

# Join us in welcoming the newest ALZ-NET Sites

- Indiana Regional Medical Center, Indiana, PA
- Weill Cornell Neurology, New York, NY
- MedStar Franklin Square Medical Center, Baltimore, MD
- Mayo Clinic Rochester, Rochester, MN
- NYU Langone Barlow Center for Memory Evaluation and Treatment, New York, NY
- Kingfisher Cooperative LLC, Spokane, WA
- Washington Regional Medical Center, Fayetteville, AR
- Hawaii Pacific Neuroscience, Memory Disorders Center, Honolulu, HI
- AdventHealth Orlando, Orlando, FL
- University Hospitals Cleveland Medical Center, Beachwood, OH
- Medical College of Wisconsin, Milwaukee, WI
- DHR Health Institute of Research and Development, Edinburg, TX
- Upstate Medical University, Syracuse, NY

## **Operations Updates**

#### January

- ALZ-NET received Advarra IRB approval for an updated Protocol (New Version Date: 1/10/25) and Informed Consent Form (New Version Date: 1/23/25). Approvals and instructions have been disseminated via email.
- Launch of the ALZ-NET Site
   Operations Toolkit which is your
   comprehensive guide to successfully
   participating in the network. The
   most up-to-date toolkit can be
   found on alznetproviders.org

#### **February**

 Launch of the highly anticipated ALZ-NET Imaging Network - a national network of imaging facilities scanning patients enrolled in ALZ-NET. Imaging facilities performing brain scans for patients with AD are encouraged to register.

#### March

 Launch of the ALZ-NET Portal, a web application for patient registration that will streamline data collection processes and help facilitate an inclusive and comprehensive archive of diagnostic and safety neuroimaging studies.

#### Resources for Sites

Share your participation in ALZ-NET with your community! Request the ALZ-NET Logo Toolkit or request material approval from ALZ-NET. All marketing materials must be approved by ALZ-NET prior to use. Email <a href="mailto:alz-net@acr.org">alz-net@acr.org</a> for all requests.

Please read the **ALZ-NET Advertising Policy**.

### **Tips and Tricks**

- If you cannot complete a patient registration in one sitting, you can save your progress in <u>RMS</u>. Just remember to complete it within 7 calendar days!
- 2. Bookmark the <u>Support for Sites</u> page on the ALZ-NET website for quick links to Office Hours and other helpful resources

# Participate in Upcoming Events

Save the Date for an ALZ-NET Pre-Conference at AAIC25

Date: July 26th 8a.m-7p.m Location: Toronto, Canada

ALZ-NET is hosting an invite-only, full-day, workshop for ALZ-NET Sites and Investigators that will include updates, best practices, and open discussion for cross-collaboration. To help us understand what would be of interest to your site, please complete this survey.

### Join us at American Academy of Neurology (AAN) - Research Hub Session

Date: April 6th, 1-1:30p.m. Location San Diego, CA

The ALZ-NET Team will be hosting a Research Hub Session. You can also meet us at the Alzheimer's Association booth throughout the meeting

Find other events and educational opportunities throughout the year on <u>alz-net.orq</u>

### **ALZ-NET Site Spotlight**

Hawaii Pacific Neuroscience - Memory Disorders Center, Infusion Center & Alzheimer's Research Unit Honolulu, Hawaii

What does being a part of ALZ-NET mean to you? Hawaii Pacific Neuroscience - Memory Disorders Center, Infusion Center & Alzheimer's Research Unit specialists and team, our patients, caregivers, families are honored to be selected as the first Hawaii site to be part of this global AD network to contribute to its important mission. We hope to especially contribute diversity data to this important network especially Alzheimer's data on Asian Americans and Native Hawaii and Pacific islanders.

What was the challenge you overcame when implementing ALZ-NET at your site? Once our research coordinator was able to get our site initiated, we were very fortunate that the ALZ-NET staff were very helpful in ensuring we have the right tools to get things implemented for our site.

How has it been enrolling patients in your clinic so far? We are very fortunate that our patients are more than willing and glad to contribute to sharing their data as only through working collaboratively with other sites including those at academia, industry, federal agencies can ALZ-NET advance innovative research and improve clinical care to improve detection, diagnosis, and access to treatments.

Want your site highlighted in a future newsletter? Contact ALZ-NET@acr.org to learn more



How was the start-up process for your site that allowed you to take only 44 days from invitation to activation? Our amazing team here at the Hawaii Memory Disorders Center & Alzheimer's Research Unit led by Kimberly Ko and Erick Delgado has a reputation for rapid start up and known for our efficiency and consistently top performing sites for studies. Credit goes to coordinator Baylee Valenzuela for her dedication, hard work and commitment to the Hawaii ALZ-NET study.

What advice do you have for other sites to help ALZ-NET operations go smoothly? Follow the resources on the ALZ-NET "Join the Network" website to get started. Get buy-in, involve and work closely with clinicians and staff at memory clinics to ensure eligible participants are asked to be included in study while they are in clinic or getting their infusions.

### **ALZ-NET Operations Team**

The ALZ-NET Operations Team at the American College of Radiology is available for network support, including protocol training, at any point during your participation in ALZ-NET. Office Hours are hosted twice every week on **Zoom**. No appointment needed Tuesdays 12-2p EST, Wednesdays 2-4p EST.

#### **ALZ-NET Operations**

Website: www.alz-net.org Email: ALZ-NET@acr.org Phone: 215.574.3181

### Data Management Team

Email: ALZNET-Data@acr.org

Phone: 215.574.3216

**Contracts and Legal Team** 

Email: ALZNET-Contracts@acr.org

#### IT Team, RMS and Medidata Rave Application Support

Email: ALZ-NET@acr.org Phone: 215.574.3181

**Regulatory Team** 

Email: ALZNET-Regulatory@acr.org

Phone: 215.574.3177

**TRIAD Image Submission Support** 

Email: Triad-support@acr.org

Phone: 703.390.9858