

INDIGENOUS CULTURAL UNDERSTANDINGS OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

ICARE

FALL/WINTER 2020 NEWSLETTER

ICARE Research Team (Role in ICARE team):

A THANK YOU MESSAGE FROM THE ICARE RESEARCH TEAM

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ONTARIO

WISCONSIN

As the season shifts into fall here in the Great Lakes region, it's accompanied by reminders of winter, such as a glistening snowfall, the migration of animals, and the approaching winter solstice. The change in season allows us to reflect on the many transitions we have experienced during this year and express gratitude for those around us, including those who help keep us grounded, bring us joy, and keep us safe.

The ICARE research team, along with the University of Minnesota Medical School and University of Wisconsin-Madison are continuing to work from home. All of our team meetings, community researcher meetings, and community advisory meetings continue to take place using video or telephone conferencing. While adapting to the new technology has been frustrating and challenging at times, it has also provided us with an opportunity to stay connected and support each other, as well as share stories and lots of laughter. Thank you for your patience, commitment to the research and learning with us as we transitioned to continuing the research while working remotely. We miss seeing everyone face to face, visiting with the advisory members, community researchers, and community members, and look forward to the time when it is safe to resume these activities.

With the support of the communities partnering with us on the ICARE research, we have made important progress during these uncertain times. We would like to thank the communities, tribal leaders, community advisory members, and community researchers that oversee the ICARE research in: Red Lake Nation, Minnesota, Grand Portage Band of Lake Superior Chippewa, Minnesota, Oneida Nation of Wisconsin, and the seven First Nations communities on Manitoulin Island, Ontario.

We would like to extend a special thank you to all the teachers, health care providers, local leadership, and essential service workers. We would also like to thank you, our readers. The purpose of this newsletter is to share the research that is being done, including what is happening in your community as well as in the other communities that are partnering with us. We value your readership and are committed to addressing Alzheimer's disease and related dementia needs in your communities.

Thank you and be well, 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 ([Spring/Summer 2020](#)), the community researchers have been wrapping up key informant interviews via telephone, Zoom, and email with administrators, physicians, nurse practitioners, specialists, traditional knowledge keepers, Elders, community historians and language speakers. We are so grateful to everyone who has shared their time and expertise with us.

After the interviews are completed, members of the research team review, categorize, and summarize the information shared by the key informants into major themes, also referred to as preliminary findings. Once this process is complete, we will bring the preliminary findings back to the community advisory members for further analysis and feedback. This step is really important in that the community advisory members help the research team better understand some of the information that is being shared, and ensures that community voices and knowledge are at the center of everything we do. In the next newsletter (Spring/Summer 2021), we will give more of an update on findings and how they are being shared with the broader communities.

In addition to the key informant interviews, the community researchers will be conducting a series of focus groups with personal support/care workers and staff that work with older adults and people with dementia. These focus groups will help the research team have a better understanding of community supports and needs for people with dementia during the early, moderate, and late stages of the disease. Due to COVID-19, these group meetings will take place virtually through Zoom or telephone. The community researchers have been practicing their Zoom skills and training on how to conduct virtual focus groups throughout the fall.

In the community updates, on the pages that follow, the community researchers share their journeys with the research process and connecting with community and advisory members during a pandemic.



Community Researcher Meeting July 8, 2020

Top row: Nick Lambrou, Jessica Chiovitte (not pictured), Karen Pitawanakwat;
Middle row: January Johnson, Lois Strong, Marlene Summers;
Bottom row: Collette Pederson, Annamarie Hill, Rhonda Trudeau

ICARE GRANT SUBMISSION UPDATE

In the Spring/Summer newsletter we shared that team submitted a grant application to the National Institutes of Health (NIH) – National Institutes on Aging (NIA) for phase II of the ICARE project, extending the research for another five years. We are still waiting for a funding decision from the NIH – NIA grant committee and will contact with community partners as soon as we find out.

WHERE IN THE WORLD IS THE ICARE NEWSLETTER?

At each publication of this newsletter, about 5,000 print copies are delivered to households in Red Lake, Grand Portage, Oneida Nation, and the seven First Nations communities on Manitoulin Island. The newsletter also has a global reach on our websites (www.I-CAARE.ca and MemoryKeepersMDT.com). It is read widely across the US and Canada!

WISCONSIN RESEARCH PARTNERSHIP: ONEIDA NATION OF WISCONSIN

An update on the Oneida Nation provided by Lois Strong, Community Researcher

To protect the health and welfare of members, employees and community, it's without a doubt, the COVID-19 pandemic has presented a number of challenges for our Oneida Nation's leadership. From the March mandates to close business operations and many governmental programs, Oneida is now only slowly resuming business and tribal activities under proactive safety guidelines. During the past COVID-19 months of "Stay at Home" mandates, we have been experiencing creative approaches to social distancing. We have seen drive-by birthday celebrations, drive-thru farmers' markets, daily drive-by COVID-19 testing, drive-by flu vaccinations, drive-by emergency food pick-up, and drive-by funeral services in our community. Oneida Communication provides virtual tribal updates through Facebook to the membership weekly. We are learning that virtual communication is becoming more commonplace. Who would have predicted we would need to define a new normal?

Planning for the welfare of our community has taken teams of people. There is not enough time/space to mention the many key players who contributed to the comprehensive plan to approach COVID-19. Only designated essential tribal operations were approved to continue to meet the needs of our members.

The health care system is designated as an essential service. We are so thankful for our Oneida Community Health Center (OCHC) and Anna John Resident Centered Care Community staff, under the direction of Debra Danforth and Dr. Vir, for providing guidance in addressing health care needs during COVID-19 and now the flu season. The OCHC implemented health safety measures early in order to minimize positive COVID-19 cases and to flatten the curve. The staffing is not at full capacity, so staff is extremely busy meeting the demanding medical needs of our community. Yaw^ko (thank you) to all medical staff for their dedication to maintain services throughout this COVID-19 pandemic.

Another essential tribal program is the Emergency Food Program which proved to be a life-saver for community members. Through networking with local and state food vendors and other resources, Marlon Skenandore, Emergency Food Program Manager, was successful in obtaining food donations for the Oneida community. He connected with programs like Feed America and USDA Farmers to Family, and they sent 25-35lbs boxes of nutritious food to Oneida. During the October 9th USDA Farmers to Family distribution, 1,750 boxes were delivered to cars in a drive-thru service. Marlon coordinated the logistics of ordering, delivery and housing of the boxes of food along with pulling in volunteers to help deliver food boxes to the cars. To date 13,230 boxes of food have been distributed to support the nutritional health and well-being of our community. Yaw^ko to Marlon and all the dedicated volunteers who helped make this food delivery operation successful.

As I mentioned, a village worked to identify plans to keep the Oneida Nation safe during COVID-19. The ones mentioned are just two of them. We have been informed that the leadership has identified plans to re-introduce services to our community on incremental stages taking into consideration the status of COVID-19 changes in our area. Unfortunately, COVID-19 cases are not slowing down in our community and Wisconsin continues to be a primary hotspot of the entire nation. There are a number of factors playing into the increase in positive COVID-19 cases. Therefore, we need to remain vigilant with the recommended health safety measures---stay at home, wash hands, wear masks, social distance. Protect yourself. Protect your neighbor.

WISCONSIN RESEARCH PARTNERSHIP: ONEIDA NATION OF WISCONSIN

An update on the research process provided by Marlene Summers, Community Researcher

It is now November and in our last update we were no longer able to do face-to-face interviews. We continued to work on the transcripts (copies of the recorded interviews) and getting them back to the Oneida research participants by mail and by talking to them on the phone. We had the opportunity to come up with a list of people to interview once we can do that again. We were having ICARE Community Researcher meetings weekly but went to every two weeks. We also have our Community Alzheimer's Board (CAB) meetings and ICARE Team meetings once a month.

The first part of July, 2020, Dr. Nick Lambrou asked to change our IRB and request if we could do interviews by phone, Zoom, or WebEx. We got the okay and we were able to get our administrative interviews done by phone.

We had a little set-back trying to get interviews of health care professionals - physicians, and nurses. As of this writing, we have three set up to do. We had to get a person to advocate for us. We needed them to give the clinic staff approval - for example, if asked to do an interview, that they would be able to take time to do the interview. Lois Strong got our dementia specialist on board and she took our situation to the doctor, who is the head of our Tribal Clinic and he will let his staff know they may participate in our research if interested in doing so. So we are hoping to move right along and finish up the interviews.

We will then start on our focus groups. We are training and working on the sequential focus group guides. Our CAB has been an active part of our journey. We have veterans, students, community members, elders, and doctors. We would like to thank them for their support of this project and the involvement they show to this.



This picture is from when we first started to form our Board. Once we are able to meet again in person we will take an updated picture. We now have 24 members

From right to left back row is: Melissa Metoxen, Sacheen Lawrence, Carey Gleason, Lois Strong, Pat Lassila, Marlene Summers, and Crystal Metoxen. Front row from left to right: Megan Zuelsdorff, Florence Petri, Dellora Cornelius, Debbie Miller. Since then, we have new members and they are: Nick Lambrou, Eli Metoxen Sue Exworthy, John Breuninger, Carol Elm, Kerry Metoxen, Don White, Betty Williams, Sunshine Wheelock, Dale Webster, Ariana Ventura, and Lynn Metoxen.

WISCONSIN RESEARCH PARTNERSHIP: ONEIDA NATION OF WISCONSIN

We have been in touch with a few of the CAB members and would like share a couple of quotes they shared about why they are supportive of this board.

John Breuninger, Veteran, says: *The CAB attempts to be all-inclusive of representing all citizens of the Nation. As a previous health provider of over 40 years of service, a senior citizen, and a veteran, I feel my knowledge, experience, and unconditional commitment drive my support and participation on this most important committee.*

Dellora Cornelius, Elder community member, says: *I support our CAB because the members come from all walks of life. So many ideas and suggestions from everybody. We all love our Elders and will try to find answers for whatever their needs and questions may be.*

Pat Lasilla Elder, very active in our community, says: *We need to continue with the CAB to educate and to collect data to improve the quality of life for our Tribal Elders and their caregivers.*

We would like to thank everyone on our Board for the input and support you have given to this project, as well as the Tribal government and our Oneida Health Clinic for supporting the research on Alzheimer's disease.



The Oneida Emergency Food Program led by Marlon Skenandore, Emergency Food Program Manager, along with several volunteers coordinated the delivery of boxes of nutritious food to cars in a drive-thru service.



For more information on the Oneida Food Pantry, including how to volunteer or donate, please visit:

<https://oneida-nsn.gov/resources/food-pantry/>

Find their Facebook page by searching:
@OneidaFoodPantry

The Emergency Food Pantry can be reached at:
Email: foodpantry@oneidanation.org
Telephone: 920-869-6165

It is located at:
N7372 Water Circle Place
Oneida, WI 54155

ONTARIO RESEARCH PARTNERSHIP: MANITOULIN ISLAND

An update provided by Rhonda Trudeau, Community Researcher

As the leaves are changing, we are doing what we can to prepare for the next season. We will be entering colder months and for many this means more time staying home. We have enjoyed many outdoor hobbies over the spring and summer months and we will now shift to our colder outdoor activities. Autumn brings our hunting and harvesting days which are filled with fun and hard work. We have been harvesting the last of our gardens and preparing the gardens to enter this new season. We have been setting out in the early morning hours in hopes to have a successful hunt. This season, community members have kept busy by canning and storing our harvest, as well as preparing medicines. The last days of on-the-water fishing are upon us until we can enjoy ice fishing. Community members have enjoyed the hiking trails that are in our area, admiring the many colours of the forest at this time of year, and later we will be snowshoeing and cross country skiing on these same trails. Many community members have set out to moose camp and have had a successful hunt. Successful hunters can participate in island food projects by donating 1/3 of their meat to be shared with community members. Across the island, people are decorating their front lawns to celebrate these harvest days and will soon be decorating for the holiday season.

Our next steps for the ICARE project in partnership with First Nation communities will be continuing to identify community-specific dementia care needs, build research capacity, and create sustainable interventions for Alzheimer's disease and related dementias in the First Nations. We will analyze data from First Nations to examine the lived experiences of dementia through an Anishnaabe lens. This will help us to identify cultural factors that can improve culturally appropriate care and the dementia illness experience across the disease trajectory. We will identify culturally appropriate approaches to dementia health education, care, and treatment practices in Anishnaabe communities to inform the development of Indigenous dementia education materials and approaches to care. The ICARE research project's ultimate goal is the development of culturally-grounded education tools and care interventions to improve outcomes and quality of life for indigenous families living with dementia. We have been regularly (virtually) meeting with our Community Advisory Committee (CAC). Our CAC consists of 13 members of knowledge keepers and language speakers from across Manitoulin Island. Our CAC members are all very talented and we will spotlight some of those talents in each upcoming newsletter.



This is Roseann Debassige of M'Chigeeng First Nation. Roseann has been a part of our CAC for many years. Through her guidance, we have completed many projects and are working towards the next steps of more upcoming exciting projects. During the harvest season, one of the ways Roseann prepares for the winter months is by canning. On the next page is Roseann's 'Stove Top Pickled Beets,' which is one of the many recipes that Roseann uses during this time of year. The finished product can be eaten in many ways, including as a side for a special meal, in salads, in baking, or as a quick snack.

ONTARIO RESEARCH PARTNERSHIP: MANITOULIN ISLAND



Stove Top Pickled Beets

Harvest beets from the garden

Clean and wash the beets

Leave ½ of the tops and tails

Simmer in a pot of water for two hours

In the meantime, prepare the following in another pot:

4 cups of vinegar

4 cups of sugar

1 teaspoon of salt

1 tablespoon of pickling spice in a cheesecloth pouch

Boil this mixture for a half hour

Next, peel the beets and add them into your sterilized glass jars.

Fill the jars by adding the vinegar mixture and seal.



Words of the Season

Baashkaakodin Giizis – November

Minidoo-Giizis – January

Minidoo-Giisoonhs – December

Makwa Giizis - February

Niibaa-nam'aam – Christmas

Gsinaa – Cold (weather)

Nimkodaadim – New Year's

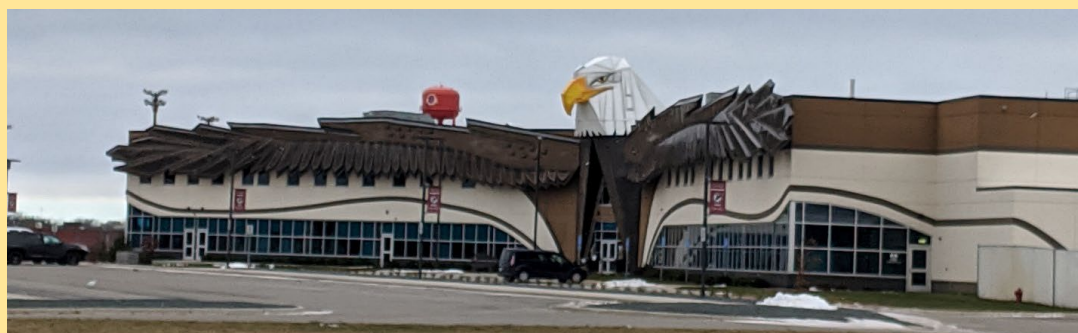
Zoogpo – Snowing

MINNESOTA RESEARCH PARTNERSHIP: RED LAKE BAND OF CHIPPEWA INDIANS

Meaningful Research Carried Out Safely Amid a Pandemic – an update provided by January Johnson, Community Researcher

I started working as a community-based researcher for the ICARE project in October of 2019. It's been a year full of transitions - from getting back into the workforce and learning my role in the data collection process as ICARE'S Red Lake community-based researcher, to modifying existing data collection methods amid the COVID-19 pandemic to ensure everyone's safety. It has been an enlightening experience working for ICARE, which leads me to make positive lifestyle changes. I believe in this research project. It encourages a positive change within our community by ensuring the needs of our community members are met. Tribal leaders have access to the research findings, allowing them to make informed, progressive decisions when shaping the future of our community. Additionally, the research findings may help with securing funding for improving current, or creating new Alzheimer's disease and related dementias (ADRDs) programs and resources.

There was a lot to take in when learning what my role consisted of as an ICARE community-based researcher. The training ensured all research procedures and protocols are followed. I was required to complete four training modules that covered community-based research practices, administration related research duties, and data collection practices. Some modules refreshed, if not deepened the skills I've learned at University and in prior research roles. I was also recertified in Human-Subject Protections by the Collaborative Institutional Training Initiative (CITI) Program. We researchers were also given the opportunity to help improve the training, by offering input on what we found difficult and what could be improved. I felt that showed how thorough the project really is. I understood this role as a researcher to be challenging, but in a good way. I knew it would push me out of my comfort zone and I would be given a chance to reconnect in the community. I was also reminded of the process of putting together meetings, focus groups and interviews. When I first started collecting data through key informant interviews, there was so much to plan out. It was quite the process - recruiting participants for interviews and scheduling a time that is convenient for them. There was really a lot of planning and time management involved. I was to find and reserve a quiet and secure meeting space for the interview to take place, and I would have to arrive early to set-up the interview area. I would prepare for the interview by packing needed materials such as the recording device, consent and honorarium forms, beverages, and tissues. There was a feeling of more connectedness when carrying out the interviews in-person. After COVID-19 hit and the pandemic shut down the United States, the data collection process was put on pause until a new safety plan was put in place to carry out the research. When we resumed data collection, we had to transition to virtually connecting with the interview participants. All of our data collection methods had to be carried out virtually through the Zoom meeting app or over the telephone. In some cases, participants were allowed to complete the interview through a questionnaire.



**Red Lake Nation
College**

Photo taken by:
Annamarie Hill,
Community
Engagement
Specialist

MINNESOTA RESEARCH PARTNERSHIP: RED LAKE BAND OF CHIPPEWA INDIANS

Since I have taken on this researcher role for the ICARE project, I have learned much about Alzheimer's disease and related dementias, as well as becoming aware of my own family's disease history. I am realizing how high-risk I am for developing diseases such as diabetes, high blood pressure, and cancer - all of which increase the chances of me developing a type of dementia. Understanding that dementia is an umbrella term that thinking impairment and Alzheimer's diseases fall under, kind of scares me. I am overcome with the pressure of not only wanting to, but needing to make major lifestyle changes. I also realize many other people in my community are affected the same way I am, and I would like to maybe one day be an example of change. Although, I know I have a long journey ahead of me, it would be so worth it to show it is possible to make those changes. As cliché as it sounds, if I could do it, so can others. We need to keep in mind that how we treat, and what we feed our bodies is key to healthy aging. Lack of routine exercise, paired with the consumption of a high-sodium and sugary-based diet, will increase the risk of developing diseases such as diabetes, high blood pressure, cancer, kidney disease, and stroke - all of which our people are affected by.

Another way we increase our chances of developing these diseases are through substance abuse. Substance abuse may lead to an addiction, which is considered a brain disorder. Substance abuse/addiction increases exposure to physical and emotional trauma, and any blunt trauma to our head puts us at risk for dementia. I have struggled throughout my life with chemical dependency and relapses, however, after learning so much from the research of the ICARE project, I know what my future holds if I ever go back down that road. Which is why I need to make the change to a nutritionally-balanced diet and incorporate routine exercise, while abstaining from substance abuse. I'm not saying it's going to be an easy transition, but I know it will be worth it. ICARE has been a source of a lot of valuable information that provided an awareness I wouldn't have had unless I worked here. If I can learn this much from the research, I have high hopes that others in the community could benefit as well. And since the tribe has access to the research findings, I believe our community will benefit from it as well.



**Red Lake Nation
Veterans Memorial
Park**

Photo taken by:
Annamarie Hill,
Community Engagement
Specialist

MINNESOTA RESEARCH PARTNERSHIP: GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

Updates on Grand Portage provided by Collette Pederson, Community Researcher

Grand Portage ancestral homeland recognized in new designation of Isle Royale: July 2019

Grand Portage community members and friends boarded the Grand Portage - Isle Royale ferry boat, the Sea Hunter, back on July 23, 2019 to head to Isle Royale for a unique celebration. Isle Royale - or Minong- has received "Traditional Cultural Property" status, a federal designation, as home of the Grand Portage Band of Lake Superior Chippewa.

The first stop was to offer tobacco to the Cedar Spirit Tree and then on to the sunken Steamship America, located near Washing Harbor at Isle Royale. Weather conditions were perfect to view the submerged vessel.

A large group of National Park Service staffers were on hand at the Windigo dock to welcome the Grand Portage group. All gathered in the pavilion for a celebration. The Stonebridge Singers offered a drum song, followed by a traditional blessing.

Two Grand Portage flags were presented to the Isle Royale National Park Superintendent, which will be flying proudly over the Windigo dock.

The Stonebridge Singers, who so gently transported their drum, played many songs.

Speakers spoke of the significance of the day, offering the gift of sweet grass, sage, tobacco and wild rice to the Park Superintendent. The Superintendent, in return, offered lake trout that some of her staff had caught and prepared.

The Stonebridge Singers offered another drum song, followed by a feast of wild rice and berries, fish cooked in several styles, and blueberry bannock. It was a beautiful occasion and day.

Parking Lot Bingo with the ENP

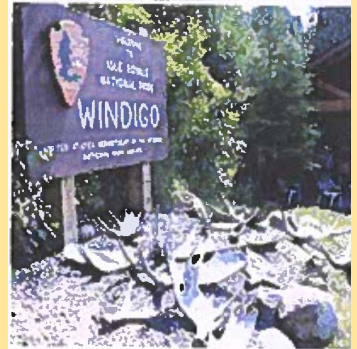
With a day in the low 50's and a few more clouds than we hoped, we set out to have a good time and get together while staying apart. Polly James, the director of our Elderly Nutrition Program (ENP), ordered a transmitter that uses two cell phones to broadcast sound to a radio station that people can tune their radio to.

The caller's tent and prize tent were set up at the north end of the lot and cars were parked around the lot facing in. We played 20 games of various varieties including the letters "E", "N", and "P".

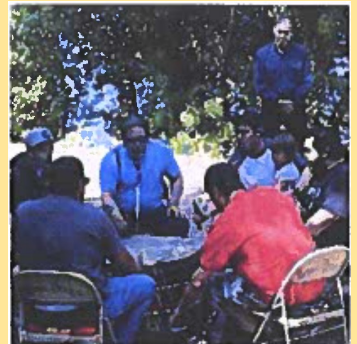
Eleven cars showed up to give it a go with several having multiple family members in the car. A good time was had by all. Since it was such a success, we did it again. 😊



Isle Royale



Windigo Welcome Sign



Stonebridge Singers



Polly James, ENP Director



Parking Lot Bingo

MINNESOTA RESEARCH PARTNERSHIP: GRAND PORTAGE BAND OF LAKE SUPERIOR CHIPPEWA

Grand Portage Gardens

This summer we have made an extra effort to grow as much fresh produce as possible to be included in the meals being delivered by the Elderly Nutrition Program (ENP) and the Summer Food Program for school children. The ENP is delivering an average of about 185 meals a day and Summer Food produced about 70.

Early this spring, the Agricultural Coordinator was able to till and plant early crops in the new ENP hoop house. With the early crops in, we started seeds for the school greenhouse and the school and community planters in front of the community center. The Tobacco Prevention Coordinator planted in a raised bed garden and green house behind the wellness center. So far, we have harvested almost 300 pounds of produce.

A refrigerator was donated by a local from Grand Marias as a place to store the produce for easy access by both program cooks. We also received small grants from the Cook County Whole Foods Co-op to support both feeding programs.

In addition, extra produce has been made available to the community through our CACHE - Community Agriculture through Culture, Health, and Education - farm market. The market was expanded this year to include local craft vendors and the Portage Band played to create an excellent social event. Many of our Elders regularly attended the market and sampled recipes made from fresh, locally-produced fruits and vegetables.



THE THREE SISTERS: CORN, BEANS, AND SQUASH

Throughout the newsletter, each of the community researchers touched on the importance of food sovereignty, from community access, growing gardens, harvesting, as well as the importance of healthy foods in protecting our heart, our minds, and our bodies. Corn, beans, and squash, collectively known as the “Three Sisters,” hold special significance in many Indigenous cultures. Techniques for growing, harvesting, and processing the Three Sisters have been passed down through our families, our communities, and shared with other nations.

With the winter months quickly approaching, we wanted to include a recipe for using the Three Sisters in making a hearty and healthy soup that will help use up some of the harvest from the fall. The following recipe comes from the First Nations Development Institute Recipe page and is shared by Donna LaChapelle and Patricia Chandler (<https://www.firstnations.org/recipes/three-sisters-soup/>)

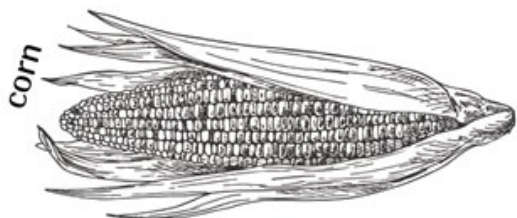
Three Sisters Soup Recipe (serves 4)

Ingredients

3 tablespoons butter
4 cups chicken or vegetable stock
1 cup onion, diced
1 clove garlic, minced
1 butternut or acorn squash, pre-baked and pureed
1 teaspoon curry powder
½ teaspoon salt
½ cup yellow corn kernels
¼ teaspoon ground coriander
½ cup hominy, cooked
1 cup white beans, cooked
1/8 teaspoon crushed red pepper

Directions

Melt butter in a large saucepan over medium-high heat. Add onion and garlic, cook for 3 to 5 minutes or until tender.
Stir in spices, cook for 1 minute.
Add stock, corn, hominy, and beans, and bring to a boil. Reduce heat to low and cook, stirring occasionally, for 15-20 minutes to develop flavors.
Stir in pureed squash, cook for 5 minutes or until heated through.
Serve warm with chives and plain yogurt as a garnish.



Get in touch with the team

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