

# ICARE

## INDIGENOUS CULTURAL UNDERSTANDINGS OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

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@MemoryKeeperMDT

### A MESSAGE FROM THE TEAM

The sounds of spring are all around! The birds have returned, the frogs and crickets have woken up and are singing their songs. Here in Duluth, MN, at the Memory Keeper Medical Discovery Team office, staff have watched the big ships return to the harbor and have even ventured over to the local Portland Malt Shoppe over lunch for ice cream. We have expanded our team to include Brandylyn Arredondo, Research Analyst, who joined the team at the beginning of January 2022. We also welcomed back Brooke Lees, Communications Coordinator and ICARE newsletter creator, in March 2022.

Since the last newsletter, the ICARE team has been busy. Over the winter we have worked closely with the community advisory members to go through the findings from Phase I of research and create community level reports. Once Tribal and First Nations Leadership reviews and approves the community level reports, they will be available for download at (<https://memorykeepersmdt.com/mk-reports/>.)

This spring, members of our team were able to come together to present at the Honoring Elders Wisdom Conference, held at the Northern Lights Casino, Walker, MN, on April 5, 2022. For many of our team members, this was the first time coming back together after two long years and a first time for some of the community researchers to meet each other in person. Dr. Kristen Jacklin (PI for the ICARE project) was the keynote speaker and presented "Understanding Dementia in Indigenous Populations: Research Honoring Indigenous Knowledge." The ICARE Community Researchers shared their experiences conducting or doing research in their communities during a presentation panel titled: "Motivating Alzheimer's Disease & Related Dementia Awareness Through ICARE."

Dr. Jordan Lewis (ICARE Co-Investigator) recorded his presentation titled "Caregiving Makes Me Wiser: The unexpected blessings of caregiving when given a second chance with your family member." Dr. Jacklin and Dr. Lewis's presentations can be found on the Memory Keeper MDT website (<https://memorykeepersmdt.com/honoring-elders-wisdom/>).



The community researchers have also started data collection for Phase II, starting with interviews with healthy older adults. These interviews focus on understanding quality of life and what healthy aging means to adults in your communities. Additional questions ask about cultural understandings of dementia, dementia screening, diagnosis, and access to care, as well as dementia education needs within the communities. Over the next several months we will continue with data collection and will be starting interviews with caregivers to people living with dementia in the late stages. If you are interested in finding out more about the project or seeing if you are eligible to participate, please contact your local community researcher or the project coordinator, Melissa Blind at [mblind@d.umn.edu](mailto:mblind@d.umn.edu).

Before I turn the newsletter over to the community researchers, we want to give a special Chi Miigwech-Thank You! to all who have worked with us as we waded through unfamiliar waters during the pandemic and survived by supporting this ongoing research project with your Tribal Nations, including Grand Portage, Red Lake, MN, Oneida Nation, WI, and Manitoulin Island, ON, Canada. The ICARE research team has resumed in-person meetings in most communities, and you will hear about the great work in pages to come.



## GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

Yes, it was a long winter, but many good times came throughout the season. Community members were once again able to come together and gather with each other. The Elder Nutrition Program was in full swing with indoor lunches and programs for the elderly and activities in the afternoon. I did notice some extreme individuals who just couldn't wait for summer, surfing on the wild waves of Lake Superior. This seems to be a new adventure for many, and I have to agree that it is quite entertaining. With the borders open, more tourists are coming through, people have been idle for so long, and the freedom is welcome and refreshing. There are certain requirements when crossing the border, but the restrictions have been lifted to make the transition much easier.

The Honoring Elder Wisdom conference was held on April 5th in Walker, MN. What an honor to finally meet everyone in person. We had only met virtually until then, and we felt like a family who had never met in person. The conference was wonderful and the joy of listening to the speakers was incredible.

The Advisory Board and I have been diligently working on many projects throughout the winter and spring. The ICARE R01 Phase II, which entails interviewing healthy older adults, is going well. This summer, the Advisory Board will be busy preparing for the health fair, the walk-run during Rendezvous Days, (which we will be sponsoring along with the Grand Portage Clinic), and distribute the results of research for the years 2018 -2021, once finalized. The preliminary results have been achieved and the finalization will soon be completed.



### Upcoming Community Events:

- June 11-Grand Portage Health Fair
- July 19-Community Listening Session with Alzheimers Association
- August 13-Rendezvous Walk/Run

### Past Events:

- April 22-George Morrison Commemorative Stamp Celebration
- April 22-Community Seed Exchange

## RED LAKE BAND OF CHIPPEWA INDIANS

Research activities are in full swing on the Red Lake Reservation. In the midst of spring season, while iskgamizigan (Sugarbush) is in full force, so are the healthy older adult key-informant interviews. On April 5, I had the honor of being invited to speak on a research panel at the Honoring Elder Wisdom Conference in Walker, Minnesota. Along with my other ICARE community researcher friends, we shared each of our own experiences regarding our roles on the ICARE project and what the research means to our communities. It certainly was an honor to be invited to present amongst such line-up. We are not just here to do the work and leave; I foresee lasting positive effects from the research.

On April 12, the Red Lake Tribal Council meeting was held at the Seven Clans Casino Event Center. The Red Lake Advisory Council and ICARE team members came in to show their support for the ICARE project presentation. Ensuring full transparency of the research, Dr. Kristen Jacklin and I stood before Red Lake Tribal Council leadership to present the research findings from Phase 1 and to ask permission to disseminate the findings more broadly throughout the Red Lake community and the Memory Keeper's website. We received permission and the report can be found at <https://memorykeepersmdt.com/mk-reports/>.

I have begun the healthy older adult interviews; I've completed eight as of June 1. In recruiting participants, It's important to maintain flexibility in this role because various approaches are successful as it varies from person to person. I've grown a lot since my first few interviews, and now, I am a lot more comfortable speaking to people. I am so appreciative of what people share with me, and I learn so much from everyone I talk with. It's been such a rewarding experience! If you are reading this, and would like to participate in the interviews please reach out to me at [joh20247@d.umn.edu](mailto:joh20247@d.umn.edu). Miigwech!

Lastly, I am hosting an educational podcast series on Alzheimer's Disease and Related Dementias (ADRD). The Podcast will be broken down into 9 subtopics covering information on the basics, causes, signs & symptoms, diagnosis, living with the disease, treatments, related dementias, caregiving, research, and resources. Subscribe to my channel here:

<https://memorykeepersmdt.com/adrd-awareness-podcast/>





## ONTARIO-MANITOULIN ISLAND

Aanii!! We hope this newsletter finds you living the good life! Fulfilling all your spiritual, physical, mental, and emotional self-care needs. Our next project that we are currently setting up will require some recruiting for pairs of participants who are people living with dementia and their caregivers. Recruiting has been good with the help from our health care partners, our advisory council, and by sending flyers out with our local programming partners. In the recent months, we have completed two projects that we had recruited healthy older adults over the age of 45. We would like to again thank our community partners for assisting us in completing projects it has been a great experience to discuss dementia care. This winter was a challenging time to complete these projects with November-March having different community COVID protocols. We want to say K'Chi-Miigwetch to those who volunteered their time to meet with us for that project. Our next project is interviewing dementia caregivers and their loved one. Our goal with these research projects is to improve the lives of our Anishinabek persons with Alzheimer's disease and related dementias by investigating the impact of the disease on patients, families, and communities.

This spring and summer season we would like to provide some ideas for some activities to connect with loved ones and to help with brain health. Some activities can be shared with other generations in your home/family/neighborhood. A rainy spring day indoors can be filled with puzzles/word games, teaching your loved one a card or dice game, asking a loved one for help, organizing old family photos, watching a new or old favorite movie/tv series, trying new or old favorite berry recipe together, organizing a seed swap or reaching out to community programming for assistance in a raised garden bed. Warmer outdoor activities include smoking salmon, preparing and tending to the garden and harvesting.

As always we want to express the importance of making connections with loved ones. Calling a friend or family member to check in and see how they are doing can spread happiness to others and to yourself. Sharing stories of humor or the way things were when you were growing up can provide happiness and pride in sharing knowledge. Teaching younger generations your skills or what you enjoy in a current season can create a connection with another generation.

### **Words of the season:**

Mnookmi-Spring, Shka-kamigkwe-Mother Earth, Zisbaakdake –Making Maple Syrup, Giigoonh-Fish, Niibin-Summer, Baashkaabgonii–Blooming, Demin(an)-Stawberry(s), Mskomin-Raspberry.

If you are interested in learning more about our projects you can connect with us by calling Karen Pitawanakwat or Rhonda Trudeau at 705-859-3164 extension 9323.

## ONEIDA NATION

Is it Spring or Winter? Lois and I have made it through the mild winter we had and it seems winter doesn't want to go away. COVID has let up here in our area. I hope we don't go backwards anymore and move forward to some kind of normalcy once again. Our "GREAT LAKES NATIVE AMERICAN ELDER ASSOCIATION" was able to have our meeting once again. The Sokaogon Chippewa Tribe of Mole Lake hosted us. Our educational speaker was Dr. Dempsey from University of Madison. He spoke on the Stroke Prevention Project that he is doing in the Oneida community. Both Lois and I are part of the Stroke prevention and so far it has been interesting and educational and helping us to get motivated to be more active and live a more healthy lifestyle. Another highlight of this spring is being able to be on a panel at the "Honoring Elder Wisdom Conference". The panel talked about each of the communities that is doing the ICARE research and what it means to the community and us. It was good to see the rest of our researcher's once again instead of having a zoom meeting.

The ICARE Phase 2 funding has finally started. We have started interviews with healthy older adults. We have been learning a computer program called RedCap and it is getting better, and I feel we just have to jump in with both feet and get it done. Lois and I continue to do webinars and other educational programs. We had a training session on computers which was a refresher course for me and Lois. A couple of articles came upfront in discussions that we had. One was the "The Two Spirited" in regard to LGBT. The other one was "What should we call ourselves?" This was in regard to being Indigenous or Native American, First Nations and American Indian. Who are we? Things to think about or Google. Until next newsletter ~ have a great Summer!





# ICARE RESEARCH TEAM

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**ROGER BEAUDIN**

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**SERVICES**

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# HELPFUL LINKS

[I-CAARE.ca](http://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/>

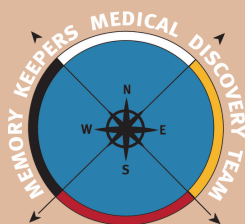
**Alzheimer’s Association, USA National site**  
<https://www.alz.org/>

**Alzheimer’s Association, Minnesota-North Dakota Chapter**  
<https://www.alz.org/mnnd>

**Alzheimer’s Association, Wisconsin Chapter**  
<https://www.alz.org/wi?set=1>

**Alzheimer’s Society, Canadian National site**  
<https://alzheimer.ca/en/Home>

**Alzheimer’s Society, Sudbury-Manitoulin North Bay District**  
<https://alzheimer.ca/en/sudburymanitoulin>



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