ICARE

INDIGENOUS CULTURAL UNDERSTANDINGS OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

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A ROUGH YEAR BUT A BRIGHT FUTURE

Memory Keepers Medical Discovery Team

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SIGNS AND SOUNDS OF SPRING

As the birds return and the sun shines upon us, this is the time of transition, reflection, growth and hope. This year has been a tough one for many of us. One year of COVID-19, one year of Zoom meetings and adjustments to our social life can take a toll on anyone, but we are hopeful that more vaccines are reaching community partners and for healthier days to come!

All of us on the ICARE team hope you enjoy this new format for the newsletter. We wanted to commemorate the changing of the seasons and the next phase of our research with a redesign to further showcase the incredible work that is being done across all sites.

Since the last newsletter, the community researchers, advisory members, and other advisors for Memory Keepers have been sharing tips on how to stay healthy and stay connected to family, friends, and community members in light of COVID-19. We wanted to create some resources to share with our community partners and our readers. The resources can be downloaded from https://memorykeepersmdt.com/covid-19-factsheets/.

WHAT HAS THE ICARE TEAM BEEN UP TO?

We have two new members joining our team, Megan Zuelsdorff and Jordan Lewis. There are two members moving on to other adventures, Neil Henderson, who is retiring, and Jim Allen, who is semi-retiring. Since our last newsletter (Fall/Winter 2020), the community researchers in Red Lake, Grand Portage, Oneida, and Manitoulin Island have been busy conducting sequential focus groups with health care workers and formal care workers. The focus group meetings were held with the same group of people over the course of 3-5 meetings and discussed early, moderate, and late stage dementia. All of these meetings were held virtually through Zoom.

We have also been meeting with our community advisory members at each site to go through some of preliminary findings from the interviews. We still have a lot more information to go through with each of the interview groups and will ask our advisory members to guide us on the best ways to present these findings back to the larger community.

PHASE II-Memory Keepers Medical Discovery Team Awarded \$7.5M to Improve Knowledge of Indigenous Cultural Understandings of Dementia Care

We will continue to build on the research activities conducted in phase I with our research partners from the seven First Nation communities on Manitoulin Island, Red Lake and Grand Portage Tribal Nations in Minnesota, and the Oneida Nation in Wisconsin. The five years of funding allows us to create a foundational database of American Indian and Anishinaabe lived experience of ADRD that can be used to examine and inform the creation of culturally appropriate and safe approaches to improve dementia diagnostics, care, and outreach.

Our research activities will include:

- Interviews with healthy older adults
- Interviews with people with dementia in the mild and moderate stages and their caregivers
- Interviews with caregivers to people with dementia in the late stages

We will continue to work closely with our community advisory members, research team members, and community partners to further discuss and explore the findings of the study through a member checking process. This will better explain how culture influences quality of life, diagnosis, and assessment of ADRD in American Indian and Anishinaabe communities and develop culturally appropriate dementia health promotion and education tools such as fact sheets, videos, and/or training modules.

MINNESOTA RESEARCH PARTNERSHIP: RED LAKE BAND OF CHIPPEWA INDIANS

Chi-miigwech William (Bill) May, and Giigawaabamin Minawaa

The week of March 17, 2021, we heard sad news that William (Bill) May had transitioned on into the spirit world. In addition to his many inspiring and beloved roles in his community and family, Bill was a member of Red Lake's Community Advisory Council. By providing advice and sharing his traditional teachings and wisdom, Bill has helped guide us in respectfully carrying-out our research here on the Red Lake Reservation. It has been an honor; he will be forever in our hearts and deeply missed. Chi-miigwech Bill for your efforts in guiding us and all you have shared. Giigawaabamin Miinawaa

William (Bill) May



Photo Credits: William May Jr.

MINNESOTA RESEARCH PARTNERSHIP: RED LAKE BAND OF CHIPPEWA INDIANS

Baamapii and Chi-miigwech Richard Gibbs

On March 22, 2021, We received additional sad news that Richard Gibbs has passed on into the spirit world. Adding to his many beloved roles in his family, Richard was a member of Red Lake's Community Advisory Council. We are truly honored and grateful to have learned from him. With him in our hearts, his presence will truly be missed. Baamapii, Richard and Chimiigwech for all that you shared with us.

Richard Gibbs



Photo Credits: Tina Gibbs.

An update from Marlene Summers and Lois Strong, Community Researchers

Spring and Summer Newsletter already - what a winter our community had. The community had so many deaths from COVID and some not COVID related. I believe the hardest thing for community members was that you could not go and support the family or even have services for them.

It is helpful if you have support of family and the support that Lois and I have had from our ICARE Research Team at Duluth, Madison, Grand Portage, MN, Red Lake, MN and Manitoulin Island, Ontario. We have had weekly, bi-weekly, and monthly meetings, and it was always good that we would start with a "check in." That is where we can share what's on our minds. I'm sure I speak from all of us on the teams that being able to share got us through some rough times during this pandemic.



Lois Strong with her son, Jameson, and grandson, Paxton, at the Wilson family Maple Sugar Camp.

The ICARE project is moving right along. I like to think of our project in phases. We are almost done with the first phase. We have finished all the trainings, and all sites have hired their Community Researchers. Each community has developed an Advisory Council or Board.

In Oneida, we have interviewed community members who are traditional key informants, administrators, nurses, practitioners, doctors, and specialists in the health field. The last step in Phase I is to recruit and interview participants for Sequential Focus Groups. Our goal is to have the Sequential Focus Groups completed by the end of April 2021. Then we will begin Phase II - the ICARE R01 Project.

Just as we are finishing up the first phase of ICARE, we got the best news ever that we were awarded 5 additional years of funding. That will be ICARE Phase II - the NIA RO1 Project. We got the funding through the National Institution of Aging (NIA).

An update from Marlene Summers and Lois Strong, Community Researchers Continued...

In this next phase, we will continue to do many of the same research activities as in Phase I. We will be interviewing healthy non-symptomatic older adults, those with mild/moderate dementia and caregivers of people with dementia. For now, it looks like we will continue to conduct interviews virtually, but we are hoping to resume face-to-face interactions soon. Also, we plan to hold our first Great Lakes Native American Elder Association GLNAEA meeting in September 1st and 2nd of 2021 with Mole Lake hosting us. This will be the first GLNAEA meeting since the pandemic. This is something we very much look forward to.



Ridgeview Plaza where the new Oneida Community Research offices will be located



Marlene Summers at the Maple Sugar camp of her son

At the end of February and first part of March when we hear the Thunders return to wake our Mother the earth, the Maple ceremony begins. When the warm winds begin to circulate a day is set aside to give thanks and a tobacco burning is done to honor the Maple trees. Maple Sugar camps begin to emerge on the reservation. Each camp in the community will have their own tobacco burning. This is an opportunity for friends and family to come hang out, set up camp, collect sap, gather wood to cut, shift ashes or learn about the boil down process. Of course, COVID safety protocols were followed.

An update from Marlene Summers and Lois Strong, Community Researchers Continued...

Reflecting on what is happening in Oneida as we create the "new normal".

- Any changes are based on public health care guidelines established by the tribal government. Concern about public health will remain top interest as plans of reopening tribal services are implemented.
- The rollout of Covid-19 vaccines in Oneida has progressed through the age groups and now it is open to all tribal adults and 16+ yrs youth with underlying health conditions
- The Oneida Tribal School system has started a hybrid approach of part-time on-site and virtual learning. This is something both parents and students are excited about.

Exciting events are happening in Oneida.

The Oneida Alzheimer's Outreach staff is increasing in Oneida. We thank the UW-Madison Alzheimer's Disease Research Center (ADRC) and Dr. Carey Gleason for bringing additional funding through grants to provide needed research to help alleviate the health disparities among Native Americans. Sacheen Lawrence and John Danforth are two new Native American Outreach Specialists supported by grants through Dr. Gleason and UW-Madison ADRC. For several months now Sacheen has been sharing "accurate Covid-19 information" with the Oneida community through social media networks.

Dan King, Oneida Veteran, will be joining the Oneida Alzheimer's team as a liaison to specifically work with veterans.

Traditional Oneida meal delivered to Oneida participants in UW-Madison Alzheimer's clinical studies. Meal with swag bag includes tobacco pouch w/tobacco made by an Oneida artist, face masks, face shield, Alzheimer's information, & certificate of appreciation.





An update from Marlene Summers and Lois Strong, Community Researchers Continued...

Recently Sacheen and John planned, organized and carried out an appreciation event for 38 Oneida community members who are participants in Alzheimer's clinical research studies in Madison. In March they delivered a swag bag of gifts along with a traditional Oneida meal prepared by Jamie Betters and staff at the Oneida Cannery. The scrumptious meals consisted of wild rice with berries, corn mush with berries, corn bread, strawberry drink and soup. Gift items in the swag bag were a certificate of achievement, box of disposable facemasks, face shield, tobacco pouch made by a local Oneida artist, and brain health information. Several comments from recipients indicated appreciation for the meal and gifts. For example, recipients shared comments on social media, including: "My sister and I are part of the research group. That food was sooooo delicious. Yaw-ko (thank you)" and "Mom and I are part of the Alzheimer's research. We were gifted with some scrumptious food and gift items. A big YAW-KO (THANK YOU) to the program that gifted it to us." Marlene and I were both happy recipients of this appreciation meal and swag bag of gifts, as we also participate in the Alzheimer's clinical research studies at UW-Madison ADRC.

The Oneida Alzheimer's Community Advisory Board (CAB) has remained active during the past year through Zoom and telephone contacts. Our CAB continues to meet monthly to advance the following specific aims: 1) to guide culturally tailored outreach, education and research, 2) to reach middle-aged adults, military Veterans and youth with Dementia curriculum, 3) to work to reduce stigma associated with Alzheimer's and Related Dementias by providing outreach and education, and 4) to continue efforts to optimize access to culturally competent dementia diagnostics. The CAB consists of a wide range of dedicated Oneida community members, students, elders, Oneida program representatives and staff from UW-Madison.

Through the support of our CAB and approval of the Oneida Business Committee, Mary Wyman, PhD, UW-Madison, launched an **Oneida Helping Oneida survey** in January 2021. The survey seeks information from caregivers and about resources available to them. Advertising of the survey took place through Facebook posts, flyers, direct mail when requested, and word of mouth. As of March 2021, 500 people have responded to the survey. An analysis of the survey results will be shared with the Oneida CAB and community.

MINNESOTA RESEARCH PARTNERSHIP: GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

An update from Collette Pederson, Community Researcher

As one year has passed since Covid-19 came upon us, Grand Portage has been very cautious and updated as to all the changes that have to be made. I'm pleased to report that we have experienced only one confirmed case here in Grand Portage. We live in a large County and to date there have been 135 confirmed cases throughout the County. This is an incredible statistic. Wearing masks, staying apart the proper distance, washing hands and being aware of other people's well-being is the top priority for people. Let's remain to stay safe and mindful of others.

A "HUGE SHOUT OUT" to the Nurses at Grand Portage Clinic. They have been working very hard at administering Covid-19 vaccinations. To date, they have administered roughly 300 doses. That is awesome! Thank you Nurses!

Let us not forget one of the most important and essential services provided in the Grand Portage Community. The EMS, or Emergency Medical Services. Because of the commitment and dedication of these volunteers, the safety and health of all Reservation residents has been greatly improved. Both Emergency Medical Technicians (EMT's) and First Responders (EMR's) require rigorous training and bi annual recertification. Monthly trainings on various protocols are given by the Training Officer who is part of the overseeing board. Since the Covid-19 pandemic, they have adapted additional protocols to ensure the safety of the patients and themselves. This includes screening of all patients and the use of personal protective equipment. At present, there are 6 full-time EMT's; Jen Sorenson, Dani Reilly, Tess Bailey, Jon Sage, Mary Sherer and Rick Anderson. The EMR First Responders are Quincy Davidson, Ricky Rankin, Howard and Desi Likiaksa, along with dedicated drivers, Erik Carlson, Ernie Deschampe, Ed Ryden and Krysten Flett. Next time you see one of these people, you might want to take a moment to thank them for their service. Please reach out to all other EMT's also. They are very dedicated and especially now during the difficult times they are facing.

It seems like yesterday I was listening to the growling stomach of the iced-over Portage Bay and her desperate booms. She would sound off as she was letting me know that it was time to remove the weight on her shoulders. Today, she is comfortable and breathing the beauty she worked so hard to achieve. Her beautiful blue jacket is back on and she is back to flashing her diamonds for everyone to see. What a showoff.

MINNESOTA RESEARCH PARTNERSHIP: GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

An update from Collette Pederson, Community Researcher Continued...

Grand Portage will be hosting their annual Wellness Fair on Saturday, June 19, 2021, from 10:00 am to 1:00 pm. This is always a fun time and very eventful. It will be held outside this year, due to Covid, and will have numerous vendors attending. There will be a tent this year, filled with informational packets that the Memory Keepers are pleased to share. Following the outside lunch that will be served by the ENP crew, there will be a dementia/Alzheimer's walk for those who choose to do so. Many helpful and interesting handouts are present throughout the event. The Advisory Group will be handing out water, a bleacher blanket, and water bottle for those in attendance. We are looking forward to seeing everyone and answer any and all questions you may have.

The research projects for Grand Portage have gone so well. Our Sequential Focus Group was very informative and fun to do. I want to thank the wonderful participants for all their time and effort. The group was very comfortable with each other and that made it easier to share personal stories and talk about anything they wanted to bring forward. Their trust in each other, knowing that anything they said would not go any further, was outstanding. The ideas, suggestions and possibilities for the future to help dementia awareness and individuals was wonderful. Thank you all. A big thank you to Melissa and January for all the help. I could not have done it without you.

We are looking forward to Phase II. There is so much more to learn and the need for education in any form, needs to be acknowledged. This research will improve the lives of American Indian and Anishinaabe persons with dementia by examining the impact of Alzheimer's disease and related dementias on patients, families and communities. We had a wonderful time getting together at the Lodge for our Advisory Group Meeting. It was great seeing everyone in person and hearing about the results of the Traditional Knowledge Keepers. Many thanks to everyone on all the enthusiasm that was shown in moving ahead on all our phases and upcoming events. Thank you Melissa for all your hard work. We truly appreciate it!







MINNESOTA RESEARCH PARTNERSHIP: GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

An update from Collette Pederson, Community Researcher Continued...

AN OJIBWE LEGEND ON HOW THE BEAVER GOT HIS TAIL

Once upon a time there was a beaver that loved to brag about his tail. One day while taking a walk, the beaver stopped to talk to a bird. The beaver said to the bird, "Don't you love my fluffy tail?"

"Why, yes I do little beaver," replied the bird.

"Don't you wish your feathers were as fluffy as my tail? Don't you wish your feathers were as strong as my tail? Don't you wish your feathers were just as beautiful as my tail?" the beaver asked.

"Why do you think so much of your tail, little beaver?" asked the bird. This insulted the beaver and he walked away.

After walking away for a while, he stopped for a drink by the river and saw a muskrat. He walked to the muskrat and said, "Hello little muskrat. What do you think about my tail?"

"Well, it is very beautiful and big and fluffy," answered the muskrat. "Is it also a strong tail?"

"Why, yes it is," the beaver answered. "Do you wish you had a tail like mine?"

"I didn't say I wanted a tail like yours. I just asked if it was strong," the muskrat replied with a disgusted voice.

The beaver quickly turned and began walking back to his dam. He was angry because he felt that the animals were being rude to him. He was very upset and decided to take out his frustration by cutting down trees. After cutting down a couple of trees, he came to a very large one. He knew that it would be a great challenge for him, so he went to it. As he was cutting, he kept thinking about his tail and didn't notice that he was cutting at a bad angle. Before he knew what was happening, the tree began to fall toward him. He jumped to get out of the way, but he didn't jump fast enough, and the huge tree fell on his beautiful tail! He tugged and pulled and finally dug away the earth to free himself.



When he finally pulled his tail from under the tree, he was horrified to see that it was flat. The beaver was very sad and started to cry. As he was crying, he heard a voice. It was the Creator.

"Why are you crying?" asked the Creator.

"A tree has crushed my beautiful tail," the beaver cried. "Now no one will like me." The Creator told him that a beaver is not liked for his tail but for his kindness and wisdom. He also told him how to use his flat tail. "Now your tail will help you swim rapidly," the Creator said. "And when you want to signal a message to a friend, all you have to do is slap your tail on the water." Hearing this made the beaver happy again. When the animals saw his flattened tail, they were shocked! But the beaver said, "It's better this way." From that day on, the beaver never bragged about his tail, and all the animals liked him. That's how the beaver got his tail.

MINNESOTA RESEARCH PARTNERSHIP: RED LAKE BAND OF CHIPPEWA INDIANS

An update from January Johnson, Community Researcher

Yoga, Wellness, Happiness!

We have all heard the phrase "the key to a good life is happiness." However, to know true happiness is to also know total body and mind wellness. Yoga is a way to achieve wellness for your entire being! And good news! Yoga is now offered online and is an awesome way to promote physical and mental health while stuck in our COVID-19 social bubbles! Yoga is wellness for your entire body: Strengthening cardiovascular health, building and toning muscles, and alleviating mental stress while promoting the entire union of mind, body, and spirit! What could be better!?

Introducing Yoga instructor Elizabeth Strong, member of the Red Lake Nation! Elizabeth is a professionally trained yoga instructor trained by Native Strength Revolution. "Mindfulness and Yoga" is an online class held every Tuesday, 6 pm CST. It is sponsored by "Manidooo Ogitigaanin," which means "The Spirit's Garden." Check out their cool site at www.manidooogitigaan.org! Utilizing chair yoga, the teacher modifies this beginner's class for all levels of mobility and motivates you while promoting stress reduction and diabetes prevention. Anyone can join! The class is held online using the Zoom platform. You can also find and follow "Manidooo Ogitigaanin/The Spirit's Garden" on Facebook in order to receive the latest updates on the live stream over Zoom! Mindfullness and Yoga is also offered in-person at the local Roundhouse in the Ponemah District of the Red Lake Nation. Elizabeth "Liz" also teaches a "Indigenous Elder's Yoga" class, offered through a partnership between the Indian Health Board (IHB) of Minneapolis and the Indigenous Lotus Movement. This gentle yoga class is held online streaming live over Facebook and Zoom and takes place every Friday morning, 10 a.m. CST.



Photo Credits: Elizabeth Strong

Always mindful of her student's health and mobility levels, Liz modifies this class for all levels of mobility as well as incorporating the "Traditional Ojibwe Seven Grandfather teachings" into her practice! You can access this class through live stream by sending a request to join the Facebook group, "Indigenous Lotus Elder's Yoga."

We are thankful to Liz for her continual efforts to keep our communities healthy by growing her business and providing more local and online yoga classes! Her local yoga classes are always held at the Bemidji and Red Lake areas. You can also contact her directly by email at sahkahtay23@gmail.com.

We look forward to hearing about your great experience at Liz's Yoga classes!

ONTARIO RESEARCH PARTNERSHIP: MANITOULIN ISLAND



An update from Rhonda Trudeau and Karen Pitawanakwat, Community Researchers

It has been one year since the start of the pandemic. Many communities have been hosting vaccine clinics and we are looking forward to our new normal as more and more community members are vaccinated. What are some new skills you have learned during this time? Virtual meetings, new recipes, living on the land activities, and many more. Community members have been enjoying the springtime activities of safe distancing seed swap programs, family maple sugar camps, shoreline fishing, smelting and netting trout, harvesting medicines, and community healing walks. Soon the summer months will be upon us and we will be busy on the water, fishing, hiking, enjoying the sunshine, and picking berries. There are many activities for us all to enjoy safely during this pandemic.



Dooganing Maple products by Rose and Armando Shawanda of Wiikwemkoong Unceded Territory

Maple syrup season has come and gone and we are fully stocked and have shared our bounty for the season. We asked some friends how they enjoy their over the fire made maple syrup. Many people enjoy it on pancakes, or in their tea, adding it to frosting for a spice or carrot cake, using it to make a vinaigrette, or as a glaze for a baked salmon or trout, you can also add it to your steak marinade, or in many yummy sweet recipes.

Joe Pitawanakwat, Traditional Knowledge Holder, teaches maple syrup is an important part of our culture, and this has to do with the way we live a carbohydrate desert in the spring, summer and fall. Our first carbohydrate foods, like wild rice and cat tail roots, came into season in the fall, putting everyone naturally into a ketogenic state come winter when our diet is composed of animals we hunt, trap or fish. In the winter months, we also are more exposed to the cold, which makes fat easier to burn. As a result, we become mineral depleted come the following spring. This happens just in time for super dense mineral maple water that we drink, then condense into syrup and use the sugar to preserve food for the following year. When maple syrup is made traditionally and not with the use of reverse osmosis and filtration, the mineral content is preserved. To learn more go to Creator's Garden - https://www.facebook.com/CreatorsGarden/.

ONTARIO RESEARCH PARTNERSHIP: MANITOULIN ISLAND



An update from Rhonda Trudeau and Karen Pitawanakwat, Community Researchers continued...

Our spring / summer advisory member spotlight is on Rose Shawanda of Wiikwemkoong Unceded Territory. Rose was one of the first recruits of our Community Advisory Council in 2015. Rose is an extremely intuitive community minded woman who has been a nurse, elder service coordinator and family caregiver that makes her involvement in all of the projects we do extremely invaluable. Rose is also known to share her liquid gold she and her family make every maple syrup season. Many from around the world have been able to taste the maple syrup including people from Zimbabwe, Rome, Cuba and Switzerland.

Maple Quinoa Salad



Rose Shawanda sealing bottles of Dooganing Maple Liquid Gold

Ingredients

- 12/3 cup quinoa, rinsed
- 1/3 cup extra-virgin olive oil
- 1/3 cup balsamic vinegar
- 1/3 cup pure maple syrup
- 1 cup dried cranberries or cherries (TIP: Look for unsweetened or naturally sweetened varieties.)
- 1 cup raw unsalted chopped pecans
- 4 to 5 scallions, thinly sliced
- 1 tsp sea salt, plus additional to taste

Preparation

- Cook quinoa according to package directions. Let cool completely.
- Prepare dressing: In a small bowl, whisk oil, vinegar and maple syrup.
- Add 3/4 cup dressing to quinoa. Stir in cranberries, pecans, scallions and salt.
 Refrigerate overnight.
 Serve cold or at room temperature; just before serving, stir in remaining 1/4 cup dressing and season with salt.

Words of the season:

- -Poplar buds-*Maanzaat Onimik* traditional salve ingredient harvested once a year just before spring while the ice is cracking
- -Wild Canadian Ginger-*Namepin* Wild Canadian ginger is a traditional medicine flower that can be planted this time of year
- -The small streams are flowing-Bmi-jwanoon ziibiinhsan
- -Leeks-Zhigaangwizh-iig
- -Planting-G tigeng
- -Weeding-Moon Shkweng
- -Smoking fish-Wiizhgsigeng giigoonhig

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LOIS STRONG

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"To keep our memories is to keep our stories and traditions and cultures alive forever. That's part of the reason for Memory Keepers Medical Discovery Team of researchers. Research to usher in the new buds of hope. Just like Spring!"

Annamarie Hill

Community Engagement Specialist

HELPFUL LINKS

<u>I-CAARE.ca</u> 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





American Elder Association

