

ICARE

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

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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. The first snowfall came early in Duluth (October 14, 2022). Luckily the snow melted, and we still have a couple of warmer days ahead to prepare for the upcoming winter months. This past summer has been filled with an incredible number of activities! These include attending community events, raising awareness, attending trainings, meeting with community advisory members, finalizing phase I community reports, and completing interviews with Healthy Older Adults. We have continued to learn from each other, while having a lot of fun. Our team has also continued to grow. We are pleased to welcome Josyaah Budreau, Amy Otto, and Lysie Radovich to Memory Keepers Medical Discovery Team and the ICARE team.

On June 2, 2022, the community researchers, analysts, and investigators came together to start the analysis on the Healthy Older Adult interviews. The meeting involved reading through some interviews and discussing possible themes that will help us organize and code the interviews once they are completed. Some of the community researchers attended the meeting in person, while others attended via Zoom. It was an incredible day filled with lots of sharing of information, good discussions, laughter, and food.



CONTINUED MESSAGE...

In early August, our team presented findings from phase I of the research at the AAIC (Alzheimer's Association International Conference) in San Diego, CA. We presented two posters and an oral presentation to an international audience dedicated to advancing dementia research. We are incredibly grateful to the advisory members at each site who reviewed and provided feedback on all the draft materials that go into making these presentations and posters. See them [HERE](https://memorykeepersmdt.com/icare-presentations/). (<https://memorykeepersmdt.com/icare-presentations/>)

In mid-August, we hosted an ICARE team retreat in Duluth. Community engagement specialist and ICARE team member, [Annamarie Hill](#) will share more about the retreat on the following page.

The ICARE team is continuing to prepare for the next set of interviews with caregivers of late-stage dementia. If you or someone you know is interested in participating in the research, please contact the community researcher for your community or the project coordinator, [Melissa Blind](#) at mblind@d.umn.edu.

Until the next newsletter, wishing everyone good health and joyous fall / winter season. Enjoy the updates from the community researchers.



ICARE TEAM RETREAT

by Annamarie Hill

Just as the first tiny hints of fall came to life around the north shores of Gitchi Gummi, as one began spotting the lone red maple leaf tumbling delightfully down the street in the unpredictable winds of Duluth, the entire ICARE team came together for the first time since the COVID era began. It was during the confines of COVID that two years of hard work and excited anticipation was dedicated to planning for this retreat, held in Duluth the week of August 15-19, 2022.

The week together was overflowing with research sites sharing findings, renewing in-person relationships, and celebrating accomplishments with one another. In addition to deep learning and sharing of ICARE research content, the team bonded over cultural excursions, including a rippling boat tour along the glimmering waters and shores of glorious Duluth. We also enjoyed a coach ride through the winding roads and thick northern forests surrounding Duluth while listening to Wayne Dupuis, Fond du Lac Tribal Member and Environmental Program Manager, share the Ojibwe perspectives and history of the lands leading us to a breath-taking tour of the Fond du Lac Cultural Center. Through it all, the magic of true team building was unmistakable as the team bonded through stories, laughter, tears, and hugs, while traversing the great ICARE mission to build awareness and resources for Indigenous communities' experiences with Alzheimer's dementia in Minnesota, Wisconsin, the Great Lakes Region, and Canada.

As the week ended, we said our goodbyes to one another through laughter, hugs, and tears. It was certain that each ICARE team member traveled home knowing how important their contribution is to the ICARE team and the overall mission to better understand Alzheimer's dementia and its devastating effects on American Indian/Indigenous people.

Until we meet again, let's raise our cups of hot coffee and toast bubbling glasses to a week well done! Chi Miigwech (big thank you) ICARE team!

In November, Annamarie moved to a new position as the Strategy and Outreach Director for the Regional Dean's Office at UMD. Memory Keepers is so sad to lose her, but we are excited for her new opportunity! Chi Miigwech to Annamarie for your dedication to Memory Keepers and Indian Country as a whole - we will miss you!



ICARE RETREAT

August 15-19, 2022

GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

By: Collette Pederson

The summer always seems to go by too fast. Before we know it, our Majesty, Lake Superior, will be gearing up for the winter and wearing her heavy coat. We have not been sitting idle for the last three months, in fact, we've been as busy as this beaver.

At the beginning of June, the ICARE community researchers met with the analyst team and heard from Dr. Dana Ketcher on coding analysis.



Later in the month, the advisory members and I had tables at the Grand Portage Health Fair and shared information about the ICARE project and Alzheimer's Disease and related dementias. In July, the advisory members and I met with the council to organize a community listening session and a meeting with all the department heads, to be led by the Alzheimer's Association. The meeting went well and on July 19, 2022, Jenna Pogorels and Sherry Sanchez Tibbets, from the Alzheimer's Association, Minnesota-North Dakota chapter, gave a great presentation to community members. We were all very pleased with the turn out and the great questions from the community. Dinner was catered by Bruce and Colleen Waltz, and it was delicious. The following day, Jenna and Sherry met with the council and department heads for an informational talk on dementia/Alzheimer's and what it requires to have a Dementia Friendly Community. Our sincere thanks to Jena and Sherry.

On August 13, 2022, the Memory Keepers Team and the Grand Portage Clinic, held a walk/run for Rendezvous Days. It was well attended and everyone enjoyed the event. We also held an Alzheimer's walk on September 10, 2022, at the Community Center. The donations were wonderful and the turn out was great. Thank you to everyone and please join us again next year. The report for Phase I is completed and Phase II, Healthy Older Adults Interviews, have been completed. We also had two incredible retreats! The ICARE retreat in Duluth (which was awesome) and a full Memory Keepers MDT retreat at Larsmont Cottages in Two Harbors. Great meetings, food, company, and tours. Great time! So much hard work is done by the ICARE team and it is greatly appreciated. Miigwech. *See pictures on the last pages of this newsletter.*

RED LAKE BAND OF CHIPPEWA INDIANS

By: January Johnson

BoozhooIndinawemaaganigog (Hello all my relatives). Since our last update, I have completed all 10 healthy older adult (HOA) interviews. Memory Keepers and I have been working collaboratively with the Community Advisory Council on developing dementia awareness efforts for the Red Lake Nation. I've also attended numerous community events, and other professional development opportunities. Currently, we are preparing to move forward with the caregivers of late-stage dementia interviews. It was a great experience carrying out the HOA interviews; they were amazing! I've had the honor of getting to know a lot of wonderful people who've shared many fascinating, inspiring, and enriching life experiences.

As of October, I have wrapped up member-checking the HOA interview transcripts with the participants and submitted all final edits for further analysis. I love that I have developed friendships through these interviews. In addition to building relationships in the community, I also developed professional relationships through networking and attending community events. Annamarie and I had set up a booth for Memory Keepers MDT at Red Lake Nation's Community Health Day event on July, 28, 2022. We had many community members approach our booth and engage in conversations about their loved ones experiencing memory concerns. We were able to provide dementia information factsheets, an ear to listen, and to talk about how the research could potentially help bridge dementia service gaps in the community.

I was also able to network with healthcare professionals in surrounding communities outside the reservation. So, networking will be especially helpful during the next phase of interviews with caregivers of person with dementia. It would be beneficial to have a list of as much dementia resources and services readily available for them if needed. I've also had the privilege of attending many other professional development opportunities over the past few months. I've attended Wisdom Steps and learned about preventative health and other healthcare resources for our Native Elders. I've also attended a theatrical play called "Fortune Cookies" by The Remember Project, which was hosted at adult day services in Bemidji MN. The Remember Project is a group of theatre professionals who utilize the arts to bring awareness and reduce stigma surrounding memory loss.

And more recently, I've attended Teepa Snow's Positive Approach to Care (PAC) Conference. I've learned skill-focused dementia education such as: optimizing care environment, creating mobility to support independence, promote movement and exercise, as well as supportive hygiene efforts. I encourage anyone to attend dementia awareness/education events as it helps build understanding and compassion for caregivers and people with dementia. *See pictures on the last pages of this newsletter.*

ONEIDA NATION

By: Lois Strong & Marlene Summers

Lois Strong- Harvest time is happening in Oneida. There are events that draw in the community to participate in our traditional ways that emphasize the significance food plays in maintaining a healthy, balanced diet by using our traditional foods such as white corn, beans, and squash.

Recently Robert Golden, MD; Dean of UW School of Medicine and Public Health along with several UW-Madison professionals (Nicholas Lambrou, PhD; Carey Gleason, PhD; Banally Thompson, MD; Danielle Yancy (Native American Center for Health Professions [NACHP]) visited Oneida to learn more about the Oneida community and the different projects Oneida and UW-Madison collaborate on. These include Alzheimer's Disease Research, Stroke Prevention, NACHP, Tsyunhehwa, Food Sovereignty. Dean Golden paid a visit to our Native American Research and Outreach Initiative offices where he met with employees at this location. We look forward to future meetings with Dean Golden to promote our partnerships with UW-Madison.

The transition of summer to the changing temperatures and colors of fall is a spectacular time to experience. It means cool crisp walks in the woods, while taking in the various sounds of the many birds as they fly to their winter destination. It is a time to enjoy the crispy taste of different types of apples, each type having a unique taste. This time of year means being able to leave one's windows open to allow fresh air in while listening to the symphony of various wind chimes that echo from my daughter's home next door.

Marlene Summers- As an Elder, going through these past months from the last newsletter, I am feeling the quote: *"You are never too old to learn"*. We are going through training, and it's a little more in-depth, but also very interesting. With the interviews of the healthy older adults, we are finishing up and have also learned in doing these interviews that we need to be more in-depth or fruitful. We can tell by the first two interviews, that yes, we need to be more in-depth. We like the fruitful concept.

Lois and I had the honor of presenting at the University of Madison, at the Diversity Summit. We shared the relationship that we have with Madison and what our ICARE research is and those involved, including Duluth and the other community researchers. It was another experience that Lois and I enjoyed doing. Our office space is getting full with the AMICA grant that we are thinking of new space to house everyone. That will take a little time and hopefully we will get there. So far our work is going smoothly, sometimes there can be set backs but that is ok, that's how we learn. Until next time - have a fruitful harvest. *See pictures on the last pages of this newsletter.*

ONTARIO-MANITOULIN ISLAND

By: Rhonda Trudeau

Over the course of the summer and into the fall months, Karen and I have been visiting the Elder Centres in each of the communities we are working with on Manitoulin Island. We hope to complete our Elder Centre tour before our fall months are over.

In each community, we are visiting with the Elders to give updates on our program and the opportunities to get involved in the research. We are currently looking to connect with dementia caregivers to hear their stories and experiences with caring for a loved one with dementia. We have enjoyed attending programming days and have been so impressed with all the programming that is being provided to our Elders. The Elders Centre calendars are filled with projects and get-togethers that promote healthy living, and opportunities to visit one another. We have enjoyed discussions of how open the Elders Centres are in giving Elders the opportunity to suggest what programs they want to see in their communities.

While visiting communities, a common question asked is, "What can I do to prevent dementia?" When we look back to our Dementia Factsheets (<https://www.i-caare.ca/factsheets>): Preventing Dementia in Indigenous Peoples by Aging Well, we see "Healthy Body –Healthy Mind". Taking care of your body means treating your body well with good hygiene, sleep, and nutrition, as well as being physically active through sports, regular exercise, walking and outdoor activities. Being physical is a great way to lower the risk for dementia. In the fact sheets we also see the importance of staying connected and maintaining strong and positive relationships to nature and community.

Dementia can also be prevented by taking the time to heal from illnesses or emotional pain. Prevention can begin at all stages of life by living a well balanced wholistic lifestyle. Some ways to stay active and connected over the fall and winter months can be: hunting, fishing, harvesting, canning, crafts, story telling, beading, walking, and calling a loved one/friend/support person. These activities be done across generations to stay connected with those younger and older. We hope you have a safe, healthy, enjoyable fall and winter months and look forward to connecting with anyone interested in being involved in our projects. If you are interested in learning more about our ICARE project, you can connect with us by calling Karen Pitawanakwat or Rhonda Trudeau at 705-859-3164 extension 9323.



ADDITIONAL PICTURES



Grand Portage Alzheimers Walk,
Sept. 10



Grand Portage Alzheimers Walk, Sept. 10



Grand Portage Alzheimers Walk,
Sept. 10



Red Lake Teepa Snow PAC conference



John Morrin & Mary Harrelson,
ICARE Retreat



Collete Pederson, ICARE Retreat

ADDITIONAL PICTURES CONTINUED



ICARE Retreat



ICARE Retreat



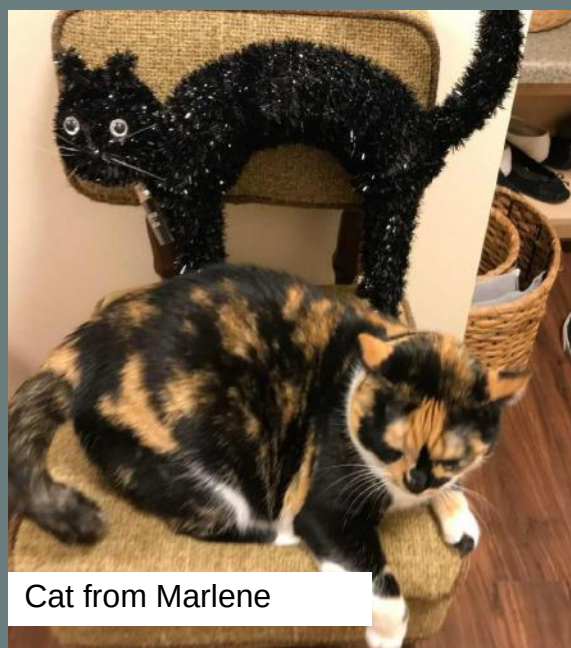
Data analysis team meeting



Canned tomatoes from Oneida



Corn drying from Oneida



Cat from Marlene

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

BRANDY ARREDONDO

Research Associate

AMY OTTO

Research Associate

JOSYAAH BUDREAU

Research Associate

ANNAMARIE HILL

Community Engagement Specialist

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 LEES

Communications Coordinator

ONTARIO

KAREN PITAWANAKWAT

Community Researcher

RHONDA TRUDEAU

Community Researcher Assistant

WIKWEMIKONG HEALTH

CENTRE

Community Partner

DIANE JACKO

Community Partner

DANIELLE WILSON

Community Partner

NOOJMOWIN TEG HEALTH

CENTRE

Community Partner

CRAIG ABOTOSSAWAY

Community Partner

MNAAMODZAWIN HEALTH

SERVICES INC.

Community Partner

ROGER BEAUDIN

Community Partner

M'CHIGEENG HEALTH

SERVICES

Community Partner

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?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>



**GLNAEA Great Lakes Native
American Elder Association**



Memory Keepers Medical Discovery Team

624 E. First St. Suite 201

Duluth, MN 55805