

ICARE

INDIGENOUS CULTURAL UNDERSTANDINGS OF ALZHEIMER'S DISEASE
AND RELATED DEMENTIAS-RESEARCH AND ENGAGEMENT

In This Issue

THE PLACES WE'VE GONE

RESEARCH PARTNERSHIP UPDATES

LOTS OF PICTURES!

MEMORY KEEPERS MEDICAL DISCOVERY TEAM

p. 1-833-329-3370

e. memorykeepers@d.umn.edu

<https://memorykeepersmdt.com/>



@MemoryKeeperMDT

A MESSAGE FROM THE TEAM

Aanii, Boozhoo, Shekoli, Tansi, Greetings!!

Since the last newsletter, the ICARE team has been busy! From early June through the end of September, the community researchers, advisory and team members have been attending and/or hosting community events to raise awareness about dementia and the ICARE project. In the following pages, the community researchers share some of the activities that have taken place, along with pictures from the events.

On July 16-20, 2023, members of the team presented our work at the Alzheimer's Association International Conference (AAIC) in Amsterdam, Netherlands. To see the posters that were presented at the conference, please visit our website at www.memorykeepersmdt.com/icare-presentations.

The entire team was able to come together in Oneida, Wisconsin, the week of October 16-20, 2023, for an ICARE Team Retreat. Dr. Nick Lambrou, Coordinator for the Wisconsin team, shares more about the retreat activities on the next page.

Most of the ICARE team travelled to Honolulu, Hawaii, to attend the very first International Indigenous Dementia Research Network (IIDRN) Conference on November 7-9, 2023. This is the only international conference that is focused on Indigenous dementia. There were over 140 people from across the world, including researchers, community members, and Elders, who shared their stories, research, and lessons learned about dementia.

Our team had two poster presentations and three oral presentations drawing from the ICARE phase I findings, which included interviews with Traditional Knowledge Keepers and Carriers, Administrators, Physicians

and Health Care Providers, as well as sequential focus groups with formal caregivers. One poster gave an overview of the ICARE project, and the second poster shared overall recommendations from the interviews and focus groups.

- January Johnson, Community Researcher from Red Lake, MN, presented: “Traditional knowledge keepers understandings of dementia and the medicine wheel teachings: Perceptions on aging, caregiving, and the four stages in the circle of life.”
- Karen Pitawanakwat, Community Researcher from Manitoulin Island, ON, presented: “The richness of Indigenous languages in explaining concepts around aging and dementia: Examples from the ICARE project.”
- Drs. Kristen Jacklin and Dana Ketcher presented: “Identifying ways to make dementia diagnosis culturally safe among Indigenous communities in the great lakes region of North America: Evidence from the ICARE project.”

Lois Metoxen Strong, Community Researcher from Oneida, WI, shares a little more about the conference on page 04 and highlights the presentations that came out of the University of Wisconsin-Madison Alzheimer’s Disease Research Center.

The community researchers are wrapping up interviews with caregivers who currently care for or have cared for a loved one in the later stages of dementia. In the new year, they will be recruiting people who live with mild or moderate memory loss or dementia and their caregivers to share their story. The stories shared throughout the research are important in learning about how dementia is understood and diagnosed in the community, how people living with dementia are cared for and supported throughout the progression of the disease, as well as to better understand what caregivers need and what they would like others, including health care workers, to know. If you or someone you know want to participate in the research, please reach out to one of the community researchers (Individual contact information on the following pages).

Enjoy the rest of the newsletter and have a very happy new year!

ICARE RETREAT

By: Dr. Nick Lambrou

For the first time in ICARE history, the retreat was hosted by the Oneida Nation in Wisconsin during the week of October 16-20, 2023. Autumn colors were beautiful and vibrant, as was the entire gathering. The week was filled with generating creative ideas for next steps in the research and bonding through cultural immersion. One stand-out feature of each ICARE retreat is the honor of being welcomed into partnering communities and learning about the environment, history, and culture. Day 1 began with the Edge of the Woods welcoming ceremony followed an afternoon project overview presentation that included attendees from Tribal and University leadership. On days 2 and 3, the team reviewed preliminary analysis from the healthy older adult interviews and started planning research activities for next year.

In addition to dedicated meeting time to discuss the project, the team was able to take a guided bus tour throughout the Oneida Community and learn about the staples of the Oneida Nation diet - Three Sisters (beans, squash, & corn). The team created artwork with the seeds. The retreat wrapped up with a traditional meal at the Veteran's Services Center. At dinner, team members recalled their favorite parts of the retreat. This included a tour of Webster Farms, which is dedicated to growing and sharing traditional foods and traditions. Team members reflected fondly upon visiting the trading post at Webster Farms, which highlighted the importance of community and relationships and that all have unique and valuable gifts to share.

We look forward to next year's retreat, where the team will once again gather in the beautiful land of Manitoulin Island, Ontario. Yaw^ko to the Oneida Nation and the ICARE Team for bringing us one step closer to each other and our mission of caring for Indigenous communities experiencing Alzheimer's disease and related dementias.

ONEIDA NATION

By: Marlene Summers

Spring finally came and the way I seen it, summer happened overnight. We had a few hot days, but it was a good summer. It was a busy summer for the ICARE team Oneida hosted our ICARE Team Retreat in October. We had put together a planning team earlier this year; we met and things just seemed to fall into place.

Lois and I were also on another committee with the University of Wisconsin-Madison Alzheimer's Disease Research Center (ADRC) outreach staff and American Indigenous Cognitive Assessment (AMICA) staff, and we planned an open house. We had a Cars and Guitars community event that shared information on work the ADRC does and the partnership they have with the Oneida Nation. We had a local group show their old cars. We also had a local band with good music, good food, and a very good community turnout. We need to do more of these kinds of events to let our community know what we are all about. The other researchers put together posters for the IIDRN Conference in Hawaii. Lois shares more information about this conference on the following page.

With all the events and planning that Lois and I were a part of this past summer and fall, we managed to get most of the ICARE interviews with caregivers to loved ones with late-stage dementia completed. We have two more to do and will be done with these interviews. We will be recruiting dyads in the new year. So, the dyads will include people living with mild and moderate dementia or memory loss and their caregiver. If you are interested in participating in these interviews or want more information, reach out to Lois and I.



HAPPY HOLIDAYS.
Marlene and Callie.



msummers4@wisc.edu

ONEIDA NATION

By: Lois Metoxen Strong



The Oneida Nation Alzheimer's outreach staff presented on current topics in dementia research at the inaugural International Indigenous Dementia Research Network conference in Hawaii, November 2023. This conference was attended by researchers from Canada, the United States, Australia, New Zealand, and Samoa to share Indigenous-led dementia research, mutual learning, and collective knowledge. What a great honor it was to be invited to take part in the IIDRN event. For too long, research efforts have not included Indigenous people, and it was enlightening and inspiring to learn about current topics in Indigenous dementia research from those in attendance.

Below are a number of presentations that were given at the IIDRN by Oneida and University of Wisconsin-Madison ADRC team.

Oral Presentations:

- Dr. Carey Gleason: Understanding the cost of dementia: Estimates based on Wisconsin Healthcare Utilization Among American Indians with or without ADRD.
- Sacheen Lawrence: "Family is Everything": Perspectives on the use of caregiver resources among dementia family caregivers in the Oneida Nation in Wisconsin
- Dr. Lauren Yowelunh McLester-Davis: Indigenous Alzheimer's disease and related dementias data sovereignty in the context of big data.
- Dr. Lauren Yowelunh McLester-Davis: The relationship between biological aging and dementia assessment performance in a diverse sample of Indigenous and Black participants of the Wisconsin Alzheimer's Disease Research Center.
- Lois Metoxen Strong and Dr. Nickolas Lambrou: Improving dementia outcomes through community-based participatory action research collaborations: The story of the Oneida Nation and University of Wisconsin Madison.

Poster Presentations:

- Dr. Megan Zuelsdorff: Lessons learned from Indigenous centered adaptations and connections in the STRIDE (stress and resilience in Dementia) study.
- Margaret King: Community engagement activities with the Oneida Nation in Wisconsin: Empowering Indigenous communities in Alzheimer's disease research.
- Dr. Nickolas Lambrou: Recommendations to improve dementia care in four diverse Indigenous communities in Canada and the United States: Key findings from the Indigenous Cultural Understandings of Alzheimer's Disease and Related Dementias—Research and Engagement (ICARE) project.



lstrong3@wisc.edu

GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

By: Collette Pederson



Summer has come and gone but not without feeding the community with abundant treasures from the Community Garden. Every week, a farmers market with tubs of produce, homemade healthy entrees, baked goods, crafts, flowers, and music is held for the community, which is absolutely incredible and fun. A Harvest Feast was held through the Food Sovereignty Project and was well attended by the community. Thank you to all involved. The students at Oshki Ogimaag Charter School also had a huge garden. Led by Tess Bailey, who works with the Snap Nutrition Program, students start by planting seeds in the classroom, transfer to the garden, and harvest the following school year. Awesome project.



Rendezvous Days, which transports all of our senses into a time period from over two centuries ago, was another huge success and a very busy time for the community. The advisory group kept busy by volunteering with the walk-run, hosting the Alzheimer's Association Walk to End Alzheimer's, participating in the Grand Portage Wellness Fair, the Elder's Pie Social, and keeping in contact with fellow researchers through Zoom meetings and in-person advisory group meetings.

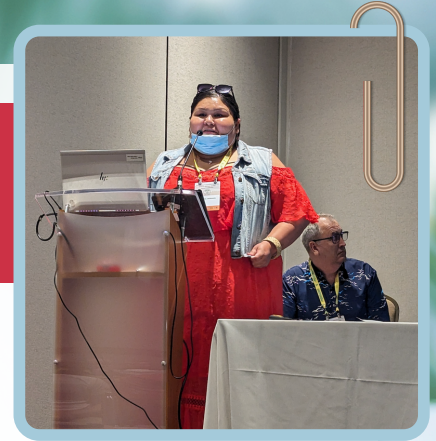
The International Indigenous Dementia Research Network (IIDRN) Annual Conference was held on November 7-9, 2023, in Honolulu, Hawaii. The conference was supported by the Memory Keepers Medical Discovery Team and was a great success. The theme "Weaving Knowledge" reflected a multi-purpose conference program designed to share research findings and ideas through oral and poster presentations and to network, mentor, collaborate and find shared objectives for future research. The conference was well attended by other countries.



pedersoc@d.umn.edu

RED LAKE BAND OF CHIPPEWA INDIANS

By: January Johnson



Boozhoo Indinawemaaganigog (Hello all my relatives), Red Lake's Community-Based Researcher, January, back to give Miskwaagamiwi-zaaga'iganing (Red Lake Reservation) updates on the progression of ICARE's research in the community.

As we enter the cold winter months, I've been actively recruiting for interviews with caregivers to relatives living with late-stage dementia. These interviews have been so rich and provided valued insight into the experiences of our community members affected by dementia. Many of the family caregivers expressed gratitude for the safe space given to talk about their experiences. As we begin the new year, I will continue recruiting caregivers of relatives in the late stage of dementia, while simultaneously prepping for the dyad interviews with relatives living in early to mid-stage dementia and their caregivers. So, I will actively be recruiting for both caregivers of late-stage and the dyad interviews throughout the winter months.

I think it's noteworthy to continually inform our communities that we use a strength based-approach when analyzing the interviews, so in addition to assessing areas for improvement, we focus on identifying strengths, skills, and positive attributes to help organize the needs within the community. We want to assure interview participants that we are not here to judge but rather to help identify the needs of the community surrounding dementia.

This past summer and spring, I have participated in many community engagement and professional development activities. We've set up booths at Red Lake Health Fair in July, in which community engagement increased since the previous year as community members are showing more interest in learning about dementia. We also set up a booth at Leech Lake's Intertribal Youth Conference to engage with the younger generations, and we collaborated with community partners and sponsors for an Alzheimer's Awareness Walk. Community Advisory Member Karen Holstein writes about the walk below.

A walk to raise awareness and show support for families who are impacted by Alzheimer's Disease was held on Saturday, September 30th in Red Lake. Approximately 35 participants gathered at the Red Lake Nation Tribal College to hear about dementia from the walk organizers: January Johnson (University of Minnesota Duluth/Memory Keepers), Karen Bedeau (Dementia Outreach/Community Educator for Northwoods Caregivers), and Jenn Cole (Dementia Program Manager for Northwoods Caregivers). Kelly Iceman offered the opening prayer and drum song for the walkers. Those who were able to walked as far the Red Lake Trading Post and back to the tribal college where everyone was provided with bags filled with items to remind them of the importance of taking care of themselves as they care for others. -Karen Holstein



joh20247@d.umn.edu

ONTARIO-MANITOULIN ISLAND

By: Rhonda Trudeau & Karen Pitawanakwat



Aanii, Boozhoo kina weya!!

We hope this newsletter finds you living the good life and fulfilling all your self care needs, be it spiritual, physical, mental, and emotional!

Over spring/summer months Karen and Rhonda have been attending community gatherings like open houses, health fairs, a seniors' conference & jamboree. While visiting communities, we shared our resources that can be found on our website at <https://www.i-caare.ca>. We had a special interest on our fact sheet Signs and Symptoms of Dementia: An Indigenous Guide. We loved attending events in the First Nation communities of Manitoulin Island. Along the way, we met so many people interested in dementia care! We have also met with communities to provide updates on our work.

We are looking to recruit participants interested and eligible for two projects. The first project is a study to understand how people living and aging in their community use their environment, or life-space, which is a term used to describe the physical and social environment of where a person does their day-to-day activities. You may be eligible to participate in this study if you are a caregiver for a loved one who has dementia and if that person you care for still lives in their home. The second project is also a study for Indigenous people living with memory loss or dementia and their caregivers. We would like to interview Anishnabek adults aged 45+ who are experiencing memory loss or dementia and their caregivers, aged 18 and older, to share their experiences. Please connect with us or have a look at your local health centre for more detailed information on our work.

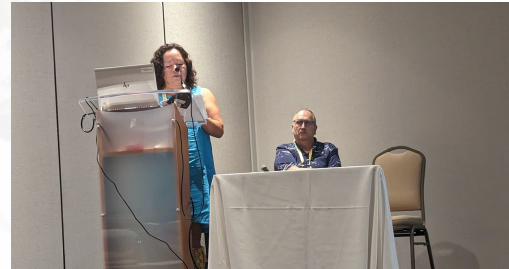
In October, Karen and Rhonda had travelled to Oneida Nation in Wisconsin to join the rest of the team at our 2023 ICARE Team Retreat. We really enjoyed our time there! It was filled with so many opportunities to connect, discuss ideas, inspire one another, and learn. We had a tour to some very beautiful sites of the nation. We learned about their services they have available and loved learning about their culture and having opportunity to view their art.



ONTARIO-MANITOULIN ISLAND-CONTINUED

By: Rhonda Trudeau & Karen Pitawanakwat

In November, Karen and Rhonda travelled to Waikiki, Hawaii, for our International Indigenous Dementia Research Network (IIDRN) Annual Conference. At the conference, Karen presented “The richness of Indigenous languages in explaining concepts around aging and dementia: Examples from the ICARE project.”



We are excited to announce that our advisory has grown and now has two new members. We thank them so much for guiding our work. We are grateful for the time we can come together to meet with our advisory. Our advisory meetings have been in M’Chigeeng First Nation this fall. During the winter months, we will meet in Wiikwemkoong Unceded Territory and Whitefish River First Nation.



Let’s learn together about best practices in aging well. There are things we can do to prevent dementia all year, and we will highlight some Fall/Winter months activities: Craft hobbies, enjoy a new recipe or an old one with a friend, share stories of past experiences in these seasons with loved ones, spend time with other people, especially kids and youth and connect with other older adults in your community and have fun!

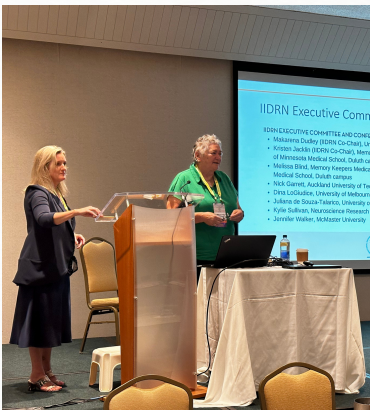


rtrudeau@d.umn.edu
kpitawan@d.umn.edu

ICARE Retreat at Oneida Nation - Picture Collage



IIDRN Conference in Hawaii - Picture Collage



ICARE RESEARCH TEAM

MINNESOTA

KRISTEN JACKLIN

Principal Investigator

WAYNE WARRY

Co-Investigator

JORDAN LEWIS

Co-Investigator

MELISSA BLIND

Research Coordinator

LYNSIE RADOVICH

Research Manager

MINDY DERTINGER

Research Associate

DANA KETCHER

Research Associate

AMY OTTO

Research Associate

JOSYAAH BUDREAU

Qualitative Analyst

KAREN BEDEAU

Community Collaborator, Red Lake

ORAN BEAULIEU

Community Partner, Red Lake

SUSAN NINHAM

Community Partner, Red Lake

JANUARY JOHNSON

Community Researcher, Red Lake

JENNIFER SORENSON

Community Partner, Grand Portage

COLLETTE PEDERSON

Community Researcher, Grand Portage

BROOKE METZ

Communications Manager

NATALYA WALKER

Community Engagement Coordinator/Manager

MIKAELA WILLIAMS, MA

Qualitative Analyst

SHEAMUS CAVANAUGH, MA

Research Associate

ONTARIO

KAREN PITAWANAKWAT

Community Researcher

RHONDA TRUDEAU

Community Researcher Assistant

WIKWEMIKONG HEALTH

CENTRE

DIANE JACKO

Community Partner

NOOJMOWIN TEG HEALTH

CENTRE

DEB FRANCIS

Executive Director

MNAAMODZAWIN HEALTH

SERVICES INC.

CRAIG ABOTOSSAWAY

Executive Director

M'CHIGEENG HEALTH

SERVICES

FLOYD ENSE

Health Director

WISCONSIN

CAREY GLEASON

Co-Investigator & Wisconsin

Lead

MEGAN ZUELSDORFF

Co-Investigator

NICK LAMBROU

Research Scientist

WES MARTIN

Community Collaborator

MARLENE SUMMERS

Community Researcher, Oneida

LOIS STRONG

Community Researcher, Oneida

HELPFUL LINKS

I-CAARE.ca is the Memory Keepers Medical Discovery Team (MK-MDT) “sister” website in Canada. The site highlights several years of research partnerships and showcases the results of the Ontario research in the form of fact sheets, tools, guide books, and other resources.

Memory Keepers Medical Discovery Team

<https://memorykeepersmdt.com/>

Wisconsin Alzheimer’s Disease Research Center

<https://www.adrc.wisc.edu/>

Northwoods Caregivers (Beltrami County, MN)

<http://northwoodscaregivers.org/>

Alzheimer’s Association, USA National site

<https://www.alz.org/>

Alzheimer’s Association, Minnesota-North Dakota Chapter

<https://www.alz.org/mnnd>

Alzheimer’s Association, Wisconsin Chapter

<https://www.alz.org/wi>

Alzheimer’s Society, Canadian National site

<https://alzheimer.ca/en/Home>

Alzheimer’s Society, Sudbury-Manitoulin North Bay District

<https://alzheimer.ca/en/sudburymanitoulin>



Giiwedining Northland

GLNAEA Great Lakes Native American Elder Association



Memory Keepers Medical Discovery Team

624 E. First St. Suite 201

Duluth, MN 55805