

INDIGENOUS CULTURAL UNDERSTANDINGS OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

ICARE

SPRING/SUMMER 2020 NEWSLETTER

ICARE Research Team

(Role on ICARE team):

MINNESOTA

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Community Researcher, Oneida

LOIS STRONG
Community Researcher, Oneida

A MESSAGE FROM THE ICARE TEAM

We would like to extend a heartfelt thank you to all of the healthcare providers and those working in essential service positions during the COVID-19 pandemic. Your compassion and dedication during these unknown times demonstrates the courage, strength and perseverance of your community. The ICARE research team is confident resilience will prevail.

As many of you are aware, the University of Minnesota Medical School and University of Wisconsin-Madison has prohibited all faculty and staff travel between now and June 30, 2020. Laurentian University in Ontario has cancelled all community-based research activities through August 31, 2020. We will continue to provide updates as more is known.

Following University policies and good public health practices, ICARE research staff will be telecommuting for at least the next several weeks and cannot travel to community research sites. Over the coming weeks or months, we will look to the communities and the ICARE advisory members in each community for guidance on when it is safe to return.

In the meantime, we are using telephone and videoconferencing to continue meeting as a team and strategizing unique ways to continue our research activities while working remotely.

As issues of health and equity have become front and center, our work is viewed as even more important. Thank you, our partners, for your hard work and patience as we make these adjustments. Should you need to reach us during this time, please contact our project manager, Dr. Melissa Blind at: mblind@d.umn.edu.

Stay safe and be well.

With respect, the ICARE Research Team

ICARE PARTNERS



GLNAEA Great Lakes Native American Elder Association



Giiwedining Northland

WHAT HAS THE ICARE TEAM BEEN UP TO?

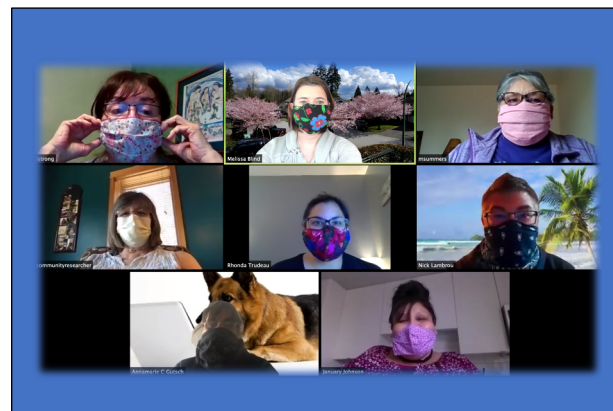
Since our last newsletter ([Fall / Winter 2019](#)), the community researchers in Red Lake, Grand Portage, Oneida, and Manitoulin Island have worked closely with their community advisory members to recruit potential participants for key informant interviews. In order to better understand dementia care services, along with cultural understanding of aging and dementia in each community, the community researchers have conducted interviews with:

1. Administrators / program managers;
2. Physicians / nurse practitioners / specialists; and
3. Traditional Knowledge Keepers, Elders, community historians, language speakers.

When COVID-19 hit, the interviews and in person community advisory meetings for each site were put on hold. The community researchers across the different sites were able to meet weekly through Zoom. These meetings allowed us to share how COVID-19 was affecting our families and communities, reflect on the research, as well as learn new skills from each other. We were also able to have some fun and include some props into our meetings.

The pause in the research also gave the community researchers the time to write their own community updates for this newsletter and share a little about themselves, their communities, as well as their reflections on the research process. We hope you enjoy what they have included in the following pages.

Over the next couple of months, we will return to our regular research activities, including interviewing, focus groups, and reconnecting with the community advisory members. A lot of this work will be done remotely through telephone and video conferencing until it is safe to resume this work in person. In fact, we recently received University ethics approval at all three sites to continue key informant interviews using distance technology and look forward to resuming the research.



ICARE Community Researcher Zoom meeting

April 29, 2020: "Let's see your COVID-19 facemask"

Top row: Lois Strong, Melissa Blind,
Marlene Summers

Middle Row: Collette Pederson, Rhonda Trudeau,
Nick Lambrou

Bottom Row: Annamarie Hill Gutsch,
January Johnson

ICARE GRANT SUBMISSION UPDATE

The ICARE investigators and research staff worked closely with our community advisory members and Tribal Leadership across the different sites to obtain the necessary support to apply for the second phase of the ICARE project. In early March the team submitted a grant application to the National Institutes of Health (NIH) – National Institutes on Aging (NIA). The project, *Indigenous Cultural-understandings of Alzheimer's – Research and Engagement* (ICARE) is a five-year extension of the current research and focuses on the urgent need to address the increasing burden of Alzheimer's disease and related dementias (ADRD) in American Indian (AI) and First Nations (FN) populations. This study represents an important step in identifying effective, culturally grounded approaches to address dementia-related inequities in AI/FN populations and will include the development of health promotion/education tools, such as fact sheets, videos or training modules.

"The entire team has my gratitude for all that went into the grant submission!" said Dr. Jacklin, Principal Investigator, ICARE. "This includes staff, partners, community leadership, advisors, and investigators. It really took a collective effort and the result was a strong and competitive application that we can all be proud of."

The NIH-NIA grant committee met the first week of June to review the submission, but because of backlogs at NIH funding decisions will not be known until October.

MINNESOTA RESEARCH PARTNERSHIP: GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

An update from Collette Pederson, Community Researcher

With the COVID-19 impact, things have slowed way down. Feeling fortunate to revise certain transcripts and drive down memory lane in my mind, reviewing the great interviews that have taken place. So interesting and so thankful that people will share their incredible encounters and stories. Anxious to hear when we may resume, but meanwhile our Community Advisory Group (CAG) friends sit idle and safe, some still working, some at home.



**Grand Portage Community
Advisory Group meeting**
February 19, 2020

Left to right: Emma Carlson,
Rebecca Deschampe, Jennifer
Sorenson, Patty Winchell-
Dahl, Collette Pederson,
Shirley Stevens.
Not pictured: John Morin

Our Elderly Nutrition Program (ENP) is very busy keeping our Elders safe and fed. They prepare lunch and dinner for them and deliver the meals to their home. They are preparing gift baskets for the Elders, which contain toiletries, snacks, daily necessities, puzzle books, etc. Goodies to help them pass the time at home and keep them busy.

The community has all come together doing an incredible job of providing food. The Grand Portage Trust Lands Agency will be providing subsistence foods to the community during the quarantine period to assist the community during the shelter-in-place period and for as long as there is a need. They will be offering fresh lake trout and deer meat while processing their catches, collecting biological data for assessment purposes, and delivering to our programs. Deer will be sampled for biological samples, processed and packaged, and provided to the ENP, Human Services and Cache program for distribution.

Our community garden will be expanding their produce this year. You name it, they grow it. The produce helps feed our community along with other programs. It's a beautiful sight and hard to imagine what a tiny little seed produces. Magical.

The Grand Portage Band held its first ever State of the Band gathering on Monday, February 3, 2020. The gathering included a closed session for enrolled members of the Grand Portage Band, followed by a presentation open to the broader community.

The event kicked off with the drum, by the Grand Portage Stonebridge Singers. The Grand Portage American Legion Honor Guard carried in the flags and staffs and an invocation was given. The State of the Band gathering was making history by livestreaming online.

Speakers included Councilman Anderson, Trust Lands Manager Tony Swader, and Tribal Chairwoman Beth Drost.

The gathering was well attended, and a great feast was served to all.

MINNESOTA RESEARCH PARTNERSHIP: GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

Getting to know the Grand Portage area: High Falls and Pigeon River

With the sprouting of spring, High Falls will be showing the re-birth of her majestic power and beauty as the snow and ice start to melt. She's like a beating drum. Her strength and pounding as she races her way to Lake Superior, vibrates in your soul. Her river, the Pigeon River, keeps her working overtime. The mighty river roars for 31.2 miles, one of the larger rivers on Superior's North Shore. This great river, which alternates between navigable waters and cascades over waterfalls, pounds into two spectacular gorges, one being High Falls, the highest waterfall in Minnesota, and the other, Middle Falls. The river forms part of the Canada-United States Border. She's a Beauty!

Pigeon River

Location

Countries: Canada and United States

Region: Minnesota and Ontario

Physical characteristics

Source:

Location: Mountain Lake

Elevation: 614 feet (187 m)

Mouth location: Lake Superior

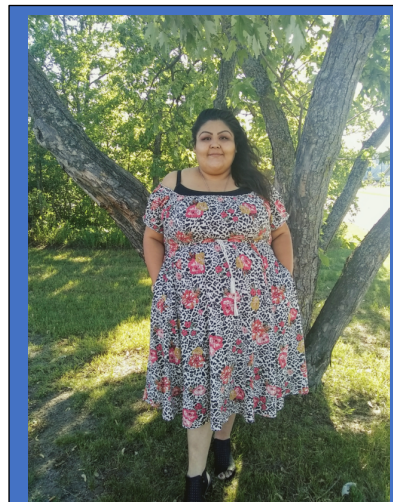
Length: 31.2 miles (50.2 km)



MINNESOTA RESEARCH PARTNERSHIP: RED LAKE BAND OF CHIPPEWA INDIANS

Meet the Red Lake Community Researcher: January Johnson

Boozhoo, my name is January Johnson. I represent the eagle clan from the Red Lake Band of Chippewa Indians. I was born and raised on the Red Lake reservation, only leaving to pursue a formal education both in my adolescence and adulthood. I graduated from Fond du Lac Tribal and Community College with a degree in Liberal Arts and moved on to major in Social Work at The College of St. Scholastica. I am currently one semester away from receiving my bachelor's degree. When I returned home, it was difficult reconnecting in the community, and unfortunately during that time I lost the motivation to return to school and finish my degree. In retrospect, I realize it had a lot to do with what I was feeding my body as well. However, this researcher position has been a blessing in so many ways. I have regained the motivation and passion to continue on a path in the Social Work field, while also gaining an awareness of what I feed my mind and body.



Red Lake Community Researcher
January Johnson

This experience has allowed me to reconnect with my community. It has been an honor to work with such a passionate and motivated group of individuals who devoted so much of their time and resources in helping our Native American and First Nations communities work towards health equity by providing Alzheimer's disease and related dementias (ADRD) educational tools and resources to the communities. Reflecting back on the formal training for the community-based researcher position and recognizing that I am working for a Western educational institution, I gained a better understanding of the importance in building and maintaining relationships within my community because tribal populations had such traumatic experiences in the past with the US and Canadian governments. The training helped sharpen my research skills, allowing me to be more culturally competent while engaging with the research participants. In addition, the training allowed me to be recertified in human subject protections, meaning I understand the ethics of human subject research studies and will protect research participants identifiable data by remaining HIPAA compliant. The training also taught me how to facilitate focus groups and community advisory meetings.

I became knowledgeable of ADRD through preliminary research and I realize I can reduce my own risk of developing ADRD by eating healthy, exercising and eliminating mind-altering substances in my body. I am now more conscientious of what substances I put into my body. Brain health is very important and what we feed our bodies ultimately affects our brain function. Not only that, exercise also plays a vital role in keeping a healthy brain. Red Lake provides some programs that improve the quality of life such as free community fitness centers, the 4 Directions Food Initiative Program, which teaches participants to grow and sustain their own gardens as well as ways to preserve the food grown in the gardens. Red Lake also provides a Food Distribution Program which offers people food commodities that are no longer high in sodium or sugars.



Welcome Darlene Johnson!

Darlene recently joined the ICARE team as the newest member of the Red Lake Community Advisory Council.

MINNESOTA RESEARCH PARTNERSHIP: RED LAKE BAND OF CHIPPEWA INDIANS



Red Lake Community Advisory Council

February 2020

Back row: January Johnson
and Alexis Mason

Middle row: Richard
Gibbs, Bill May, Eileen
Miller, Karen Bedeau, and
Melissa Blind

Front row: Tina Roybal,
Susan Johnson, Susan
Ninham, Nancy Richards
Not pictured: Annamarie
Hill Gutsch



Get to know Northwoods Caregivers of Bemidji, Minnesota

Northwoods Caregivers (NWCG) of Bemidji, Minnesota is a small non-profit organization providing services in the areas of home health care, respite, homemaking, shopping assistance, aging life care management and some local transportation. NWCG's service area includes all of Beltrami County, and portions of Koochiching, Cass, Hubbard, and Clearwater counties. These service areas encompass all of the Red Lake Nation and part of the Leech Lake and White Earth reservations in northern Minnesota.

Northwoods Caregivers provides much needed services to support caregivers who are taking care of family members with Alzheimer's disease and other forms of dementia. These services include: caregiver coaching, dementia awareness education, stress assessments, respite and referrals. Among the tools used by NWCG staff to support family caregivers are evidence based programs such as "Powerful Tools for Caregivers", "Navigating MCI and Dementia", "The Basics: Memory Loss, Dementia and Alzheimer's Disease", "Know the 10 Signs – Early Detection Matters", "Dementia Friends", and "REACH – Resources for Enhancing Alzheimer's Caregiver Health", as well as providing monthly support groups.

NWCG has a special emphasis on collaborating with the area reservations by developing a communications and support network called "Giiwedinong Northland." This group is comprised of Native elders, support staff members from Leech Lake, Red Lake, and the Minnesota Chippewa Tribe, as well as staff representing Bemidji State University Nursing Program and the University of Minnesota Duluth (UMD) Medical School - Memory Keepers Medical Discovery Team (MK-MDT).

How to reach Northwoods Caregivers:

Website: <http://northwoodscaregivers.org/>

General phone: 218-333-8262

Karen Bedeau, Dementia Outreach Specialist and Advocate, 218-333-8098

Karen Bedeau, pictured above, is an enrolled member of the Red Lake Band of Chippewa Indians and also a member of the ICARE Red Lake Community Advisory Council

WISCONSIN RESEARCH PARTNERSHIP: ONEIDA NATION OF WISCONSIN

An update from Lois Strong and Marlene Summers, Community Researchers

When we finished our community researcher training, what a relief for both of us. Not in a negative way, but so much to learn and take in and so interesting for the both of us. The height of training was to be able to go to Manitoulin Island, Ontario, Canada last June and meet with the researchers that have been doing this type of research that we are now doing. That helped us a lot.

The next part of training was to get everything we needed to get going (technology-wise) and I believe that held us back a little bit. We needed apps for our laptops and recorders and had to be trained on the recorders. That went well, but technology can be challenging.

We did several traditional knowledge keeper interviews and one thing we learned was we didn't have to keep the interview questions exactly to a script. We could probe and go deeper into the questions. At the end of the interviews, we completed interview summaries, which were difficult at first, but eventually we got them done.

Where we are now since the pandemic: We had some administration interviews set up when we were told we couldn't do them due to the pandemic, so we cancelled them. The Administrators told us when we are ready to go again that they will still do the interviews, which is good to know.

Prior to the "Stay at Home" mandate, the Community Advisory Board (CAB) met face-to-face, but since it has been meeting virtually and via telephone.

Thank you to all who helped us get to where we are now. Thank you to our Community Advisory Board for supporting this research and being involved, also we thank our Tribal government for supporting Alzheimer's Research.



Oneida Community Researchers, Marlene Summers and Lois Strong



UW Madison Lead, Dr. Carey Gleason and Marlene Summers



Post-doctoral fellow, Dr. Nick Lambrou and Marlene Summers

WISCONSIN RESEARCH PARTNERSHIP: ONEIDA NATION OF WISCONSIN

Getting to know Oneida Nation:

The Oneida Nation is located in Northeast Wisconsin. The original reservation boundaries comprise 65,400 acres. A major goal of the Nation is to eventually purchase all lands that were in the original Tribal boundaries.

There are 4,432 enrolled Oneidas who live on the Oneida reservation. Enrolled Oneida elders aged 55+ make up 25.7% of the enrolled Oneida population on the Oneida Reservation. There are 17,333 total Oneidas enrolled living throughout the world. 3,388 Oneidas live off the reservation in Brown and Outagamie Counties that border the original reservation boundaries. 2,159 live in the Milwaukee area and 2,344 live throughout the State of Wisconsin.

Until the coronavirus pandemic struck in Wisconsin, the Oneida Nation served as the second largest source of employment in Brown County with approximately 56% enrolled Oneidas and 7% enrolled in other Tribal Nations. As of March 12, 2020, approximately two-thirds of the employed staff became unemployed. The coronavirus pandemic has had an impact on our major economic activities. The Nation owns and operates three gaming operations along with six convenience stores, and two hotels within reservation boundaries. Other economic activities include government, agriculture, recreation, and tourism. A majority of Tribal services have been significantly down-sized.

The Oneida Nation Community Health Center continues to provide services on a limited basis as a result of the coronavirus. During the Tribal "Stay at Home" mandate, services are provided by telephone or virtual communication. Our Nursing Home, the Anna John Resident Centered Community Care, is a 48 bed, 24-hour skilled nursing facility for long-term care and short-term rehabilitation patients. The nursing home is currently on complete lock down status.

Oneida Elder Services continue to provide care to our elderly. The noon on-site meal service has been stopped until further notice. In its place, 250 elders who signed up can have two weeks supply of one meal a day for five days delivered meals for seven days a week.

Because of the impact of coronavirus, the tribe has eliminated all but one tribally elected and appointed boards, committees, and commissions. The Oneida Nation "Stay at Home" mandate was in effect until June 11, 2020. Our Tribal Government continues to communicate virtually through Facebook and has weekly updates from various departments.



ICARE team Zoom meeting April 3, 2020

Top row: Jessica Chiovitte, Kristen Jacklin, Melissa Blind, Lois Strong, Marlene Summers

Second row: Andrine Lemieux, Nick Lambrou, Mindy Dertinger, Collette Pederson, Neil Henderson

Third row: Jim Allen, January Johnson, Wayne Warry, Annamarie Hill Gutsch, Rhonda Trudeau

Bottom row: Carey Gleason, Tracy Kemp, via phone: Karen Bedeau, Wes Martin

ONTARIO RESEARCH PARTNERSHIP: MANITOULIN ISLAND

An update from Rhonda Trudeau, Community Research Assistant and Karen Pitawanakwat, Community Researcher



Karen Pitawanakwat,
Community Researcher

Meet Karen, our Community Researcher. Karen Pitawanakwat is an Anishinaabe Kwe from Wikwemikong, Ontario, Canada. Karen is a mother of two children, grandmother to one, and lives in Wikwemikong with her husband of 30 years. She belongs to the Thunder Bird Clan and is an Anishnaabemowin language speaker. She has worked in health care as a nurse and additional roles on Manitoulin Island for over 26 years. Karen has been involved in community-based research projects concerning diabetes, dementia, and cancer since 2006. Her commitment to advancing the health and wellbeing of Indigenous people can be seen in her work.



Rhonda Trudeau,
Community Research
Assistant

Meet Rhonda, our Community Research Assistant. Rhonda Trudeau is from Wiikwemkoong Unceded Territory. She is from the Bear Clan and her Anishinaabe name translates to “knowledge sharer.” Rhonda is a mother of two sets of twins and married to her husband for 12 years. She comes from a family of Anishnaabemowin language speakers and has a goal to expand her fluency. Rhonda has worked with community dementia research projects since 2016 and especially enjoys connecting with our Community Advisory Council (CAC). Rhonda has previously worked in the finance field for 18 years and is a community volunteer on various projects including finance, education, and arts.

Over the Fall & Winter months Karen and Rhonda have completed 13 interviews. We have had the honour of interviewing traditional knowledge keepers, administrative staff, and physicians. We have been connecting with community elders, caregivers, and providers, bridging needs and improving care for the elderly. We have been collaborating with caregivers informally and formally. Rhonda, along with the other community researchers in Minnesota and Wisconsin have completed community research training that was developed by our ICARE research team. Rhonda and Karen continue to connect with our partnering community researchers and Community Advisory Council as well as connecting with community research partners and updating them on this project and upcoming projects.

During this time we are reflecting on continuing our journey to explore our own backyards. Creating or recreating our gardens, calling our neighbours, connecting with loved ones in new ways, and praying for our communities. Our communities are reaching out in new ways to connect with others while staying home and staying safe. We have seen so much kindness paid forward in many different ways. We have seen examples of communities that are all helping each other with tasks like grocery shopping, or local businesses showing generosity by having draws for grocery baskets. We have seen support and appreciation given to our health care workers and community essential service workers. We give many thanks to those who give us hope during these times. If you are an Ontario senior and are having a difficult time you can call the Ontario senior safety line at 1-866-299-1011 for telephone safety planning and supportive counseling. This line is available for all of Ontario. If you are interested in connecting with your community garden or signing up for a good food box, you can ask your health service provider for more information.



Netaawging Gtigaan

“Vegetable Garden”

This lovely sign was painted by a community member for her vegetable garden.

ONTARIO RESEARCH PARTNERSHIP: MANITOULIN ISLAND



Ontario Community Advisory Council

January 15, 2020

Wikwemikong Health Center

Back row: Bonita Bebamash, Joe Peltier, Edward Osawamick, Bill Antoine, Roseanne Debassige, Rhonda Trudeau

Front row: Roselinda Peltier, Marion McGregor, Rosella Kinoshameg, Evelyn Roy, Karen Pitawanakwat

Not pictured: Rose Shawanda, Jean McGregor-Andrews, Jules Osawamick, Monica Pheasant

HELPFUL LINKS

I-CAARE

Indigenous Cognition & Aging Awareness Research Exchange

Website: www.i-caare.ca

Twitter: @I_CAARE

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>

Get in touch with the team

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