

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,

What a winter! Here in Duluth, MN, we broke the record for most snowfall, with 140.1 inches falling this season. Hopefully, the snow has stopped and we can embrace the sounds of spring.

Over the last six months, the ICARE community researchers have completed the healthy older adult interviews and have started interviews with caregivers of late-stage dementia. If you or someone you know is from one of the four sites and has cared for or is currently caring for a loved one with late-stage dementia and want to share your experiences, please let us know.

The analyst team has been reviewing the healthy older adult interviews and preparing a coding framework to help organize the stories and information that has been shared. The analyst team has been meeting with the community researchers to better understand any community-specific questions that might arise from the interviews.

The entire team has also been preparing abstracts for an upcoming conference that Memory Keepers Medical Discovery Team is very proud to host, the International Indigenous Dementia Research Network (IIDRN) Conference in Honolulu, Hawaii, November 7-9, 2023. This conference is the first to focus on Indigenous dementia from a global perspective. Researchers and community partners from Canada, US, Australia, New Zealand, along with other countries will come together to learn from each other, share their research findings, and build collaborative relationships to continue the important work that is being done in Indigenous brain health. For more information on the conference, please visit <https://memorykeepersmdt.com/iidrn-conference/>.

CONTINUED MESSAGE...

In terms of summer plans, many of our Community Researchers will be taking part in community events, such as health fairs, community walks, or research days, and sharing information about the project. Members of the team will be presenting at the Alzheimer's Association International Conference (AAIC) in Amsterdam, Netherlands, July 16-20, 2023. Our full team will also come together for our annual retreat in October in Oneida, WI.

We would also like to welcome our new Community Engagement Coordinator, Natalya Walker! She oversees and coordinates relationship development with rural and Indigenous communities in Minnesota and is foremost concerned with supporting sustainable community collaborations that support brain health equity research.

Until the next time, wishing everyone good health and a wonderful spring / summer season! Enjoy the updates from the Community Researchers! *Below you will find the pictures that go with each of the communities updates. The further pages will show their full update.*

ONEIDA NATION



GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA



ONTARIO-MANITOULIN ISLAND

ONEIDA NATION

By: Lois Metoxen Strong & Marlene Summers

I'm sure everyone, like me, is wondering where spring is; I think winter extended itself, but then I look at my small flower garden and there are three bunches of tulips popping out of a pile of snow.

We are recruiting participants for the caregivers of late-stage dementia participant group, meeting with the nursing home and caregivers, organizing resources, and writing. We are trying to update our community dementia resources, and get help from the administrative assistant from our Alzheimer's Disease Research Center (ADRC). One thing I can't be fruitful with are writing the abstracts for the International Indigenous Dementia Research Network (IIDRN) Conference, taking place in Honolulu, Hawaii, November 7-9, 2023. Again, it's a learning lesson.

For the ICARE project, we have two caregivers of late-stage interviews completed, two participants consented into the project, and have scheduled interviews. We have also met with the ICARE analyst team about the healthy older adult interviews and building a coding framework, which will help organize the information gathered from the interviews. It's very much appreciated to be able to know how our coding system works and be part of it. Training is ongoing and helps us to be better researchers. We also had a Great Lakes Native American Elder Association (GLNAEA) meeting March 8 & 9, 2023. Our next meeting is June 7 & 8 in Red Cliff, WI. I hope our researchers from up north are able to attend.

The COVID epidemic severely impacted our Oneida community. We experienced economic distress, closing of schools, stores and services, along with social impacts such as loneliness, social isolation and uncertainty. Now that the climate is warming up and Tribal programs are finally opening for in-person services, it will be reassuring to connect directly with community service providers. To get a picture of current services to Elders, Marlene and I met with Elijah Metoxen, Aging and Disability Services Director, to find out what's happening. Services are not the same as before COVID quarantine. Staff were laid off and not re-hired, and there is a limited budget to provide services. The current staff is doing creative programming to reintroduce limited services such as transportation for shopping and to GLNAEA. Physical fitness activities are happening on a limited basis. A substantial grant for home restoration is approved and will be awarded soon. Another two-year grant will help fund some services. An application is also out there to help summer youth workers who will be hired to perform outside work.

The annual Elder Expo is returning on August 29, 2023. It's encouraging to learn of the energy going into programming at Oneida Aging and Disability Services. The Stroke Prevention Research Program is continuing an event they had a few months ago called "Walk with the Doc." Every first Wednesday in May through October, a doctor will walk and answer any questions the walkers may have.

Have a great summer and take time to "SMELL THE ROSES" as the saying goes (pics on page 02).

GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

By: Collette Pederson

Winter finally melted away, feeding our rivers and streams with the new birth and an abundance of water, welcomed by all living creatures. It was a long one, but now we can enjoy the natural wonders and nature's incredible display of the magical fresh beauty, and aromas she loves showing off.

The ICARE project keeps moving forward, and the community support has been incredible. We remain moving forward in the process of making Grand Portage a dementia-friendly community with hopes of designing and creating a pavilion (which will be wheelchair accessible) along with picnic tables, flowers, and access to Lake Superior's incredible view--peaceful and beautiful place for individuals to relax and enjoy.

The Advisory Group has been busy planning events for the community. We are looking forward to organizing the Alzheimer's walk, health fair exhibits/information, and more community awareness presentations. We are in the process of interviewing caregivers of late-stage. The participants are remarkable!

We had the honor of attending the Elders & Caregivers Conference, "Sharing the Care," presented by Grand Portage Elderly Nutrition and Grand Portage Nutrition programs. There were presentations by Rick Defoe, who gave the opening and closing prayer, and presentations from multiple others including the ICARE team. It was well attended and very much appreciated.

Starting on May 15, 2023, there will be a Dementia Caregiver Support Group, which will be held every third Monday of the month from 3:00 P.M. - 4:30 P.M. in the Log Building. This event is being held through the Alzheimer's Association. This is a safe, non-judgmental and confidential time for individuals facing caregiver experiences to share concerns, thoughts, and to feel safe and comfortable talking about their loved one. No need to sign up, just feel free to come.

On April 11, 2023, our newest members arrived after a very long ride from North Dakota. Grand Portage received 7 bison. This is a continued effort to create a healthy, affordable, and local food option for the community. They are kept on the Grand Portage Bizhiki Ranch on Old Hwy. 61. It's that time of year for tapping trees, and the Sugar Bush in Grand Portage is well under way with buckets hanging on many trees just waiting for the flow to begin. Should be a good season (see pics on page 02).

RED LAKE BAND OF CHIPPEWA INDIANS

By: January Johnson

Boozhoo Indinawemaaganigog (Hello all my relatives),

January here, back to give Miskwaagamiwi-zaaga'iganing (Red Lake Reservation) an update on the ICARE research activities going on in the community. Over the past winter months, we've prepared for the for the interviews with caregivers of late-stage dementia.. Working closely with the Red Lake ICARE Advisory Council, the recruitment flier and interview guide were reviewed for use in the late-stage research interviews. Recruitment efforts actively began in February, fliers have been submitted into the Red Lake Newsletter and shared with professionals at Jourdain Perpich Extended Care Facility, as well as the Elderly Nutrition Program. I have completed two late-stage caregiver interviews thus far, and I am still actively recruiting. If interested, please contact me at Joh20247@d.umn.edu or 218-508-7639.

Additionally, Memory Keepers Medical Discovery Team participated in the Red Lake Nation College (RLNC) Career fair on March 15th, 2023. Their booth was set up to meet prospective community researchers for the upcoming Addressing Alzheimer's Disease and Related Dementias Disparities: The American Indigenous Cognitive Assessment (AMICA) project, as well as share information on the ICARE project. We met many youth and college students exploring various career and educational opportunities. We also met Nadine Bill, the Executive Director of the RLNC Minneapolis Campus, as well as Dan King, President of RLNC.



ONTARIO-MANITOULIN ISLAND

By: Rhonda Trudeau

Aanii, Boozhoo kina weya!! We hope this newsletter finds you living the good life! Fulfilling all your self-care needs, spiritual, physical, mental, and emotional. Over the fall/winter months, Karen and I have been completing our Elder Centre tour and cannot wait to visit each community again! We did participant recruitment, as we are currently looking to connect with dementia caregivers.

While visiting our Elder Centres, we distributed our current resources to each of the communities that we collaborate with on Manitoulin Island. We have also completed interviews with healthy older adults. It is a real pleasure to be able to connect with community members in this work. Listening to the stories shared around the kitchen table are true blessings and the amount of knowledge shared is a true gift that we will be able to share with all the communities we collaborate with.

There are things we can do to prevent dementia all year, and we will highlight some spring/summer months activities. We can grow and/or gather our own food, visit and stay connected with loved ones, laugh, sing and dance, seek therapy and/or advice from Elders and practice kindness. We can teach young ones about foraging, fishing, trapping, and harvesting birch bark. We can attend a pow wow or community event to connect with loved ones.

Our advisory is diverse and consists of past/present health care workers, Knowledge Carriers, language speakers, and community experts from the communities we work with. We love our advisory members! Connecting with them is truly one of the best parts of our projects. We typically meet once a month and stay connected in between meetings as needed. We have been meeting in Wiikwemkoong Unceded Territory but more recently we have also enjoyed meeting in M'Chigeeng First Nation and Whitefish River First Nation.

Our advisory meetings consist of a hybrid model where others who may not be able to attend in person join via Zoom. After meetings and any presentations, we share a meal and continue to share thoughts on the projects we are working on. Soon we will be reaching out to current/past health care staff with experience in caring for someone with dementia to join our team in the role of advisory members.

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.

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

Research Associate

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

ONTARIO

KAREN PITAWANAKWAT

Community Researcher

RHONDA TRUDEAU

Community Researcher Assistant

WIKWEMIKONG HEALTH

CENTRE

DIANE JACKO

Community Partner

NOOJMOWIN TEG HEALTH

CENTRE

DANIELLE WILSON

Executive Director

MNAAMODZAWIN HEALTH

SERVICES INC.

CRAIG ABOTOSSAWAY

Executive Director

M'CHIGEENG HEALTH

SERVICES

ROGER BEAUDIN

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/>

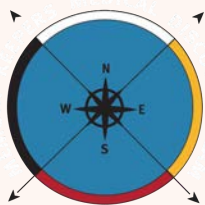
Alzheimer’s Association, USA National site
<https://www.alz.org/>

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

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



**Medical School,
Duluth Campus**
UNIVERSITY OF MINNESOTA
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Memory Keepers Medical Discovery Team
624 E. First St. Suite 201
Duluth, MN 55805