

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

## ICARE

FALL/WINTER 2019 NEWSLETTER

### ICARE Research Team

(Role on the ICARE team):

MINNESOTA

**KRISTEN JACKLIN**  
*Principal Investigator*

**WAYNE WARRY**  
*Co-Investigator*

**NEIL HENDERSON**  
*Co-Investigator*

**JIM ALLEN**  
*Co-Investigator*

**MELISSA BLIND**  
*Research Coordinator*

**ANDRINE LEMIEUX**  
*Senior Research Associate*

**JESSICA KOSKI**  
*Research Associate*

**ANNAMARIE HILL GUTSCH**  
*Community Outreach Specialist*

**PATRICK BRIGHT**  
*Research Associate*

**KAREN BEDEAU**  
*Community Collaborator, Red Lake*

**ORAN BEAULIEU**  
*Community Collaborator, Red Lake*

**SUSAN NINHAM**  
*Community Collaborator, Red Lake*

**JANUARY JOHNSON**  
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**PAULA SCHAEFBAUER**  
*Community Collaborator, Grand Portage*

**POLLY JAMES**  
*Community Collaborator, Grand Portage*

**COLLETTE PEDERSON**  
*Community Researcher, Grand Portage*

ONTARIO

**KAREN PITAWANAKWAT**  
*Community Researcher*

**RHONDA TRUDEAU**  
*Community Research Assistant*

**MARY JO WABANO**  
*Community Collaborator*

**PAMELA WILLIAMSON**  
*Community Collaborator*

**CRAIG ABOTOSSAWAY**  
*Community Collaborator*

WISCONSIN

**CAREY GLEASON**  
*Co-Investigator, & Wisconsin Lead*

**NICK LAMBROU**  
*Post-Doctoral Associate*

**WES MARTIN**  
*Community Collaborator*

**MARLENE SUMMERS**  
*Community Researcher, Oneida*

**LOIS STRONG**  
*Community Researcher, Oneida*

## AN INTRODUCTION TO THE ICARE PROJECT

The purpose of the ICARE research partnership is to better understand the lived-experiences and impacts of Alzheimer's disease and related dementias (ADRD) in Indigenous (American Indian and First Nations) populations. Minimal investments have been made in understanding the everyday experiences of ADRD in Indigenous populations worldwide, who are disproportionately impacted by dementia.

This two-year, National Institutes of Health (NIH)/National Institutes on Aging (NIA) funded grant (1R56AG062307-01), is a community-based participatory research project led by a team of investigators from the Memory Keepers Medical Discovery Team at the University of Minnesota Medical School, Duluth campus (see [www.MemoryKeepersMDT.com](http://www.MemoryKeepersMDT.com)) and Dr. Carey Gleason at the University of Wisconsin-Madison.

Key members of this team (Jacklin & Warry) began working over 20 years ago with First Nations communities on Manitoulin Island in Ontario (ON), Canada. During those years, the research revealed that culturally-bound understandings of dementia and community context are key determinants in healthcare-seeking behaviors and caregiving practices, and Indigenous knowledge is an important source of support. The research in Canada resulted in a number of community resources to improve dementia knowledge and care (see <https://www.I-CAARE.ca>)

Building on the work in Ontario Canada, we have expanded the previous research to include the territories surrounding the Great Lakes regions of Northern Minnesota and Wisconsin. The current research partners include: The Red Lake Band of Chippewa Indians (MN) and the Grand Portage Band of Lake Superior Chippewa (MN); Oneida Nation of WI; and the seven Anishinaabe communities on Manitoulin Island, Ontario, Canada.

## ICARE Research Partners



UNIVERSITY OF MINNESOTA  
Medical School



Wikwemikong  
Unceded Territory



WISCONSIN  
UNIVERSITY OF WISCONSIN-MADISON



NORTHWOODS  
CAREGIVERS

GLNAEA (Great Lakes Native  
American Elder Association)

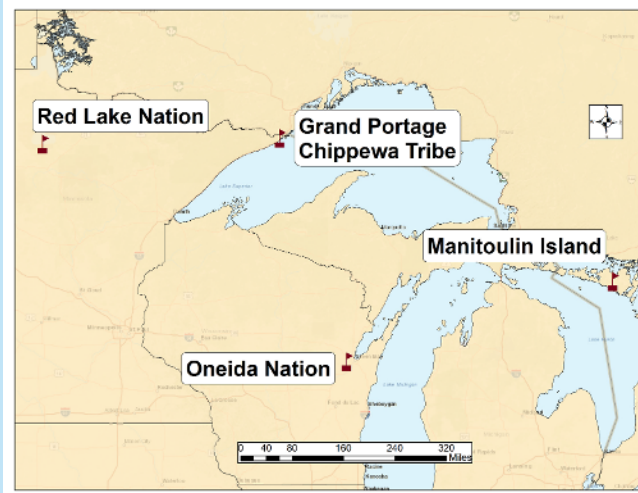
Giwedining  
Northland

## AN INTRODUCTION TO THE ICARE PROJECT (CONTINUED)

The ICARE project involves four main elements:

1. The collection of community-level data (e.g., population, health status, services, economy, social supports and community life);
2. Focus groups with healthcare workers;
3. Interviews with key informants (e.g., physicians, geriatric specialists, Elders, traditional knowledge keepers (cultural/spiritual leaders, language speakers); and
4. Attending community events and answering questions related to the research.

### ICARE RESEARCH PARTNERS



**Cartographer:** P. Bright; September 27, 2019

**Sources:** Memory Keepers Medical Discovery Team; Environmental Research Science Institute; United States Geological Survey

**MN:** The Red Lake Band of Chippewa Indians & The Grand Portage Band of Lake Superior Chippewa

**WI:** Oneida Nation of Wisconsin

**ON:** Seven Anishinaabe communities on Manitoulin Island



### ICARE GOALS

- To establish long-term relationships that build research capacity in the partnering communities.
- Continue the research by securing NIH funding (RO1 grant) for a larger 5-year study to include Persons with Dementia and their caregivers.
- Develop culturally-grounded dementia education tools and care interventions to improve outcomes and quality of life for Indigenous (American Indian and First Nations) families living with dementia.

The research activities, data collection and analysis is guided by community advisors. In each location, Community Advisory Groups have been established. The advisory groups are made up of local community members who meet with the research team regularly throughout the year to ensure community perspectives and understandings are prominent throughout the project. By partnering with local leadership and the advisory groups, local Community-Based Researchers were hired in each community. Community-Based Researchers assist with all aspects of the research.

## MORE ABOUT THE MEMORY KEEPERS MEDICAL DISCOVERY TEAM (MK-MDT)

The Memory Keepers Medical Discovery Team is a university based research team at the University of Minnesota Medical School, Duluth campus, focusing on understanding the dynamics of diabetes and dementia as interacting conditions among people living in tribal and rural communities.

**Vision:** Advancing the boundaries of health equity research to create innovative interventions to support healthy aging in American Indian and rural populations.

**Mission:** To support an environment of Team Science to conduct community-based participatory action research on diabetes and dementia in American Indian and rural communities with the aim of achieving health equity.



Entrance to Memory Keepers  
624 E 1st Street, Duluth, MN



Memory Keepers  
Collaborative Work Space



[www.MemoryKeepersMDT.com](http://www.MemoryKeepersMDT.com)



@MemoryKeeperMDT

## FORMING PARTNERSHIPS IN THE GREAT LAKES REGION

In January & February 2019, the research team came together for their first kick off meeting at the MK-MDT office in Duluth, MN. Connections were made, project goals and timelines were discussed, and an important outline was constructed detailing the plans for a future five-year grant submission (R01) to the NIH. Karen Pitawanakwat, the community-based researcher on Manitoulin Island Ontario, shared valuable stories and experiences from her many years with the team in Canada. The team ended the day with plans and anticipation for a retreat to Manitoulin Island in June.

When June arrived, the research team gathered for three magnificent days of learning and relationship building on Manitoulin Island, ON. The highlights of this trip included an abundance of the Anishinaabe communities' experiences being shared with the research group from MN and WI. The first day opened with a traditional sunrise ceremony led by Elder Bill Antoine. Team meetings followed and the day was packed with brainstorming sessions, including a review of project timelines and an overview of each community, such as the locally available health services. The day came to a close with a gathering on Birch Island for a visit to the sacred ceremonial site known as Bell Rocks. Elder and knowledge holder Leona Nahwegahbow, captivated the group with stories of the significance of the site and its importance to the people.

On the second day, the research team traveled to the South Bay Centre in Wikwemikong where they met with the Manitoulin Island Community Advisory Council. The group gathered in a large circle and relationships formed as powerful stories were shared, sometimes through laughter and tears. Deep meaning marked the time together, as Elders, knowledge keepers, community members, and researchers all came to understand the importance of the work already done on Manitoulin Island.

That afternoon, the group embarked on another journey through the deep woods and into a camp where boats were waiting to take the group across the Georgian Bay to Killarney for world famous fish and chips. Laughter, great conversations, and delicious, locally-sourced fresh fish closed the day.

On day three, meetings resumed with discussions on next steps and planning, including revisiting timelines for a future R01 grant to continue this important research. The afternoon was spent along South Bay in Wikwemikong participating in a highly informative medicine walk led by Joe Pitawanakwat (see page 8). The team was sent off in a good way with a traveling drum song provided by Lisa Osawamick, formally concluding the retreat.

### RESEARCH TEAM MEETINGS



**ICARE KICKOFF MEETING**  
JAN 31 - FEB 1, 2019  
DULUTH, MN



**SHARING CIRCLE WITH MANITOULIN ISLAND  
COMMUNITY ADVISORY COUNCIL**  
JUNE 26, 2019  
MANITOULIN ISLAND, ONTARIO



**GRANT PLANNING & NEXT STEPS**  
JUNE 27, 2019  
MANITOULIN ISLAND, ONTARIO

### ICARE: NEXT STEPS

- \* Training community-based research staff
- \* Meetings with Community Advisory Councils in Grand Portage and Red Lake to refine interview questions & approach
- \* Data collection: Key informant interviews
- \* Data collection: Sequential focus groups
- \* March 2020: Submission of larger 5-year study (R01) to the National Institutes of Health (NIH)

# ONTARIO RESEARCH PARTNERSHIP: MANITOULIN ISLAND

## COMMUNITY OVERVIEW

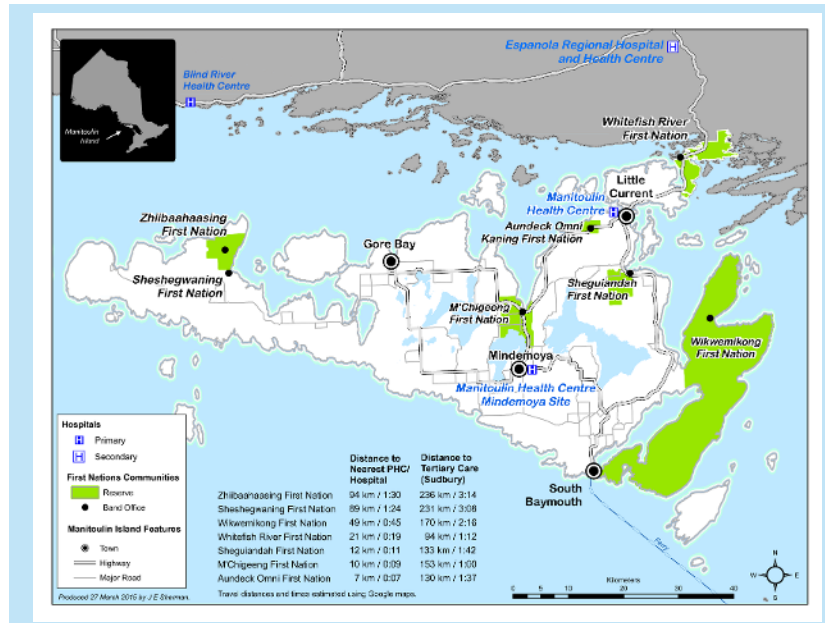
Manitoulin Island is located in Lake Huron, and part of Ontario, Canada. The island itself is approximately 3,107 km<sup>2</sup> (1,930 mi<sup>2</sup>). In the 17th century the island was part of the territory occupied by the Odawa, who referred to it as Mindoo Mnis or "Island of the Great Spirit." Today the island's First Nation population live in seven reserve communities including Aundeck Omni Kaning, M'Chigeeng, Sheguiandah, Sheshegawaning, Whitefish River, Zhiibaahaasing and Wikwemikong Unceded Reserve.

## ICARE RESEARCH AND PROJECT STAFF

Drs. Jacklin & Warry have been conducting research with First Nations people on Manitoulin Island for over 20 years. Over the last 13 years this research has been supported by Community-Based Researcher, Karen Pitawanakwat, RN. Karen has been a registered nurse for over 25 years. To support Karen in the ICARE research, Rhonda Trudeau was recently hired as a Community-Based Research Assistant, and we welcome Rhonda to the ICARE team. Also collaborating on the research efforts in Ontario, are Mary Jo Wabano, Health Services Director of Naandwechige-Gamig, Wikwemikong Health Centre; Pamela Williamson, Executive Director Noojmowin-Teg; and Craig Abotossaway, Executive Director Mnaamodzawin Health Services.

Because of the long history and research partnership with the seven First Nations communities on Manitoulin Island, a Community Advisory Council has already been established and consists of 13 members, with representation from each health authority. There is also a local research review committee known as the Manitoulin Anishinaabek Research Review Committee (MARRC), which oversees all research activities and ethics involving the seven First Nations communities on Manitoulin Island.

There has been a great deal of interest about the ICARE project from healthcare providers and knowledge keepers in the community. To date, Karen and Dr. Melissa Blind, Research Coordinator, have already completed eight key informant interviews, and will continue to collect data through the fall and winter.



The Manitoulin Island Community Advisory Council and the ICARE research team on Manitoulin Island.

Back row: Joe Peltier; Edward Osawamick; Bill Antoine; Marlene Summers; Carey Gleason; Jules Osawamick; Wayne Warry; Third row: Roselinda Peltier; Lisa Osawamick; Lois Strong; Jessica Koski; Andrine Lemieux; Rose Shawanda; Nick Lambrou; Second row: Annamarie Hill Gutsch; Rosella Kinoshameg; Marion McGregor; Kristen Jacklin; Karen Pitawanakwat; Front row: Wes Martin; Melissa Blind. Not pictured: Monica Pheasant; Roseanne Debassige; Bonita Bebamash; Jean McGregor-Andrews; Evelyn Roy



Karen Pitawanakwat, RN & Community-Based Researcher, Wikwemikong Unceded Territory, Ontario

# MINNESOTA RESEARCH PARTNERSHIP: RED LAKE BAND OF CHIPPEWA INDIANS

## COMMUNITY OVERVIEW

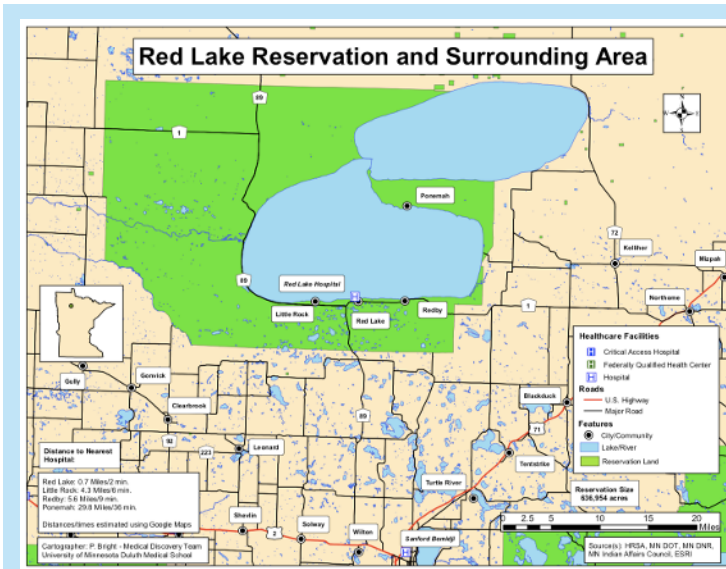
Miskwaagamiwi-zaaga'iganiing (Red Lake Nation) located in Northern Minnesota, is a large land-based (approximately 800,000 acres or 3,237 km<sup>2</sup>) Ojibwe nation and one of only two "closed" reservations in the United States. Red Lake is uniquely positioned in the state, with all lands held in trust and common by the people of Red Lake. Red Lake is not a member of the Minnesota Chippewa Tribe (MCT), which includes six of the seven federally-recognized Ojibwe bands in Northern Minnesota. Great efforts to restore the language and culture, in addition to maintaining a crucial political voice, continue with Anishinaabe language affirmed by resolution as the first language of the people of Red Lake Nation.

## ICARE RESEARCH AND PROJECT STAFF

In December 2018, the Tribal Council of Red Lake passed tribal resolution No. 232-18, formalizing the partnership between the tribe and the ICARE researchers of the MK-MDT, University of Minnesota Medical School, Duluth Campus. As the work began, the Red Lake Community Advisory Council (CAC) formed as a first step of the newly launched Minnesota Tribal ICARE partnership.

The CAC acts as advisory to the ICARE research team and is tasked with the important work of guiding the research activities at all times to reflect the perspectives of ADRD in the community. In September, the CAC held its third meeting at the Red Lake fitness center, with current plans to meet monthly. In mid-October, we hired January Johnson as the Community-Based Researcher to support the research and act as liaison between the tribe, ICARE research team, and CAC.

Supporting the ICARE research efforts along with January are important Community Collaborators Oran Beaulieu and Susan Ninham of the Red Lake Comprehensive Health Services Program, and Karen Bedeau, Red Lake member, staff of Northwoods Caregivers, and Giiwedining Committee chair.



RED LAKE COMMUNITY ADVISORY COUNCIL

From left to right: Annamarie Hill Gutsch, Kristen Jacklin, Melissa Blind, Christine Roybal, Susan Ninham, Alexis Mason, Eileen Miller, Bill May, Karen Bedeau and Richard Gibbs

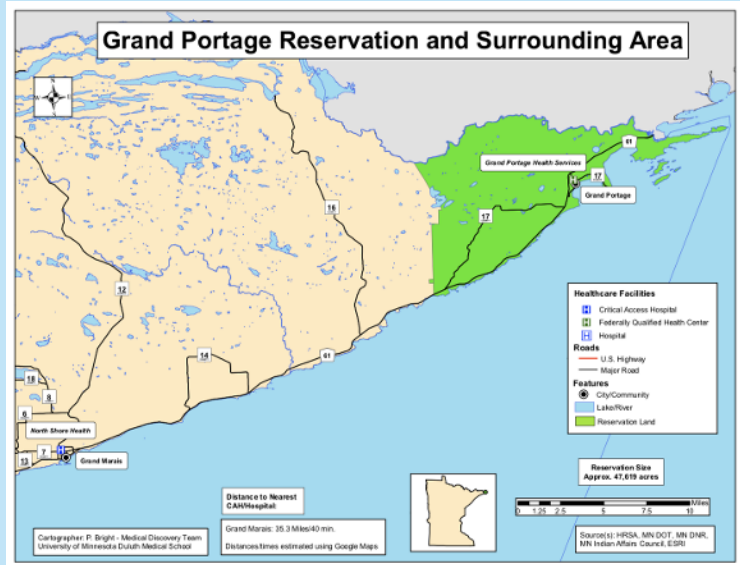


January Johnson,  
Community-Based  
Researcher and Red Lake  
member

# MINNESOTA RESEARCH PARTNERSHIP: GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

## COMMUNITY OVERVIEW

Kitchi-Onigaming (Grand Portage Band of Lake Superior Chippewa) is located on the breathtaking shores of Lake Superior in the far tip of Northeastern Minnesota, next to the Canadian border and has a land area of 74.4 mi<sup>2</sup> (192.7 km<sup>2</sup>). The name “Grand Portage” is significant representing the historic nine-mile overland portage that was necessary for transit from Lake Superior to the Pigeon River, heavily traveled and relied upon for economic growth and expansion during the fur trade era. One of seven federally-recognized Ojibwe bands of the state, Grand Portage is part of the Minnesota Chippewa Tribe, yet exists and governs as an independent sovereign nation.



## ICARE RESEARCH AND STAFF

In April 2019, the Grand Portage Tribal Council passed resolution No. 06-19, which formalized the partnership between the Grand Portage people and the ICARE research team. As part of the newly-formed relationship, the team hired Collette Pederson as the Community-Based Researcher to assist with all local research efforts.

Supporting the ICARE research efforts are important Community Collaborators Paula Schaeffbauer, Tribal Health Director and Acting Programs Administrator; and Polly James, Elderly Nutrition Program (ENP) Director.

Collette, along with the ICARE team held the first Community Advisory meeting with Grand Portage members on October 16th. We met at the Health Services office for introductions and then walked over to the log building for a nutritious, full-course dinner provided by community gardeners. Over dinner we had the pleasure of learning about local Community, Agriculture, Cultural, Health and Education (CACHE) initiatives. Afterwards, we returned to the Health Services office for the meeting which opened with a prayer in the language led by Grand Portage Council Member John Morrin. By the end of the meeting, the group had determined they would like to be referred to as a Community Advisory Group (CAG). The second Grand Portage CAG meeting took place on November 13. CAG meetings will resume again in January 2020.



GRAND PORTAGE COMMUNITY ADVISORY GROUP

From left to right: John Morrin, Shirley Stevens, Patty Wiinchell-Dahl, Collette Pederson, Jennifer Sorenson, Emma Carlson, Jessica Koski, Melissa Blind, Annamarie Hill Gutsch



Paula Schaeffbauer, Tribal Health Director and Acting Programs Administrator with Collette Pederson, Community-Based Researcher

# WISCONSIN RESEARCH PARTNERSHIP: ONEIDA NATION OF WISCONSIN

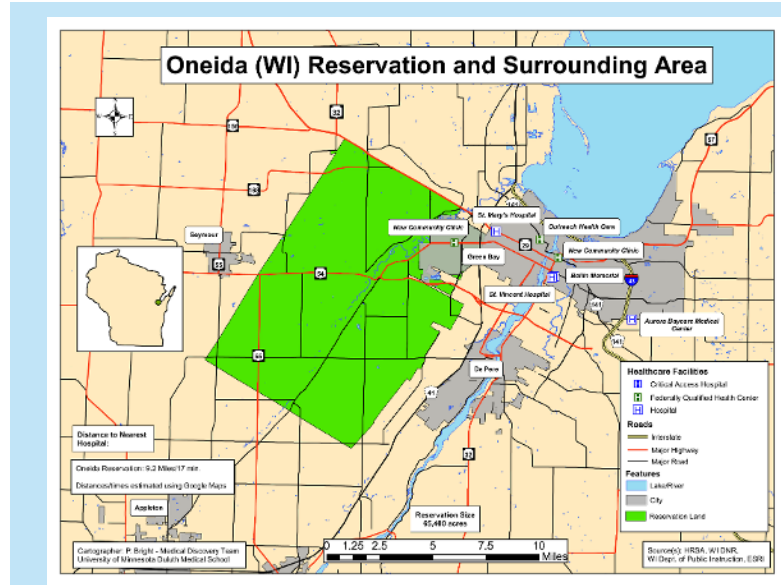
## COMMUNITY OVERVIEW

The Oneida Nation of Wisconsin is located in northeast Wisconsin; the city of Green Bay lies east and is contiguous with the reservation's eastern border. The Nation's holdings include approximately 26,000 acres (105 km<sup>2</sup>) in a checkerboard pattern, with the reservation containing approximately 12 mi<sup>2</sup> (31 km<sup>2</sup>) of land, 233 miles (375 km) of streams, and 12,000 acres (49 km<sup>2</sup>) of wetlands. Five municipalities (Ashwaubenon, Green Bay, Pittsfield, Horbart, and Oneida), have acreage located in the original reservation boundaries. Major cities close to the reservation include Green Bay, 5 mi/8 km east; Appleton, 30 mi/48 km southwest; Oshkosh, 45mi/72 km southwest; Sheboygan, 54 mi/87 km southeast; and Milwaukee, 113 mi/182 km southeast.

## ICARE RESEARCH AND PROJECT STAFF

Dr. Carey Gleason of the University of Wisconsin-Madison & the Wisconsin Alzheimer's Disease Research Center (ADRC) is the lead investigator in Wisconsin where we are partnering with the Oneida Nation of Wisconsin. Dr. Gleason had existing relationships with Oneida Nation through a Community-University Partnership Award with Wes Martin and other members of Oneida Nation. Wes is a Community Collaborator for the ICARE research, President of the Great Lakes Native American Elder Association (GLNAEA) and Chairperson with the Oneida Nation Council on Aging (ONCOA).

In Wisconsin, we are pleased to announce the hire of three new staff to support the ICARE research. Dr. Nick Lambrou joined the team as a Post-Doctoral Associate, and Ms. Lois Strong and Ms. Marlene Summers joined the team as Community-Based Researchers. All three have been trained in community-based participatory research (CBPR) using our newly developed ICARE CBPR training modules, which were created specifically for the ICARE project and launched this fall. The team will be meeting once more to practice interviewing skills and debrief on interviewing processes. The team has started recruitment efforts for individual key informant interviews and are eager to begin conducting the interviews this fall and winter.



## ONEIDA NATION COMMUNITY ADVISORY BOARD



Top row (left to right): Crystal Metoxen, Marlene Summers, Pat Lassila, Lois Strong, Carey Gleason, Sacheen Lawrence, Melissa Metoxen

Bottom row (left to right): Megan Zuelsdorff, Florence Petri, Dellora Cornelius, Deb Miller

## A MEDICINE WALK WITH JOE PITAWANAKWAT

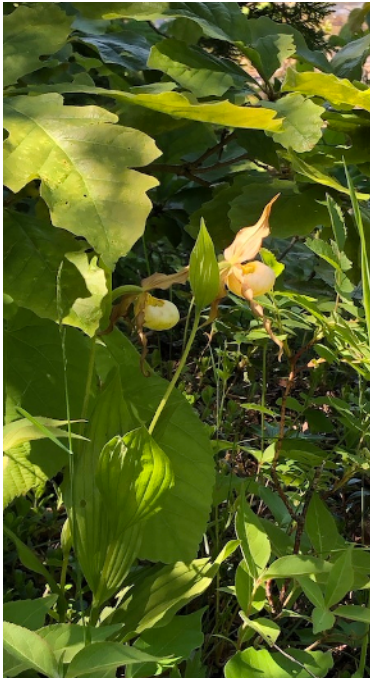
It was a lovely, sunny June day in Ontario when the ICARE research team shared in the opportunity of a medicine walk with Joe Pitawanakwat, Founder and Director of Creator's Garden, an Indigenous outdoor education business focused on teaching the legitimacy of plant-based medicine. In addition, Creator's Garden medicine and plant expert Joe, teaches his students to sustainably harvest and use every part of the beautiful forest plants. Joe taught the eager ICARE participants to envision the plants and trees with a creative, child-like mindset, respect the knowledge already within, and examine the shapes and foliage as interpretation mechanisms designed by the Creator and intended for medicines. Joe selflessly shared much of his vast and rich scientific and holistic knowledge and told us that everything we need to survive, thrive, and heal on earth is found in nature and given to us as a gift from the Creator. Visit and connect with Joe on Facebook at Creator's Garden and at <http://creators-garden.blogspot.com>

The research team gathers in Wikwemikong First Nation for a medicine walk with Joe Pitawanakwat



Joe showcases the roots of a Lady Slipper flower, which looks like the anatomy of the human brain.

Joe displays the many herbs and plants he's collected and dried.



## THE OJIBWE LEGEND OF THE LADY SLIPPER

Ojibwe Legend tells of the great courage of a girl who saves her people from illness. The girl must journey to a neighboring village to get the healing herb, mash-ki-ki. The brave girl finds her moccasins made of deer skin and lines them with rabbit fur, and braves a raging snowstorm crossing a dark frozen lake to reach the other village. Then, rather than wait for morning, she sets out for home while the villagers sleep, urgently determined to help her people. During her trek through the deep snow, she loses her moccasins and her bare feet are cut by the sharp ice; they bleed with every step until she reaches her home. The next spring beautiful lady slippers bloom from the place where her moccasins were lost and in every spot her injured feet touched. This is the story of how the ma-ki-sin waa-big-waan "moccasin flower" or Lady Slipper came to be.

Source: Lunge-Larson, L. & Preus, M. (1999). *The Legend of the Lady Slipper: An Ojibwe Tale*. Boston: Houghton Mifflin Company.

### Get in touch with the team

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