



CLARiTi CONNECT

October 28, 2024

CLARiTi Connect is a newsletter distributed by the CLARiTi administrative teams at UW-Madison and the National Alzheimer's Coordinating Center. CLARiTi Connect contains current information about study progress, operations updates, news and training opportunities. Thank you for connecting!

CLARiTi in the News

Brain scans begin for nationwide Alzheimer's disease study

CLARiTi was recently featured in multiple news outlets spotlighting the invaluable contributions of our research participants, especially those from underrepresented communities. The coverage emphasized our commitment to ensuring at least 25 percent of participants come from historically underrepresented groups, a crucial step in addressing health disparities in AD/ADRD and medical research as a whole. It highlighted the important milestone of scanning our first participants for CLARiTi. The [initial story](#) garnered at least 36 stories online and on broadcast and reached potential audiences of approximately 3.3 million broadcast viewers and 3.5 million online viewers.

CLARiTi in the news:

- WBAY, Green Bay, Wisconsin - [Volunteers begin brain scans at UW-Madison for nationwide study](#)
- WSAW, Wausau, Wisconsin - [Participants needed for Madison-based brain scan Alzheimer's disease study](#)
- Channel 3000, Madison, Wisconsin - [UW-Madison leads nationwide study into causes of Alzheimer's, dementia in different communities](#)

CLARiTi in the News

Brain scans begin for nationwide Alzheimer's disease study



Exploring Alzheimer's Complexity: Research Findings on Co-Pathologies

Notes from Dr. Sterling Johnson, CLARiTi mPI

As disease modifying therapies for amyloid proteinopathy continue to advance in clinical and research arenas, it is essential that we have an awareness of any overlapping neuropathologic change that patients and research participants may be experiencing so that treatments are better aligned with underlying pathology.

Recent research demonstrates some of the co-pathology that is present at autopsy in two papers by Woodworth et al. using NACC data (on [TDP-43 neuropathology](#) and on [LATE-NC staging](#)) and one by Corriveau-Lecavalier et al. out of the Mayo ADRC (on [limbic-predominant amnesic neurodegenerative syndrome](#)). TDP43-related pathology co-occurred with AD neuropathologic change (ADNC) approximately 35 percent in the NACC and Mayo datasets. In the Acta Neuropathologica article, Woodworth et al. show that ADNC co-occurred with some combination of LB and/or TDP43 approximately 65 percent of the time based on the numbers reported in their figure.

We may infer from these findings that some degree of overlapping pathology is present in some of our patients with presumed MCI or dementia due to AD. Gaining clarity on this state of affairs is one of the goals of CLARiTi and our efforts are shaped by the groundbreaking work being done in many of the ADRCs.

Study Start Up Updates

CLARiTI Material Transfer Agreement (MTA) Modification with

NCRAD

As outlined in the [CLARiTI Site Readiness Checklist](#), please ensure your team prioritizes making the modifications needed to the NCRAD MTA. We recommend each site initiates this task as soon as possible, since the modification process can take several months to complete.

- [Please check here to confirm if your institution has completed this modification.](#)

This task is not on the CLARiTI Study Start-up Dashboard as it will not prevent your site from being approved by CLARiTI for study activation, however, your site will *not* be able to ship blood samples to NCRAD without the required NCRAD MTA Modification to include the CLARiTI Appendix.

If you're currently in the process of modifying an NCRAD MTA, maintaining clear and frequent communication with your institution's MTA office and NCRAD can help expedite the process.

For more details on your site's status, please contact Mica Gosnell at gosnellm@iu.edu. Mica is the NCRAD contact for the CLARiTI study.

Following the completion of the modifications, Mica will provide sites with NCRAD updates and reminders (i.e., holiday closures that may affect ordering kits and shipping samples).

CLARiTI Subawards

NACC is continuing to conduct pre-processing of subaward documentation - including internal review and sending site-specific communications detailing the status of their review, requesting clarification and modifications as necessary. All sites should hear from NACC within the next week. Any questions related to your subaward status can be directed to NACC at naccgrants@uw.edu.

Study Start-Up Tools

Find resources for CLARiTI start-up on the CLARiTI website including:

- (Public) CLARiTI Study Documents for ADRC Sites Box Folder
- CLARiTI Handbook
- CLARiTI readiness checklist
- IRB Approved Documents: CLARiTI consent templates, protocol, Return of Results materials and recruitment materials

[Visit the Website](#)

Coming soon: CLARiTI Groups within the ADRC Program

Community Forum (Discourse)

NACC will soon be launching the ADRC Program Community Forum, powered by Discourse. This will be a private, moderated forum for ADRC members to ask questions, get answers, and collaborate with colleagues across the ADRC Program. CLARiTI will actively use this forum as an additional channel for sharing CLARiTI Communications.

NACC will be sending invitations to all ADRC members to join the Community Forum in late November. We encourage everyone to create an account and begin connecting as soon as you receive the invitation!

CLARiTI Study Start-Up Dashboard

Be sure to bookmark and regularly check the CLARiTI "Study Start-Up" dashboard to track your site's progress completing study start-up requirements.

- The dashboard shows progress of all sites based on the status of their site readiness checklist tasks.
- Your CLARiTI Project Coordinator can help identify any outstanding tasks and answer questions.

[View Your Site's Status](#)

Webinars & Events

Register Now!

CLARiTI WEBINAR

Updates on the SCAN Project & Plans for SCAN2

Friday, November 22, 2024
1:00-2:00pm ET



CLARiTI Webinar: Updates on the SCAN Project & Plans for SCAN2
Friday, November 22, 2024 at 1:00 pm ET | 12:00 pm CT | 10:00 am PT

Join us for this hour-long webinar where we will provide a presentation on the study guidelines for SCAN PET and MRI data acquisition, as well as an example of available data and results. We will share details and expectations for ADRCs uploading data to SCAN through the CLARiTI program or their P30 funding mechanism. We will also provide some information about the SCAN renewal (SCAN2) and ask for feedback on specific topics. Led by Imaging Core co-leads William (Bill) Jagust, MD and Clifford Jack, MD. We will conclude with an open Q&A.

Register today!



CLARiTI at the 2024 Fall ADRC Meeting in Boston
October 17, 2024

It was so inspiring to connect with our ADRC colleagues at the recent Fall ADRC Meeting in Boston. CLARiTI mPIs Sterling Johnson, Beth Mormino, and Sarah Biber presented a jam-packed session on the promising scientific impacts and infrastructure outcomes of CLARiTI in partnership with NACC.

Dr. Ozioma Okonkwo, CLARiTI mPI, presented CLARiTI's Inclusion and Engagement plans and discussed how CLARiTI will leverage culturally informed, community-engaged research methods to advance ADRC research. He also emphasized the importance of engaging with community and fostering collaboration across cores to effectively achieve the study's inclusion and engagement goals.

If you registered for the conference, you can watch the recording below. We will also be posting a YouTube version in weeks to come via our website.

Registered Attendees - Access Hubilo Recording

CLARiTI Webinar: Advanced MRI Sequences, Rationale, Goals and Procedures

September 30, 2024

Review the webinar recording for study updates about CLARiTI, followed by an overview of CLARiTI's plans for Advanced MRI sequences, rationale, goals, and procedures, led by Dr. John Detre, Advanced MRI Lead and Co-Investigator.

Watch the Recording

Inclusion Corner

Shining a Spotlight on Community Research Liaisons (CRLs)

Community Research Liaisons (CRLs) are our "boots on the ground" for CLARiTI, providing in-person engagement to the community members and organizations that make our research possible. CRLs play a crucial role in CLARiTI, helping us achieve our goal of recruiting, enrolling and retaining at least 25 percent of CLARiTI participants from groups traditionally underrepresented in research.



Faith Ocoko, Community Research Liaison at UW-Madison.

Faith Ocoko, a CRL at the Wisconsin ADRC commented, "In my role as a CRL, I hope to foster a safe and welcoming atmosphere for participants to feel as comfortable as possible. I want the process of being informed to feel easy and not overwhelming."

Faith has a BS in Neurobiology with a certificate in French from the University of Wisconsin-Madison. She was born and raised in Milwaukee where she was enrolled in a language immersion school at young age to begin learning French. Faith joined the team in June 2024 and brings a great energy and an abundance of skills she's learned from working with the African Americans fighting Alzheimer's in Midlife (AA-FAIM) study as well.

In her work for CLARiTI, Faith enjoys reaching out to the participants and forming genuine bonds with them. Her outreach work includes making phone calls to participants and future participants of the African American Diaspora, connecting them with other resources in the city of Madison, and informing them on the benefits of brain health and how to maintain healthier lifestyles.

The Inclusion Core works closely with CRLs, providing training and ongoing support. **Each ADRC site that is a part of CLARiTI is provided funding for a full-time CRL.**

If you have questions or ideas about the CRL role, please contact us at clariti-inclusion@medicine.wisc.edu.

First Meeting of the Community Science Partnership Board (CSPB)

The CLARiTI Community Science Partnership Board (CSPB) is comprised of 12 members from our stakeholder communities, including:

- Research staff (with expertise in inclusion and engagement)
- Community members
- Study participants
- Caregivers

The CSPB meets quarterly to discuss effective strategies for the inclusion and engagement of underrepresented populations in CLARiTI, including motivators and barriers to research participation in general. CSPB members also participate in reviewing and approving participant-facing outreach materials. We are happy to announce that the first meeting of the CSPB was held on September 9, 2024, with much success!

We are grateful for the warm and insightful discussions during our first meeting, and for the valuable support shown by our diverse and dedicated CSPB members.

Meet the CLARiTI Team

Erin Chin, Program Administrator

Erin Chin is the Program Administrator for the CLARiTI study leading the operational objectives of the grant, communicating with partnering institutions and other stakeholders. She started with the Wisconsin ADRC in 2016, as the regulatory specialist and then moved on to become the program manager for the Outreach, Recruitment and Engagement Core. She has previously collaborated with other ADRCs on the eConsent study, the NACC Attrition study and is passionate about the participant experience.



Erin became interested in the science and care surrounding Alzheimer's disease following the diagnosis of her father-in-law. Being involved in his care motivated her to contribute to the field so other families could benefit from the latest advancements in research.

In her free time, she enjoys fitness, including hypertrophy training, biking, and getting her steps in. She lives with her partner in Madison, Wisconsin with their two children Augustine (5), Bennett (2), and their dog, Wendell.

Laurie Robertson, CLARITI Administrative Specialist



Laurie Robertson serves as the Administrative Specialist for Dr. Sterling Johnson and the CLARITI Administration Team (CAT). She has a BA in English, with minors in Teaching English to Speakers of Other Languages (TESOL) and Environmental Studies from the University of Wisconsin-Madison.

Laurie joined the Wisconsin ADRC after losing her stepfather at age 70, following a grueling 10-year decline of Early-Onset Alzheimer's disease.

She loves her "Jane of All Trades" support role which covers everything from scheduling, planning, procurement, logistics, record keeping, onboarding, team building and more. Laurie has been with the Johnson lab (formerly supporting the WRAP study) for just about 3 years.

Beyond work, she can be found outside tending to all things, plants and fungi and participating in silent sports throughout the seasons.

Phoebe Frenette, Communications Specialist

Phoebe Frenette is the Communications Specialist for the CLARITI Administration Team (CAT). She joined the CLARITI study in December 2023 and brings a wealth of experience in health research communications to her role at CLARITI.

She enjoys her work for CLARITI, and coordinates many aspects of study communications, including orchestrating events and webinars, designing tools, maintaining the study websites, and producing CLARITI Connect, amongst other efforts.



She is thrilled to be a part of this amazing work and really enjoys getting to know the many faces of CLARITI's collaboration.

After work she enjoys taking in the great music and art scene in Madison.

[Submissions for CLARITI Connect](#)

Please share your CLARITI related news, job postings, etc., with [Phoebe Frenette, CLARITI Communications Specialist](#).

[Contact Us:](#)

Email: clariti@medicine.wisc.edu

Web: <https://naccddata.org/nacc-collaborations/clariti>



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