

MEMORY KEEPERS MEDICAL DISCOVERY TEAM




Medical School,
Duluth Campus
UNIVERSITY OF MINNESOTA
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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.

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BE A VOICE FOR YOUR COMMUNITY!

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IN MEMORY OF DR. JIM BOULGER

It is with great sadness that we acknowledge that the Memory Keepers Medical Discovery Team's Rural Advisor, Dr. Jim Boulger, recently passed away on Saturday, January 14th, 2023, at the age of 81.

Dr. Boulger's legacy in helping to build a medical school curriculum that focused on the training of rural and Indigenous physicians will not be forgotten. After his retirement from the UMN Medical School, Duluth Campus, Jim lent his pragmatic wisdom, experience and expertise in rural health, medical education and research mentoring to the Memory Keepers Medical Discovery Team (MK-MDT) and to the development of the Center for Community Engaged Rural Dementia and Alzheimer's Research (CERDAR).

Above all, Jim was a gentle, kindhearted colleague who was always concerned for the welfare of others. Many in the Memory Keepers family were very close to Jim and all of us have been touched by him in some way. His presence in this world and with our team will be missed.

CERDAR GRANT FUNDING AND PRIORITIES EXPLAINED

Many people often ask about CERDAR's funding and long-term goals. The CERDAR is currently funded primarily by the Memory Keepers Medical Discovery Team. The University of Minnesota, Medical School, supports four Medical Discovery Teams with special funding from the Minnesota State Legislature to help advance science that will improve the health and lives of Minnesotans. CERDAR also receives additional funds through the National Institutes of Health and a grant awarded by the Medical School's Academic Investment Research Program (AIRP).

The funding we have received to date has been vital to us establishing the CERDAR program including hiring our staff, developing relationships and partnerships with people and organizations in rural Minnesota and to begin small pilot research projects that helps our team better understand the dementia research needs in Northern Minnesota. We have been able to gather pilot data that can be used as evidence of the need for future rural dementia research and demonstrate to future funders that we have in place the research infrastructure and partnerships to accomplish what we propose. A pilot study is a small-scale test of research methods and procedures. Think of a "rehearsal" where potential issues and problems can be found and solved before rolling out a larger study. The results of the pilot study are then used to guide the methods and procedures of the large-scale study. CERDAR is conducting several pilot studies.

One of our important goals is to identify on-going funding so that the CERDAR program can grow and support many research projects and educational activities. We are looking at several different grant and funding opportunities that can further support CERDAR's important work to address dementia in rural communities. Over the next year, we will put most of our effort into developing grant proposals to submit to the National Institutes of Health (NIH) competitive funding mechanisms with the aim of achieving 5-year renewable federal funding. We have identified a grant writing team at the Memory Keepers Medical Discovery Team, who will review our research findings so far and develop proposals to support similar and new research projects and infrastructure. NIH grants are highly competitive and most teams who submit grants have them reviewed and then returned with suggestions to improve the research design in a resubmission. In other words, it may take two or three rounds of submissions to achieve success.

A large programmatic grant from NIH for CERDAR would allow us to make further connections with Minnesota's rural communities, to advance research investigations of Alzheimer's disease and related dementia in rural populations, and to explore new opportunities for dementia care interventions. All of this is done in collaboration with and the support of communities and agencies in northern Minnesota. We have enjoyed strong support across the region and are thankful to the individuals and organizations who have greatly assisted with our mission.

WHY CERDAR? RESEARCH PROJECTS AND NIH P01 GRANTS EXPLAINED

Current CERDAR Projects:

We at CERDAR are currently involved in five different projects. A short description of each is shown below:

Project 1: Socio-Cultural Factors in Rural Alzheimer's Disease and Related Dementias (ADRD) Care Experiences

This project seeks to understand rural people's knowledge of and lived experience with dementia, as well as the socio-cultural factors that prevent access to care and services. Project 1 is our foundational qualitative research program aimed to better understand how rural culture, geography and local context influence the experience of dementia, caregiving, dementia diagnosis and care.

Project 2: Minnesota Rehabilitation Intervention for Dementia Prevention with Exercise (MN-RIDE)

MN RIDE examines the role of exercise with people who have subjective cognitive impairment. It is designed to demonstrate that remote or virtual prevention programs can be implemented in rural areas, and to demonstrate the potential for exercise programs to prevent or reduce the risk of dementia.

Project 3: CareBand

CareBand is a device that helps caregivers monitor the location and activity of those with dementia. We are studying the idea of "lifespace," which is a measure of the quality and distance a person moves on a daily, weekly and monthly basis. Lifespace can be used to track cognitive decline over time.

Project 4: Dementia-Specific Epidemiology

Working with Essentia Health, we will examine health records to see how and where dementia is diagnosed in rural areas, where patients are referred, and how this compares to those who live in an urban setting.

Project 5: ADRC Participation

ADRCs are research centers dedicated to clinical and biomedical research on Alzheimer's and dementia. However, these centers rarely include rural or Indigenous patients in their clinical trials. Project 5 seeks to increase participation by these groups by learning what factors may prevent or encourage participation.

UPDATES ON OUR PROJECTS



PROJECT 1

BY: JOSH FERGEN, PHD

We conducted 56 interviews across rural communities in northern Minnesota on the unique barriers and facilitators for Alzheimer's disease and related dementia care. These interviews consisted of healthcare providers, health leaders and administrators, social workers, informal and formal caregivers, and healthy older adults.

Preliminary findings suggest significant barriers exist in the winter months when it comes to making appointments, remaining socially and physically active, and managing fall risks. Also, the lack of local specialty care access leads many in rural communities to have to travel. Additionally, many rural communities have seen a gradual decline in locally available services. Significant staffing challenges at existing rural clinics and Home and Community-Based Services make it difficult to maintain services and remain open. Those without financial resources or family face additional burdens navigating complex healthcare systems.

There is some good news: rural communities have a lot of informal community resources that rural people utilize to meet their healthcare needs, and CERDAR has documented the many ways our rural communities come together to support aging in place. *Close-knit communities allow rural people to be aware of their fellow residents' health and use this knowledge for interactions in the community. Close working relationships between social services and healthcare providers allow these rural communities to provide an extra level of care and monitoring to the most vulnerable.* Rural areas also rely on a strong sense of volunteerism when it comes to supporting people with dementia, whether it's riding along to the grocery store or attending doctor appointments in the cities. Rural community institutions (church groups, school boards, civic organizations) are also helpful resources that provide opportunities to maintain a high quality of life, such as socialization, event planning and caregiver support groups, while also providing access to a network of volunteers and support systems. Having family around locally is also important for regular check-ins, and while this is certainly a challenge with much of the rural youth moving to other communities, regular virtual check-ins can help maintain social connections within the community. These assets are critical and utilized in rural communities where there is a lack of medical infrastructure, geographic challenges, and winter weather.

UPDATES ON OUR PROJECTS CONTINUED...

PROJECT 2

BY: DERECK SALISBURY, PHD

The MN RIDE program was a telerehabilitation exercise program where participants exercised on a stationary recumbent cycle from the comforts of their own homes. All exercise was personalized/prescribed for each participant by a clinical exercise physiologist and all sessions were supervised live and remotely by exercise therapists over the internet. All participants were sent the needed equipment to complete the intervention including stationary cycles and blood pressure cuffs for safety monitoring. For their participation in the MN RIDE program, participants were able to keep the cycles. In addition, MN RIDE team members traveled to the participants' homes to help with the set up of any equipment or technology on an as-needed basis for the completion of the remotely-supervised exercise sessions.

The MN RIDE program was conducted over 12 weeks, where participants were encouraged to schedule exercise sessions 3 times per week in time slots that were available Monday-Saturday (7AM-6PM). In addition, participants were encouraged to schedule sessions when other participants were exercising to promote social engagement, support, and comradery. The MN RIDE program was conducted March 2022-December 2022 and had 9 participants. Overall, the average attendance was 86% (30 out of 36 sessions were attended by participants over a 12-week period). No negative effects of the telerehabilitation program were noted by participants in 195 training hours. The MN RIDE program had a moderate to large positive effect in improving risk factors for ADRD including depression, anxiety, and physical fitness. In addition, the MN RIDE had moderate to large positive effects in improving participant reported aspects of quality of life including areas reflecting physical health and psychological health.

Overall, the MN RIDE program was perceived positively by participants, with eight out of nine participants reporting that they would recommend the MN RIDE program to friends and family. The MN RIDE program that is tailored to combat barriers to exercise participation in rural-living residents represents a feasible model for delivering exercise therapies in underserved populations. This program provides preliminary evidence for a therapeutic effect on certain ADRD risk factors and improving quality of life in persons at risk for ADRD.

A NOTE ON GRATITUDE

By: Kirsten Cruikshank, Community Researcher

“In Appreciation for Community: We Don’t Do This Alone”

“Be present, take a deep breath and acknowledge gratitude for this moment and the time together with the participant.”

This is a note I read to myself before beginning an interview for Project 1. Participants include family caregivers, paid caregivers, community leaders, social workers, caregiver consultants, healthcare providers and healthy older adults. I am grateful for their willingness to participate and share their experience, I am grateful for the time they share with me – time away from work, family, and the person/people with dementia for whom they are caring.

Not only am I grateful for the participant’s willingness to share their experience, I am also grateful for everyone who helps me get to that moment. On the community end of things, community-based organizations share information and refer people to our research projects. Behind-the-scenes work on the research end includes everything from planning, grant writing, project design, analysis, and working with the Institutional Review Board to ensure ethical practices. Regional partners include the Arrowhead Area Agency on Aging and the Dancing Sky Area Agency on Aging. Additional contacts include local hospitals, fitness centers, and county human service agencies. We are also beginning to involve more faith-based organizations.

Advisory group members represent their communities and professions. Each person involved helps improve our understanding of the experience of people with dementia and their caregivers living in rural areas in northern Minnesota. We are grateful for their involvement. As I end each interview session, I feel a sense of humility combined with gratitude. Someone has just shared their personal story with me – Whether it includes professional barriers and facilitators to care, or personal burdens and joys of the caregiving relationship, all I can say is “Thank you!”

" Community-based participatory research, often referred to as CBPR, is an applied collaborative approach that enables community residents to more actively participate in the full spectrum of research (from conception – design – conduct – analysis – interpretation – conclusions – communication of results) with a goal of influencing change in community health, systems, programs or policies."

-University of Minnesota Medical School, Duluth Campus, MK-MDT

TEAM HIGHLIGHTS

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



BROOKE METZ

Communications Manager

Brooke is proud to have been born and raised in Hibbing, MN. She oversees all communication and marketing efforts for the MK-MDT, manages the websites and creates digital media and data visualization content. These creations assist with research publications, newsletters, recruitment, advertising and staff requests.

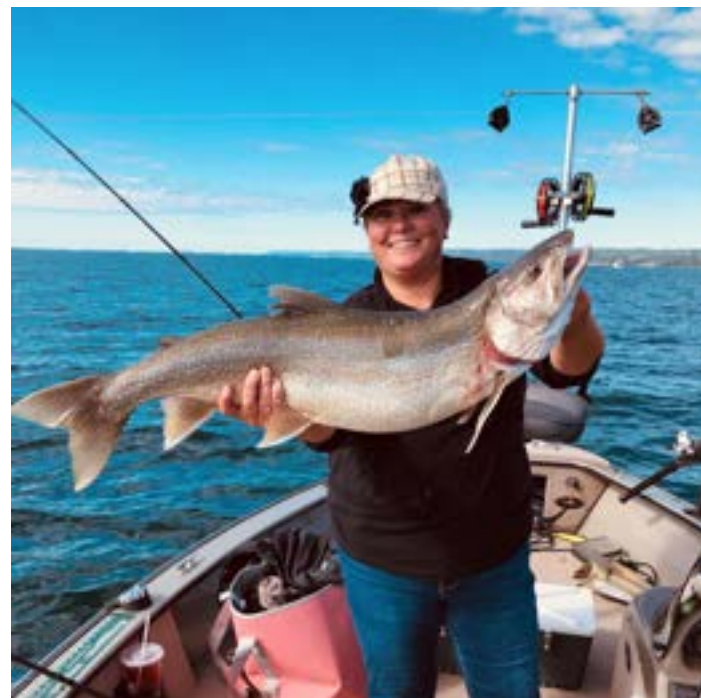
In her free time she loves to hang out with her animals (a herd of guinea pigs, chickens and more to come), work out, swim, travel and spend time with family.

LYNSIE RADOVICH, PHD

Research Manager

Lynsie is trained in Biochemistry and Molecular Biology and has years of experience coordinating clinical trials with the Medical School Duluth. While previously a bench scientist, she has pivoted her career to include expertise working with Institutional Review Boards, ensuring compliance and oversight for ongoing studies.

Lynsie grew up in the Duluth area and is happy to be able to live in a community she loves with her dog Gunnar. In the summer you can find her at the softball field or fishing on Lake Superior, and in the winter months ice fishing is a favorite hobby.



TEAM HIGHLIGHTS



VAL MATTISON

Community Advisory Group (CAG) Member

Val is a Program Developer through the Dancing Sky Area Agency on Aging. She lives east of Thief River Falls, and she covers six counties in NW MN. The counties include Beltrami, Lake of the Woods, Mahnomen, Pennington, Red Lake, and Roseau.

Her goal is to create and connect service provider networks to increase partnership and collaborations. She has three adult children and three granddaughters with another granddaughter due in May. She is excited to be a part of the CAG and to gain knowledge about the significance of people with dementia and their caregivers in rural areas.

FALL PHOTO CONTEST



Winner: Zayla Asquith-Heinz

Photo taken at the Boundary Waters between Gabbro Lake and Bald Eagle Lake
Thank you to all who submitted photos!

Your Research Team:

Memory Keepers Medical Discovery Team

Principal Investigators: Drs. Kristen Jacklin and Wayne Warry

UMN Medical School, Duluth Campus:

Dr. Amy Greminger
Dr. Catherine McCarty
Dr. Peter Nalin
Dr. Sandra Stover

UMN School of Public Health:

Dr. Joseph E. Gaugler
Dr. Carrie Henning-Smith

UMN School of Nursing:

Dr. Dereck Salisbury

Collaborator:

Dr. Stephen Waring, Principal Scientist,
Essentia Institute of Rural Health

Industry Partner:

Adam Sobol, Founder of CareBand

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Dr. Amy Otto
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Dr. Patricia Soderlund

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

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We invite you to join the CERDAR
Community

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