

ICARE

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

In This Issue

A MESSAGE FROM THE TEAM

Aanii, Boozhoo, Shekoli, Tansi, Greetings!!

It is with full and hopeful hearts that we write our final newsletter for the current ICARE grant. Team members in Duluth and Community-Based Researchers have been reviewing participants stories and working with community partners to identify top dementia care priorities. These needs are the basis for our 5-year Renewal application for the next phase of the ICARE project.

From October 19 to 23, Community-Based Researchers, Community Advisory members, and Duluth Team members gathered in Honolulu, Hawaii to attend and present at the 2025 International Indigenous Dementia Research Network Annual Conference (IIDRN). We were joined by community and academic partners from all over the world. It was amazing to see the energy and solidarity in that space, and to celebrate each other's impacts. The Caregiver and Elders Panels were once again crowd favorites!

ICARE AT IIDRN

The team has been working to share our findings with partner communities – updating the Dementia Factsheets for the United States, planning events, and writing a children's book (see Grand Portage's update for a photo)! Even though it's been busy, the Community-Based Researchers were able to spend much-needed time at community celebrations and with loved ones during the holidays. We are all so grateful for the work they do, and the care and knowledge they bring to ICARE.

With all this in mind, there is still a lot to look forward to from ICARE in 2026! Look for Community-Based Researchers at events as they shift their focus from interviews to community outreach. We are all excited for our next chapter: using everything we've learnt in this project to co-design educational interventions by and for Indigenous Communities.

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Honoring our Partners

We once again highlight our Community Advisory members and Tribal partners. Without your collaboration at every stage of the research and continued partnership, ICARE would not have been - and will not be - possible. Thank you!

We are also humbled by everyone who has participated in ICARE. To date, have interviewed over 175 community members who have shared their stories, community strengths, and advice. **But we still need to hear the stories of people who live with memory loss or dementia and their caregivers, either as pairs or as individuals.** If you or someone you know wants to share their experiences with dementia, please contact your Community-Based Researcher.



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ONEIDA NATION, WISCONSIN

By: Marlene Summers and Lois Metoxen Strong

What a difference from last winter to this one. I looked at the newsletter, and I wrote that we did not get snow till March 8th. Now we had our first measurable snowfall mid-November and within a week we had two measurable snowstorms. I like snow but not cold snaps. When it snows, I think of that song "Let It Snow."

We are back to recruiting. We are interviewing caregivers and those with memory concerns, whether they want to participate as individuals or as a pair. It has been slow going for Lois and me. We are doing our best. I enjoy helping with the interviews. Lois and Nick do a good job, and I think we get better stories about Alzheimer's and dementia.

I am feeling so good about our Community Advisory Board because they get involved in the things we are doing and give helpful feedback on the items we are discussing.

We will set up a table at the January Wellness Event, which we have been attending for at least 3 years. There are always good turnouts. We always get good questions on dementia, and we often get a few participants that way.

I hope everyone had a memorable Christmas Holiday. My New Year's thought for this year is a quote from Goran Persson: "Let our New Year's resolution be this. We will be there for one another as fellow members of humanity, in the finest sense of the word."

HO YAN (Happy New year).

GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

By: Collette Pederson



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After a long and beautiful autumn and wondering when the snow is going to blanket us, it has finally arrived. Ice pancakes have appeared on the lake, reminding us that the cold and snow are here to stay for the winter.

Many great and honorable projects happened before the colder weather tumbled in.

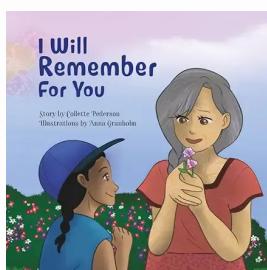
Grand Portage made history with the first-ever Indigenous Coast Guard in the nation, and launched the Genawaaboonagak. This program's name - "keeping watch while on the water" - is a reflection of its mission to protect lives and strengthen safety along Lake Superior's shore. This program will be managed by the Band's Tribal Emergency Manager, Ruth Vogel. Grand Portage's first vessel responded to a distress call from a vessel stranded in seven-foot seas near Isle Royale. It is so wonderful knowing that we now share responsibility to protect those who travel on Superior's powerful waters.

The second weekend in August is always the weekend for Rendezvous Days. The three-day event was well attended with dancers, singers, voyageur re-enactments, games, food and enjoyable company for all. Many tribes travel the shore to attend and enjoy the festivities. It was a good time for all.

On Wednesday, December 2, 2025, a service provider meeting was held in the Elderly Nutrition dining room, focusing on the "Dementia Care Guide." The discussion was great and included Grand Portage departments and other county entities. Another meeting will follow in the upcoming months.

Please remember to eat well, stay warm, and keep an eye on your neighbors with the winter months here.

Miigwech!



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RED LAKE BAND OF CHIPPEWA INDIANS

By: January Johnson

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Boozhoo gakina awiya (Greetings everybody)

Over the past few months, Alexis and I have been recruiting for interviews. We have recruited 3 people living with memory changes and their caregivers (6 total), and are continuing to recruit more. We recognize that this is a sensitive topic for some of our community members, and we strive to listen with care. As caregivers and loved ones share memory changes, we aim to provide a safe space to talk about it, and we believe that matters.

Since our last update, we have made progress in dementia education and awareness through a Brain Train initiative and Alzheimer's Awareness Walk. We followed formal governance and submitted a Tribal Resolution to the Red Lake Tribal Council, which approved that event. We sought collaboration with our community partners: Northwoods Caregivers, Red Lake Comprehensive Health Service, and Indian Health Services. The event took place on September 26th at the Red Lake Tribal College. We welcomed a number of community members for the morning session, which began with an opening prayer by Vickey Fineday. Attendees explored interactive stations to learn about dementia, including signs and symptoms, what to expect after a dementia diagnosis, the connection between diabetes and dementia, and the importance of eating healthy and other prevention practices. After the attendees finished visiting the information booths, we proceeded to do the Alzheimer's walk. This included lunch, door prizes, and closed with drum and song by James Cloud III. This event took 4 months of planning and collaborations, highlighting our community's commitment to integrating American Indian perspectives and cultural values into healthy aging and brain health initiatives. We extend our heartfelt gratitude to all our partners, sponsors, volunteers and participants for making the event a success and continuing to support dementia awareness in our community.

I presented on a community research panel at the Minnesota Gerontological Society Conference alongside community researchers from the rural and tribal research sites at Memory Keepers. I shared my perspectives while working on the ICARE project: Different approaches, what this research means to me, and how it could benefit our community. I highlighted the strengths within our community that contribute to our well-being and emphasize the importance of meaningful engagement when building trust, including the significance of tribal data sovereignty. I spoke cautiously and focused on my experiences as a Native American community researcher working on dementia-focused studies in my own community rather than data beyond my role. This and other learning opportunities will help me serve my community more effectively.

Again, we remain grateful for the opportunity to engage with community members, support local programs, and advance the goals of the ICARE project. We welcome your input, questions and collaboration opportunities. Together, we hope to make a meaningful and respectful impact on the lives of those affected by dementia.

Miigwech

ONTARIO-MANITOULIN ISLAND

By: Rhonda Trudeau & Karen Pitawanakwat



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Aanii/Boozhoo!

We hope this newsletter finds you enjoying the good life and taking care of your whole being, a very important part of dementia prevention. We often come back to one of the main teachings of this project: In each season there is opportunity to ask loved ones to join you as you teach them about your regular seasonal activities that you enjoy. All can experience these unique joys and adventures, together.

Recently, our Karen Pitawanakwat, NAADNWECHIGE-GAMIG Wikwemikong Health Centre, and Josyaah Budreau of Memory Keepers Medical Discovery Team gave a talk at the 2025 IIDRN Conference about concepts like "Good Life" and "Quality of Life." They explained how these can mean different things to different Great Lakes communities. During research on Manitoulin, listening to and learning how our participants lived with these concepts, incorporated them into daily life, and shared them with others was inspiring. During IIDRN, we enjoyed the work presented by others, networking, and being immersed in a circle with like passions of dementia research, diagnosis, and prevention.

As this project ends, we reflect on the wonderful opportunity we had to listen to the stories and teachings from many. All of this work is made possible by the people we interviewed and connected with. We were honored by having the opportunity to listen to the stories of love, community strengths, and health care needs they shared with us. We are also so honored to work alongside our community partners, the health directors, adult day workers, personal support workers, and nurses all who have supported the work we do. We have been so welcomed into each community, and it's been a pleasure visiting each centre and program. We look forward to this project's continued outcomes and the impact the work in dementia research has on our beautiful Manitoulin communities.

As this stage of the project comes to an end, we would also like to take this opportunity to give a special thanks to our advisory members for helping, guiding, and working alongside us the entire time. Our advisory members are from different areas of Manitoulin and bring their connectedness, knowledge of community needs and histories, and language ability. Each have a unique quality that they share with our circle. We are so very grateful to grow closer to each of them during this project. Chi Miigwetch to our advisory: Roseanne D., Evelyn R., Gene B., Bonnie B., Marion M., Jean M-A., Rose S., Rosella K., Roselinda P., Doris M., and Edward O. We look forward to our continued work together!

Staying Active through the Seasons

As spring and summer approach, we are in a wonderful place to take part in community events, visit loved ones, or work on outdoor projects. During these two seasons we can enjoy the changes of growth as mother nature renews by simply taking moments to appreciate our surroundings. It may be easier to enjoy some outdoor walking, or soak in the beauty of the rays of the sun from the porch. Spring comes with the joys of gardening big or small, from family garden plots to windowsill planters. If you are unable to have your own garden, you can still enjoy the bounty of the local gardens from community call outs or local food programs.

Each season offers the opportunity to take care of yourself. Do a self-check in and address any needs you may have. Staying active is important for dementia prevention; reach out to family, loved ones, friends, and community members to stay involved in your circle.

ICARE Team at the 3rd Annual IIDRN Conference



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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, guidebooks, and other resources.

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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/>

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GLNAEA Great Lakes Native American Elder Association



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