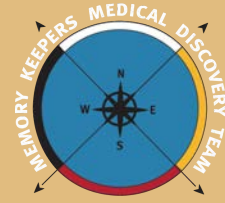


MEMORY KEEPERS MEDICAL DISCOVERY TEAM

ISSUE 04 | November 2023




Medical School,
Duluth Campus
UNIVERSITY OF MINNESOTA
Driven to Discover®



CERDAR

The Center for Community Engaged Rural Dementia and Alzheimer's Research

A deeper look into CERDAR and what we are trying to accomplish for our community members. In this issue, you will meet more members of our team and get updates on our work, including some preliminary findings from our research.

WWW.MEMORYKEEPERSMDT.COM/CERDAR/
WWW.RURALMEMORY.COM

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THE COMMUNITY ADVISORY GROUP

Within the Memory Keepers Medical Discovery Team (MK-MDT), Drs. Kristen Jacklin and Wayne Warry lead a program to develop a Center for Community Engaged Rural Dementia and Alzheimer's Research (CERDAR). This pilot research program will lead to a National Institutes of Health, National Institute on Aging P01 application, which is a grant application to support the long-term research aims concerning dementia in rural Minnesota. The goal of the CERDAR research project is to better understand the lived experiences of people living with dementia and their caregivers living in rural areas.

CERDAR has recruited representatives to form a Community Advisory Group (CAG) across northern Minnesota. The CAG acts as a structure for networking, outreach, and research consultation to rural communities in both northwest and northeast Minnesota. CAG members provide guidance, support, and advice to core investigators/project leads and other staff on the CERDAR team. For example, they negotiate and help refine the methods of the research, assist in developing recruitment strategies for the study, review research findings, and maintain community communications.



The CAG consists of respected members within the community who provide guidance on research activities that are part of the CERDAR project. Members represent diverse backgrounds, including, but not limited to: health care staff working with seniors and people living with dementia; caregivers and family members who have cared for people living with dementia; people living with early cognitive impairment or dementia; healthcare administrators; and people with knowledge of dementia services in their community or region. Our membership includes individuals from Lancaster all the way to Duluth. CAG members meet with the team quarterly via Zoom to discuss the projects.

COMMUNITY ENGAGEMENT UPDATE

It is our goal to continually engage with people living in rural communities

Where we have been

-Ely Aging Expo	May 22, 2023	-Lake County Fair- Senior Day	Aug 10, 2023
-Grand Portage Health Fair	Jun 10, 2023	-Mino Bimaadizi Community Science and Medicine Fair	Aug 27, 2023
-Rural Health Conference	Jun 12, 2023	-Walk to End Alzheimer's	Sep 9, 2023
-Arrowhead AAA Caregiver Conference	Jun 28, 2023	-2023 Age Friendly MN Conference	Sep 27-29, 2023
-Aitkin Remember Project	Jun 29, 2023	-Memory Loss Workshop	Oct 6, 2023
-Intertribal Youth Summit	Jul 24, 2023	-St. Louis County Human Services Conference	Oct 11, 2023
-Red Lake Community Health Day	Jul 27, 2023	-North St. Louis County Community Mental Health Forum	Oct 19, 2023
-Becker County Fair- Senior Day	Jul 27, 2023		
-National Night Out and Health Fair	Aug 1, 2023		
-ElderCircle & Itasca YMCA Celebrating Seniors	Aug 2, 2023		

472 PEOPLE REACHED THROUGH THESE EVENTS!

PARTNER HIGHLIGHTS

Memory Keepers Medical Discovery Team would not be where we are without the continued support from our partners

ARROWHEAD AREA AGENCY ON AGING

<https://www.arrowheadaging.org>

The Arrowhead Area Agency on Aging is one of the seven Area Agencies on Aging (AAAs) in the state and serves the Arrowhead region in northeast Minnesota. Their mission is to assist in providing local units of government and citizens groups a means to work cooperatively in identifying needs, solving problems, and fostering local leadership. These AAAs were created under the Older Americans Act of 1965. The Arrowhead AAA has members serving on CERDAR's Community Advisory Group and Rural Research Advisory Group. Arrowhead AAA leadership and staff have also assisted with promoting CERDAR projects, as well as assisting in recruitment and providing expertise on structural questions regarding local government units.

DANCING SKY AREA AGENCY ON AGING

<https://www.dancingskyaaa.org>

The Dancing Sky Area Agency on Aging is also one of the seven AAAs in the state and serves 21 counties in northwest and north-central Minnesota. Services include help for older adults as well as caregivers and people with disabilities. Home and community-based providers are also assisted. The agency also provides public awareness on important issues such as adult protection services, veteran services, and general aging advice. The agency covers almost 30% of Minnesota's land mass with a low population of citizens. Several of the counties covered have a population of approximately 750 people or less. Highlighting the need for partnerships and support services to assist those in aging in their homes or community.

Dancing Sky has been a reliable partner, assisting the CERDAR team in a variety of ways. This includes recruitment assistance, sharing vital information on local communities, and outreach and engagement help. CERDAR aims to continue building trust with rural residents and the Dancing Sky AAA has been very generous in allowing us to collaborate.

SOME PRELIMINARY FINDINGS FROM PROJECT 1 SHARED AT THE ALZHEIMER'S ASSOCIATION INTERNATIONAL CONFERENCE, JULY 2023

Location Dynamics in Northern Rural Minnesota: Barriers and Facilitators for Alzheimer's Disease and Related Dementias Diagnosis and Care

Wayne Warry, PhD, Joshua Fergen, PhD, Patricia Soderlund, PhD, Kirsten Cruikshank, MSW, Kristen Jacklin, PhD

INTRODUCTION:

Our hypothesis is that rurality, including rural culture, diversity, geography, and community context, is a significant factor determining the prevalence of Alzheimer's disease and related dementias (ADRD), dementia care accessibility, and quality of life for people living with dementia and their caregivers.

METHODS:

We conducted interviews with 62 key informants across northern Minnesota including:

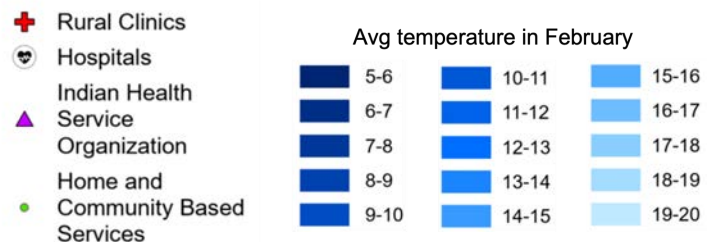
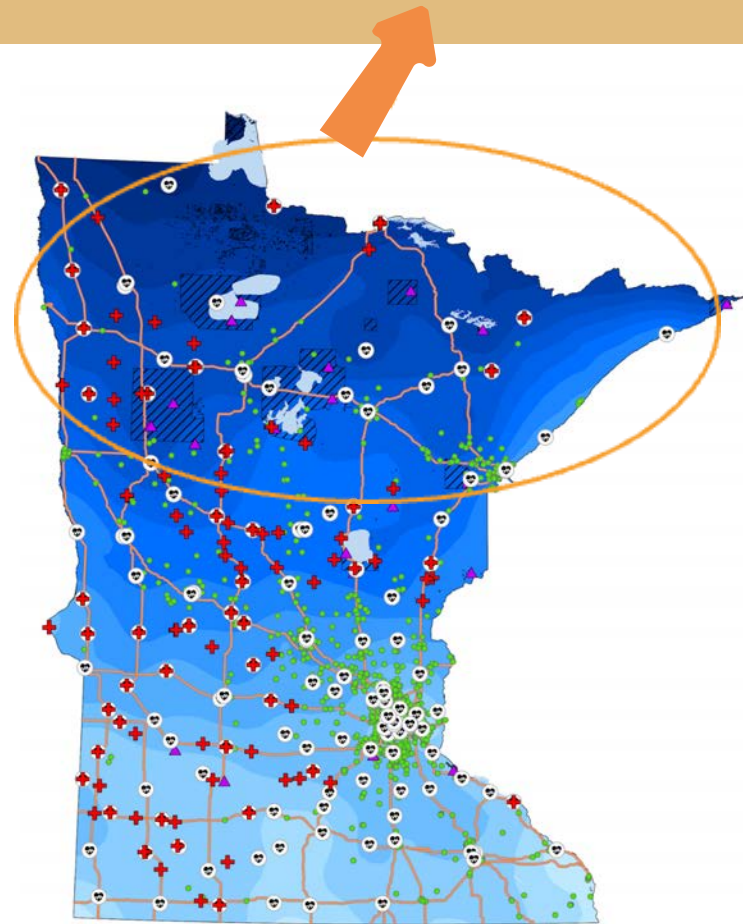
- Rural physicians
- Health care providers
- Social workers
- Formal and informal caregivers
- Healthy older adults

FINDINGS:

- Limited rural health care resources, including a scarcity of physicians, specialists, and allied professions, as well as distance to services, hinder timely ADRD diagnoses and care.
- Aging in place and family caregiving are made more difficult due to younger family members moving to urban areas.
- Winter weather exacerbates transportation challenges, increases sedentary behavior, and impacts quality of life for people living with dementia and their caregivers.
- Many people living with dementia and their caregivers view relocation to towns or urban centers to reunite with family, or transition to nursing homes, as an unfortunate, yet necessary alternative to aging in place.

Winter Weather Impacts Access to Services

Long winters add to existing difficulties of transportation and access to services. The lack of health services means people must travel further and/or requires people to relocate in order to access dementia care, which impedes aging in place.



FINDINGS FROM OUR INTERVIEWS

1. RURAL FAMILY CAREGIVING

Young family members moving away from rural areas influences patterns of informal dementia care and the ability of people living with dementia to age in place. Local family and neighbors are important sources of care and support aging in place.

“And we’re too sedentary out here... And they’re scared to slip. They’re scared to walk on the ice. They’re scared to drive in the winter.” [Health Leader]

“Also being out in the middle of nowhere means that it’s not like driving in the metro. If you have a blizzard, typically they’ll say don’t drive, we need the snow plows out... But out in the middle of nowhere, you’re on a highway, you can’t see, people don’t drive like they probably would, it’s just different.” [Social Worker]

“He started with sundowning really bad. I didn’t know what sundowning was... Because he’d be great during the daytime and all of a sudden in the fall and the winter you’d hit that five, 6:00, and it was just like who are you?” [Informal Caregiver]

3. GEOGRAPHY AND ACCESS TO SERVICES

The lack of health services in rural Minnesota means people must travel further and/or requires people to relocate in order to access dementia care, which impedes aging in place.

“Some (physicians) are really good at informing families and patients and connecting them with resources. And more than one physician has said you’re 89, you’re going to have memory problems, what do you expect? Just go home and live with it.” [Formal Caregiver]

“It’s always been done the same old way that the minute you get dementia you’re going to the nursing home and that’s a longstanding cultural thing in the rural area.” [Social Worker]

“One of the biggest problems in our area is like my whole generation moved away. We have this huge population here who don’t have children that are local.” [Formal Caregiver]

“We have neighbors here in town. If the shade doesn’t go up by 9:00, they know to go over and check on them. So, as a community, we’re super good at helping out if we know help is needed.” [Formal Caregiver]

2. IMPACTS OF WINTER WEATHER

Long winters add to existing issues with transportation and access to services, but also have impacts on physical, mental, and social wellbeing. Wandering and sundowning are specific concerns for people living with dementia. Harsh winters can affect caregiving decisions and encourage earlier transitions into institutionalized care. Winter’s cold and icy conditions also contribute to sedentary behavior.

“I would have to say if my husband did want treatment, it wouldn’t be a good place because there’s not access, he’d have to travel. And I don’t know this, but I would assume that having to travel for a person with dementia or Alzheimer’s would be difficult. It takes an hour to get to [city] and then you have an appointment, and it would be a very long day for them, and it might be very tiring and stressful.” [Informal Caregiver]

“There is no transportation within town so that’s relatively easy to find volunteers for, but trips, especially in the winter...to get to any reasonable doctor appointment is an effort and not really accessible to many people with no options... So that’s a huge barrier relatively specific to older people as they get less confident with their driving.” [Health Administrator]

4. DEMENTIA DIAGNOSIS

Rural physicians’ comfort and willingness to diagnose dementia varies greatly and is shaped by their medical education, as well as the availability of local services.

TEAM HIGHLIGHTS

Each issue will highlight different members of the CERDAR team. For this issue we are pleased to introduce...

DAVID POPILEK

Community Advisory Group (CAG) Member

David Popilek is 69 years old and resides in Two Harbors, MN. He has been a professional storyteller for over 40 years. He is known for his character Jacques La Christian, a French fur trader from the 1800s. He speaks nationally at camps for children as well as at schools, libraries, and civic and church events.

David wrote a children's book during the COVID-19 pandemic named "Grampa's Workshop" that tells a story of grandchildren going to grandpa's house; in grandpa's workshop is a canoe that the grandchildren hop into and imagine they are on a big adventure. He has written over 43 stories that depict life in the 1800s. He works hard to memorize his stories and continues to invest time into new ones.



In 2018 David had a sepsis episode of unknown origin which was very scary. He was in the hospital for a week as he recovered. Once home he experienced what is called post sepsis syndrome and dealt with fatigue, memory issues, and task and executive function problems. David was forced to take some time off from speaking. He did a tour of libraries with his partner that Fall which was physically difficult. He still has memory and time/task management difficulties and has been diagnosed with Mild Cognitive Impairment (MCI) which required schedule adjustments. Dementia runs in the family as his mother and sister both started their journeys in their 60s. He has worked out most days and takes pride in his workout routine that has assisted him greatly in fending off the disease, but changes do continue to happen.

He is in good spirits about the diagnosis, but difficulties remain as David battles fatigue and mood changes and frustration. David's partner does most of the driving these days. He is an amazingly humorous person and when things get confusing, he just flows with it most of the time as he is aware and able to recognize symptoms. He continues to excel as a personal care assistant and hospice worker as he is a very gentle and fun person to be around. David's work keeps him feeling purposeful. He loves his 3 dogs, Rocco the pit-bull, Chi Chi the chihuahua, and Cocoa, very much. David is also a spiritual mentor to many and holds a pastor's license. He continues to serve with love, understanding, and care.



KELSIE LARSON

Community Based Researcher

Kelsie Larson, RDN, joins the CERDAR team as a Community Based Researcher in Northwest Minnesota. She returns home to Minnesota after living and working in rural Southwest Montana as a dietitian in a nursing home and hospital. She recently graduated from the UMN School of Public Health with a focus in community health.

Kelsie looks forward to using her passion for healthy communities to prioritize the health and wellbeing of individuals impacted by memory and cognitive changes in rural areas.



NATALYA WALKER

Community Engagement Coordinator

Natalya has a background in environmental conservation and community engagement around water and forest resources. At MK-MDT she oversees and coordinates relationship development with rural and Indigenous communities in Minnesota and is foremost concerned with supporting sustainable community collaborations that support brain health equity research.

Natalya lives on the Iron Range with her partner Nicholas and two puppy dogs, Thea and Gunner. Growing up closer to the cities, she's lived rurally since 2016 with the goal of running a small farmstead and managing private forest land. In the spring and summer, good luck finding her on remote trails foraging for berries, when not maintaining her gardens and building up her homestead. In the fall and winter she snowshoes, hunts for chaga, and shadows Nicholas in his deer and grouse hunts.

ENJOY THIS RECIPE!

OATMEAL CHOCOLATE CHIP COOKIES

Ingredients

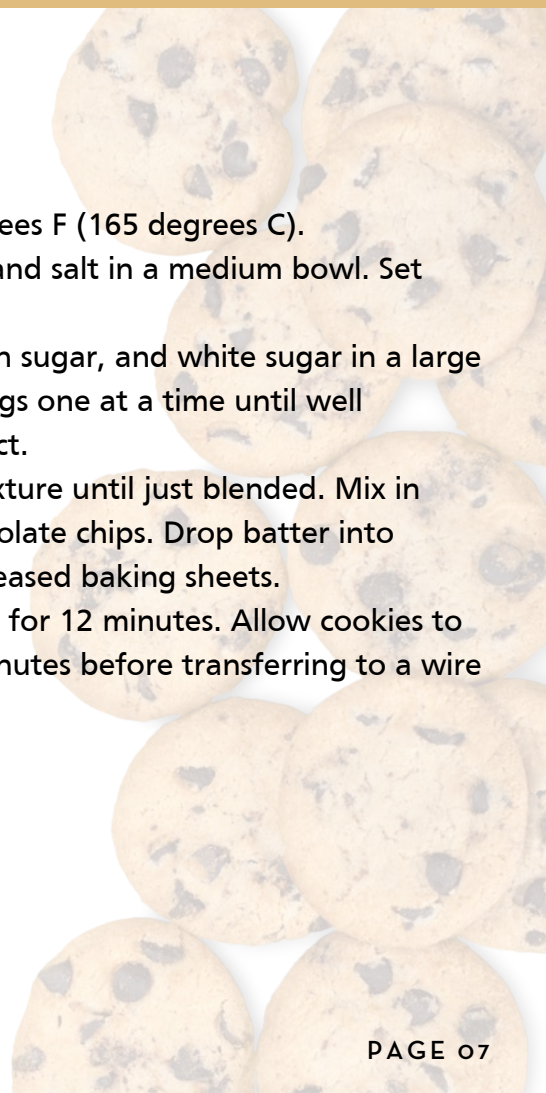
- 1 cup butter, softened
- 1 cup packed light brown sugar
- ½ cup white sugar
- 2 eggs
- 2 teaspoons vanilla extract
- 1 ¼ cups all-purpose flour
- ½ teaspoon baking soda
- 1 teaspoon salt
- 3 cups quick-cooking oats
- 1 cup chopped walnuts
- 1 cup semisweet chocolate chips

Directions

1. Preheat the oven to 325 degrees F (165 degrees C).
2. Combine flour, baking soda, and salt in a medium bowl. Set aside.
3. Cream together butter, brown sugar, and white sugar in a large bowl until smooth. Beat in eggs one at a time until well combined; stir in vanilla extract.
4. Stir flour mixture into egg mixture until just blended. Mix in quick oats, walnuts, and chocolate chips. Drop batter into heaping spoonfuls onto ungreased baking sheets.
5. Baking in the preheated oven for 12 minutes. Allow cookies to cool on baking sheet for 5 minutes before transferring to a wire rack to cool completely.

Nutrition Facts (per serving)

- 145 Calories
- 8g Fat
- 17g Carbs
- 2g Protein



Your Research Team:

Memory Keepers Medical Discovery Team

Principal Investigators:

Dr. Kristen Jacklin

Dr. Wayne Warry

UMN Medical School, Duluth Campus:

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Dr. Catherine McCarty

Dr. Peter Nalin

Dr. Sandra Stover

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Dr. Joseph E. Gaugler

Dr. Carrie Henning-Smith

UMN School of Nursing:

Dr. Dereck Salisbury

Collaborator:

Dr. Stephen Waring, Principal Scientist,

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Melinda Dertinger

Dr. Josh Fergen

Kelsie Larson

Brooke Metz (Lees)

Dr. Amy Otto

Dr. Lysie Radovich

Dr. Sung Han Rhew

Dr. Patricia Soderlund

Natalya Walker

Community Advisory Group Members

Northwest

- Karen Bedeau- Dementia Outreach Advocate, Northwoods Caregivers
- Lora Bertelsen- Counseling Psychologist
- Val Mattison- Program Developer, Dancing Sky AAA
- Jody Peterson- Informal supporter for caregivers

Northeast

- Kelly Campbell- Community Health Coordinator, Grand Itasca Clinic and Hospital
- Marcia Grahek- Retired RN Supervisor, community volunteer
- Jenna Pogorels- Senior Program Manager, Minnesota-North Dakota Chapter, Alzheimer's Association
- David Popilek- Caregiver and Performer
- Rebecca Sash- Grants Manager/Aging Services Planner, Arrowhead AAA

Rural Research Advisory Group

- Terry J. Hill, MPA- Executive Director, Rural Health Innovations, Senior Advisor for Rural Health Leadership and Policy, National Rural Health Resource Center, Duluth
- Kristi Kane- Director, Arrowhead AAA, ARDC
- Emily Onello, MD- Assistant Professor, Department of Family Medicine and Biobehavioral Health, UMN Medical School, Duluth Campus
- Megan O'Connell, PhD- Department of Psychology, Rural Dementia Action Research (RADAR) Centre, Rural and Remote Memory Clinic, University of Saskatchewan College of Arts and Science.
- Heather Pender- Aging Program Director, Dancing Sky AAA

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CERDAR is made possible by funding to the MK-MDT by the University of Minnesota Medical School Academic Investment Research Program.

Join the CERDAR Community for newsletters and to participate in our research!

www.RuralMemory.com

We are hiring!

Visit us at: <https://memorykeepersmdt.com/careers/>
to see all positions and apply