



### Introduction

Sid White, DPT, MPT, MBA
Assistant Division Director
920.869.6554
swhite1@oneidanation.org



### Housekeeping

**Meeting Format** 

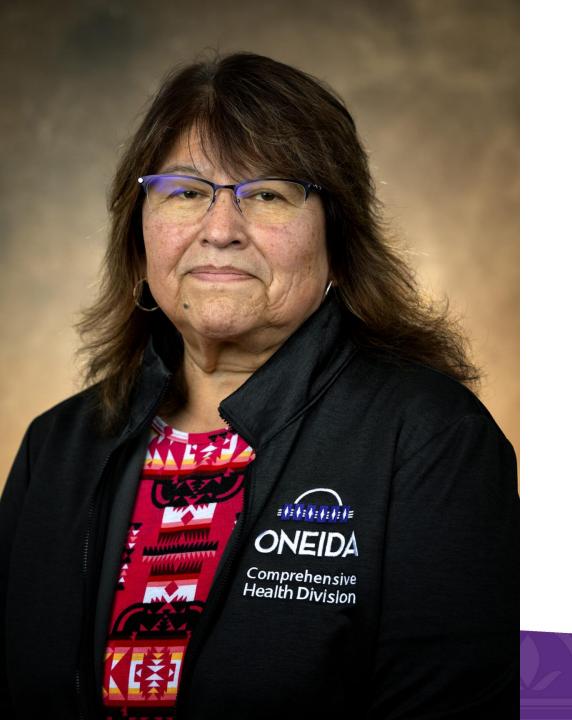
Streamed & Recorded

**Restroom Locations** 

**Light Meal** 

Staff Available to Assist





### Introduction

Debra J. Danforth, RN, BSN
Division Director
920.869.2711, ext. 4807
ddanfort@oneidanation.org



Vision: A Progressive Sustainable Health System That Promotes Tsi?niyukwalihot\( \text{(Our Ways)} \)

Mission: We Provide the Highest Quality, Holistic Health Care to Ensure Wellness for OUR Oneida Community

### Values:

Responsive Leadership Safety

Communication Culturally Sensitive

Trust is the Foundation Respect



### Five Principles Nation Building

Transformational Leadership Strategic Outlook

Strong Governing Systems Sovereignty

**Cultural Relevancy** 





### Introduction

Wendy Wolter, RN, WCC, BSN
Interim Continuum of Care Director
920.869.6746
wwagner@oneidanation.org



Connie Vandenberg 40 Years

**Betty Schwantes** 30 Years

Kelly Walenski 25 Years

Scott Lalonde 25 Years





Connie Vandenberg – 40 Years





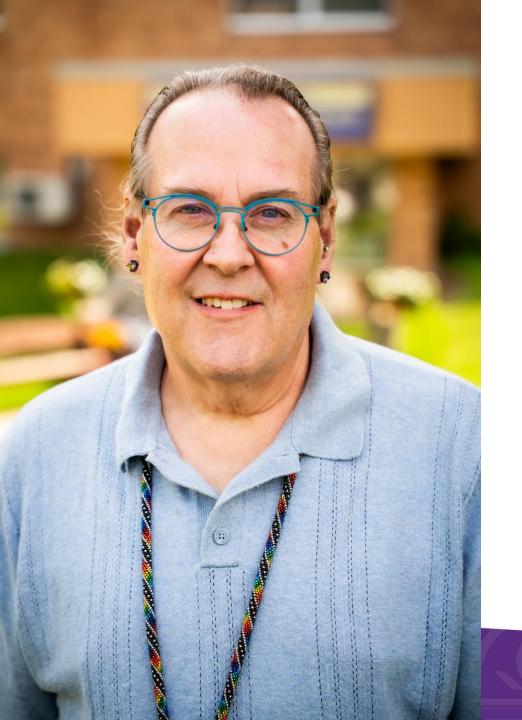
**Betty Schwantes – 30 Years** 





Kelly Walenski – 25 Years





Scott Lalonde - 25 Years







### McKenna L. Metoxen

**Student Intern - OCHD** 

University of Wisconsin-Madison (2028)

School of Nursing, certificate in American Indian & Indigenous Studies

mmetoxe8@oneidanation.org







### Margie M. Stevens

**OCHD Student Intern** 

**Business Marketing Major** 

Wisconsin Lutheran College (2027)

msteven1@oneidanation.org







### Donavin D. Laluzerne

**Student Intern - Pharmacy** 

University of Wisconsin-Madison (2028)

**School of Pharmacy** 

dlaluzer@oneidanation.org







### Kaya L. Danforth

Student Intern-Physical Therapy/ HPDP

University of Wisconsin- Green Bay (2028)

Human Biology with an Emphasis in Exercise Science

kdanfo15@oneidanation.org







### Carey Gleason, PhD, MS

Professor
University of Wisconsin
Division of Geriatrics
School of Medicine and Public Health

## LAND ACKNOWLEDGMENT and My Positionality

The University of Wisconsin–Madison occupies ancestral Ho-Chunk land, a place their nation has called Teejop (day-JOPE) since time immemorial.

In an 1832 treaty, the Ho-Chunk were forced to cede this territory.

Decades of ethnic cleansing followed when both the federal and state government repeatedly, but unsuccessfully, sought to forcibly remove the Ho-Chunk from Wisconsin.

This history of colonization informs our shared future of collaboration and innovation.

Today, UW-Madison respects the inherent sovereignty of the Ho-Chunk Nation, along with the eleven other First Nations of Wisconsin.



### In Our Time Together

- 1. History of Oneida Nation and UW Madison's Alzheimer's Disease Center Collaboration
- 2. Oneida Alzheimer's Community Advisory Board
- 3. Current projects
- 4. Proposed projects
- 5. Lots of time to address questions and hear your thoughts

### **Growth of Collaboration**

#### **Research Projects**

Greatest growth in this area. Currently 4 ongoing projects. One is complete, and 2 are proposed. First Project approved by BC in 2019

Funded to start CAB in 2017

Community

**Advisory Board** 

#### Veteran's Initiatives

Concerted efforts to bring services to Veterans began in 2022

Initiative to engage Veterans in Clinical Research started in 2020

Great Lakes Native
American Elder
Association
(GLNAEA)

#### **ONCOA**

Invited to talk about Alzheimer's disease 2015

### Conversation at Alzheimer's Conference

#### Spring 2015

Conversations started.

Visited Oneida to meet with ONCOA.

#### 2016-onward

Monthly CAB meetings. AIMS:

- Culturally tailored outreach
- Culturally competent diagnostics
- Survey families about caregiving needs (w/BC resolution)

2016

2017

2018

2019

### **Timeline**

March 2022 ICARE 5-year Project started

### May 2019

Applied for new funding for CAB

2020

#### Oct 2020

Oneida Helping Oneida Project started

2021

June 2022

AMICA Project started

2022

2024

#### **July 2016**

Applied for funding to support an Oneida Community Advisory Board (CAB)

#### Feb 2019

Sought BC Resolution for CAB

#### 2019-onward

Monthly CAB meetings. AIMS:

- Culturally tailored outreach
- Reach specific groups
- Reduce stigma
- Culturally competent diagnostics

Oct 2022

2023

ADRC Recruitment

approved

#### Oct 2015

Crossed paths with ONCOA members at a conference in AZ

**Sept 2018** 

ICARE 5-year Project started Summer/Fall 2024-25

NARCH application IBACS application COPES Project

### Goals of the Collaboration - the "Why"

Among racialized groups, American Indians are at high for dementia



Treatments Diagnosing Prevention



Recognizing the disease complex Bette

Better science

### Pause for Questions



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### **Growth of Collaboration**

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#### **Veteran's Initiatives**

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#### Community Advisory Board

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#### **ONCOA**

Invited to talk about Alzheimer's disease 2015





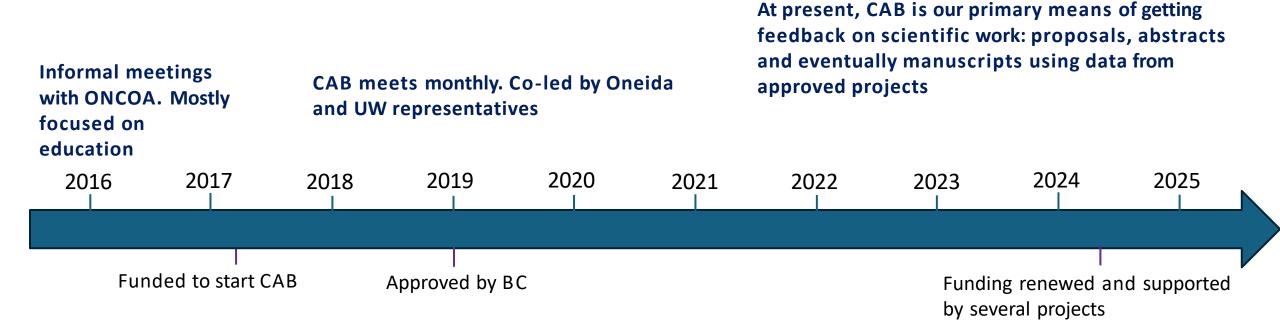
### Oneida Community Advisory Board (CAB)

Oneida Nation Alzheimer's Disease Community Advisory Board (CAB)

Oneida Business Committee Approved April 24,
 2019 - Resolution # 04-24-19-A

#### **GOALS:**

- 1) Guide a culturally tailored outreach, education and research.
- 2) Reach middle-aged adults, military Veterans and youth with Dementia Curriculum.
- 3) Work to reduce stigma associated with Alzheimer's and Related Dementias by providing outreach and education.
- 4) Continue efforts to optimize access to culturally competent dementia diagnostics





#### GOALS:

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### **Oneida CAB**

- Meets Monthly
- Standing agenda items include research, communications, clinical work

#### ONEIDA CAB BOARD MEMBERSHIP - CAB Approved March 2023

CAB Minutes Roll: List by representation area and title (e.g. alternate/board) for those present

Revised January 2025

#### CO-CHAIRS (March 2023-2026)

- Terry Hetzel (Oneida)
- Carey Gleason (UW)

#### **ONEIDA HEALTH CENTER (April 2023-2026)**

- Debbie Miller Dementia Coordinator Board
  - Providers representing Oneida Health Team (Rotating attendance)
    - Dr. Garstka
    - Dr. Lundin

#### Oneida Aging and Disability Resource Center (May 2023-2026)

- Schuyler Metoxen Board (Newly appointed)
- Jodi Tess Alternate

#### ONCOA (June 2023-2026)

- · Mary Jane Doxtator Board
- Sandy Skenandore Alternate

#### **ONEIDA VETERANS (July 2023-2026)**

- John Breuninger Board
- · Connor Kestell Alternate

#### **AFFILIATES:**

- 1. Jennifer Webster OBC Liaisons
- 2. James Bester UW Outreach
- 3. Fabu Carter UW Outreach
- 4. Mary Wyman UW Researcher
- 5. Danielle Lennon UW Wyman Lab Researcher
- 6. Taryn James UW Researcher
- 7. Yowelunh McLester-Davis UW Researcher
- 8. Lexi Nelson UW Gleason Lab Admin Support
- 9. Tracy Smith UW Gleason Lab Program Director
- 10. Jesse Montoure
- 11. Kyle Coniff

#### ONEIDA NATION & UW-MADISON (August 2023-2026)

- Melissa Metoxen (NACHP) Board
- Marlene R. Summers (ICARE) Board
- Lois Strong (ICARE) Alternate
- Sacheen Linda Lawrence (Outreach) Board
- TBD (Outreach) Alternate
- Kala Cornelius (AMICA) Board
- Carrie Trojanczyk (AMICA) Alternate

#### ONEIDA COMMUNITY (September 2023-2026)

- · Florence Petri (Community) Board
- Delora Cornelius (Community) Alternate
- · Cassandra Thomas (Caregiver) Board
- Linda Torres (Caregiver) Alternate

#### UW- MADISON (October 2023-2026)

- Nick Lambrou Board
- Megan Zuelsdorff Alternate

#### ONEIDA NURSING HOME (November 2023-2026)

- Wenona "Wendy" Wolter Board
- Karen Krause Alternate
- Jonathen Piontek Alternate



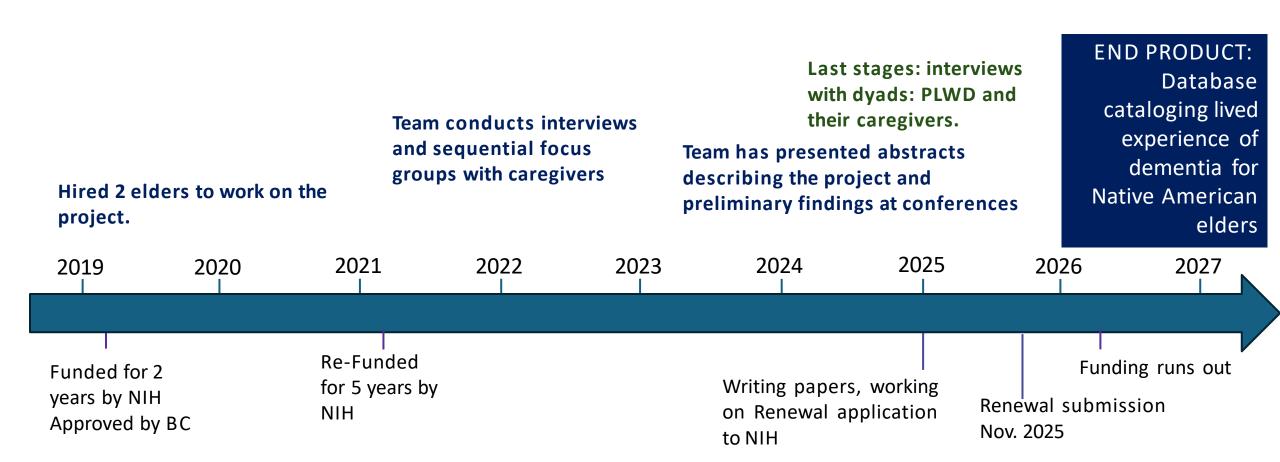
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### **ICARE** Project

Indigenous Cultural Understanding of the Alzheimer's Disease and Related Dementia Research and Engagement (ICARE) – Research Project

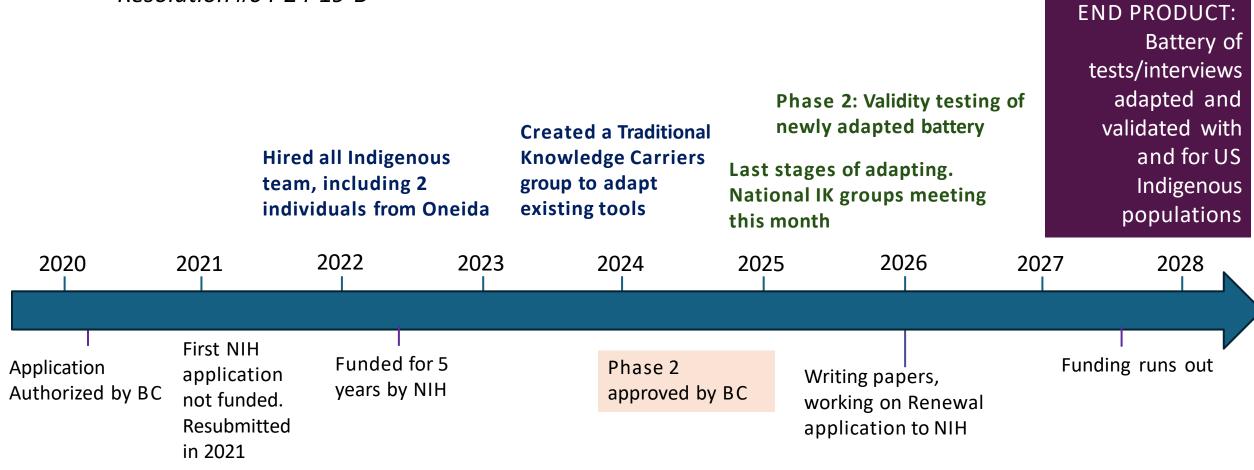
Resolution # 04-24-19-B



### **AMICA**

Addressing Alzheimer's Disease and Related Dementias Disparities: The American Indigenous Cognitive Assessment (AMICA) – Research Project

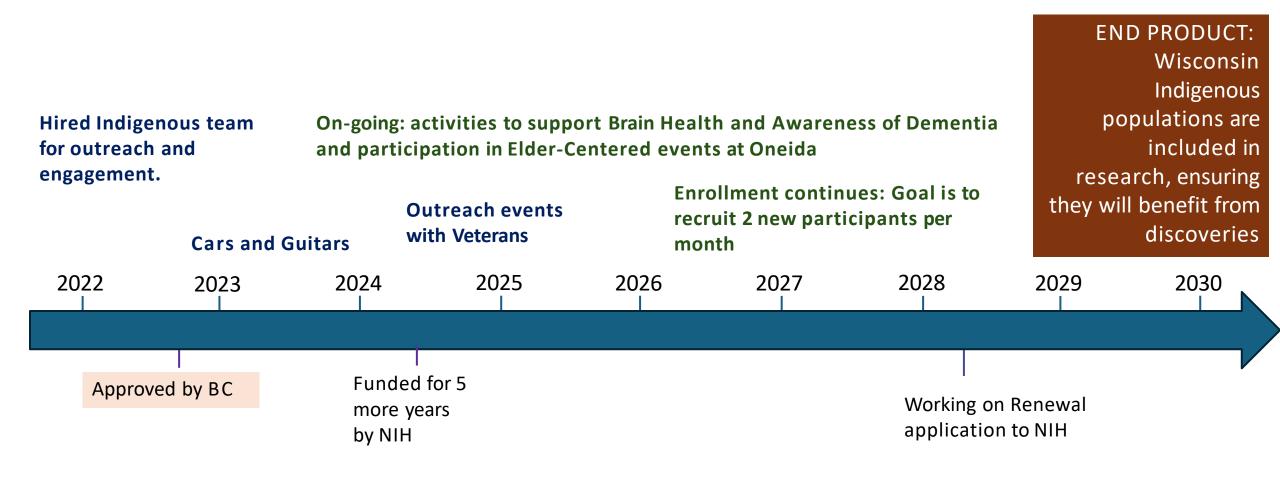
- Research authorization letter on Nov 4, 2020
- Resolution #04-24-19-B



### Wisconsin Alzheimer's Disease Research Center

Wisconsin Alzheimer's Disease Research Center Community Engaged Recruitment (ADRC Clinical Core) – Research Project

Resolution # 09-28-22-A



# Three Projects Looking for Volunteer Participants

ICARE: People caring for someone with dementia and their loved ones living with dementia

AMICA: People willing to complete a culturally safe memory checkup — starting this fall

ADRC Clinical Core: People willing to join a longitudinal project and complete annual memory check ups

### **Summary of Projects' Impact**



Oneida Community is helping direct the research (CAB)



Oneida Nation's lived experience of dementia is documented (ICARE)



Develop a diagnostic test that is validated to work for Oneida citizens (AMICA)



Oneida citizens are included in Alzheimer's research

# **Capacity Building**



HIRE FROM COMMUNITY



LOCATE IN COMMUNITY



WORK WITH ONEIDA BUSINESSES (E.G. CATERING, PRINTING)



SUPPORT ONEIDA AND INDIGENOUS LEADERSHIP



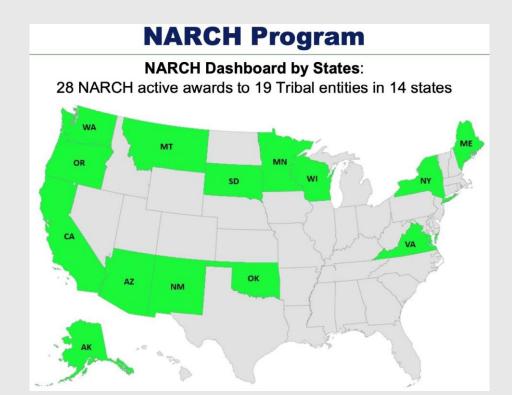
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# Collaboratio

### **Native American Research Centers for Health (NARCH)**

- Centers of Excellence funded by NIH
- Great Lakes NARCH Application Submitted
  - UW Madison supported Aim: Student Career Enhancement
  - PIs: Drs. Jeneile Luebke and Kala Cornelius
  - Goals: Culturally tailored student health and research experiences in tribal communities, Indigenous mentorship, and a community engagement research site
  - Notice of Awards ~ August 2025



### **IBACS**

Addressing Alzheimer's Disease and Related Dementias Disparities: The Indigenous Behavioral and Cognitive Symptom (IBACS) Checklists – *Research Project* 

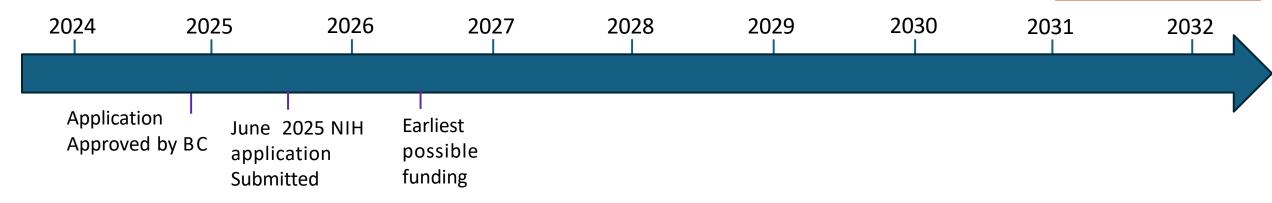
- Oneida Business Committee Approved November 13, 2024 Resolution #11-13-24-G
  - o PI: Kristen Jacklin, PhD University of Minnesota
  - MPI: Carey Gleason, PhD University of Wisconsin
  - MPI: Tassy Parker, PhD University of New Mexico

Idea: Adapt questionnaires that are helpful in detecting early symptoms of dementia

Will involve Indigenous Knowledge Keepers Advisory Group

Battery of tests/interviews adapted and validated with and for US Indigenous populations

**END PRODUCT:** 



### COPES

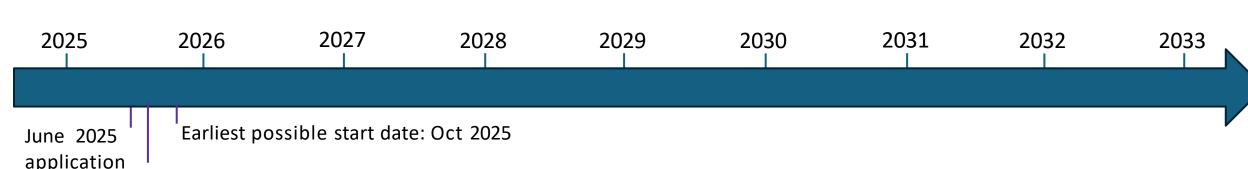
### **Community Placed Engagement Site – Service and Research Project**

• Oneida Business Committee will review on July 23, 2025 - Resolution # TBD

Idea: Generated by Oneida ADRC participants and endorsed by ONCOA

Goal: Bring research initiatives to Community, involve NARCH trainees

END PRODUCT:
Community located
and staffed site for
Training and
Research



Submitted Application reviewed by BC

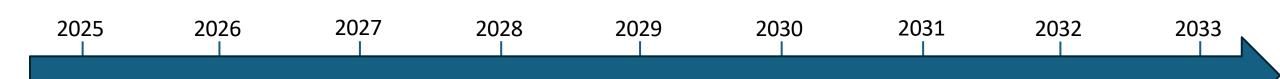
# In Development: DemDX

### **Community led Dementia Diagnostics**

not yet submitted to Oneida Business Committee

Idea: Have Tribe lead and benefit from new diagnostic technologies

END PRODUCT: Community-led dementia diagnostic infrastructure



November 2025 application due to NIH

# For All Collaborations - Priorities Include

- Serves Tribe's needs and goals
- Give first no strings
- Organic Advocacy Initiated by Oneida
- Capacity Building:
  - Indigenous leadership
  - Hiring from the community (Community researchers)
  - Involve Indigenous scholars and clinical trainees
- Data and sample sovereignty
- Cultural humility, safety and dismantling colonization

# Lots of Key Players – Many of Whom are Oneida

- Wes Martin\*
- Marlene Summers\*
- Gilda Ennis

**GLNAEA** 



- Kala Cornelius\*
- Carey Gleason
- Carola Ferrer Simo

**COPES** 



- Jeniele Luebke\* NARCH
- Kala Cornelius\* NARCH
- Megan Zuelsdorff STRIDE

School of Nursing NARCH



- Carey Gleason
- Lauren W.Y McLester-Davis\*
- Kala Cornelius\*
- Sacheen Lawrence\*
- Megan Zuelsdorff
- Melissa Metoxen\*

Alzheimer's disease Clinical Core ADRC



- Mary Wyman
- Sacheen Lawrence\*
- Jesse Montoure\*

Oneida Helping Oneida



- Marlene Summers\*
- Lois Strong\*
- Nick Lambrou
- Kala Cornelius\*
- Carey Gleason

**ICARE** 



- Carey Gleason
- Lauren .W.Y McLester-Davis\*
- Kala Cornelius\*
- Carrie Trojanczyk\*
- Cassandra Thomas\*

**AMICA** 



• TBD

Proposed: IBACS & DemDX





# Questions and Thoughts?



# **Extra Slides Covering**

- Dementia and Alzheimer's Disease
- Prevention Strategies
- Diagnosing

# Dementia? Mild Cognitive Impairment? Alzheimer's disease?

### **DEMENTIA**

General term for decline in thinking ability

Affect day to day function

### MILD COGNITIVE IMPAIRMENT

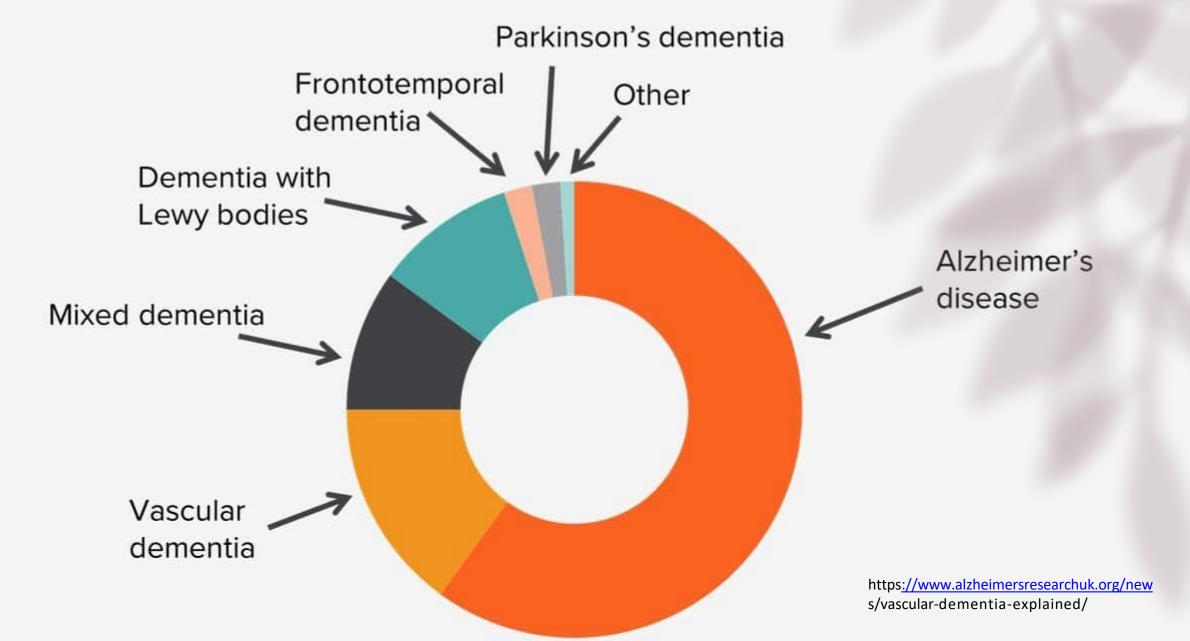
General term for decline in thinking ability

Does NOT affect day to day function

### ALZHEIMER'S DISEASE

Most common cause of these conditions

## **TYPES OF DEMENTIA**





### **Dementia**

An umbrella term used to describe a collection of brain diseases and their symptoms, which include: memory loss, impaired judgment, personality changes, and an inability to perform daily activities.



### Alzheimer's Disease

### Prevalence

60-70% of dementia cases

### Characterized by

Amyloid plaques and beta tangles.

### Symptoms include

Impairments in memory, language, and visuospatial skills.



### Vascular Dementia

### **Prevalence**

10-20% of dementia cases

### Characterized by

Disease or injury to the blood vessels leading to the brain.

### **Symptoms include**

Impaired motor skills and judgement.



### Frontotemporal Dementia

### Prevalence

10% of dementia cases

### **Characterized by**

Deterioration of frontal and temporal lobes of the brain.

### Symptoms include

Personality changes and issues with language.



### Lewy Body Dementia

### **Prevalence**

5% of dementia cases

### **Characterized by**

Lewy body protein deposits on nerve cells.

### Symptoms include

Hallucinations, disordered sleep, impaired thinking and motor skills.



### Other Dementias

### **Prevalence**

5% of dementia cases

### Dementias related to

- Parkinson's disease
- Huntington's disease
- HIV
- Crutzfeldt-Jakob disease
- Korsakoff syndrome

https://www.gardensofsuncity.com/wp-content/uploads/2022/02/dementia-infographic.jpg



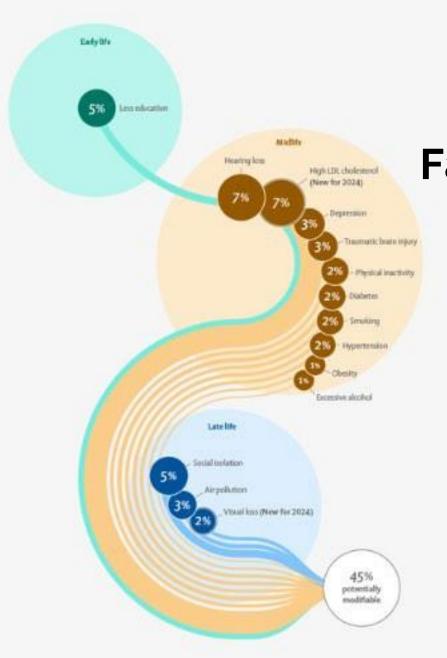
What Are The Risk- and Protective- Factors for Alzheimer's Disease and Related ementias?



### **NON MODIFIABLE RISK FACTORS MODIFIABLE RISK FACTORS** Sleep **Enviroment** Social isolation **Aging** Cognition inactivity Socioeconomic status Life Style **CNS Damage** Genetics Stress Depression Physical activity Hearing loss Alcohol Smoking Peripheral Damage Diabetes

Diabetes
Obesity
Dyslipidemia
Hypertension
Microbiota

https://content.iospress.com/articles/journal-of-alzheimers-disease-reports/adr220100



### Modifiable Risk Factors for Dementias

### THE LANCET

Dementia prevention, intervention, and care 2024

### **FACTORS LINKED TO DEMENTIA RISK**

### **EARLY LIFE**



MID-LIFE



### LATER LIFE





Quality of education 5%



Hearing impairment 7%



High cholesterol 7%



Depression 3%



Traumatic brain injury 3%



Physical inactivity 2%



Uncorrected visual impairment 2%

45% of risk is potentially modifiable



Diabetes 2%



Smoking 2%



High blood pressure 2%



Obesity 1%



Excessive alcohol 1%



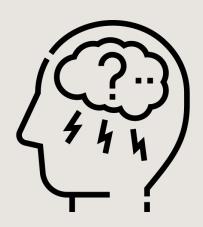
Social isolation 5%



Air pollution 3%

# How Do We Diagnose & Recognize The Condition?

# Diagnostic Visit

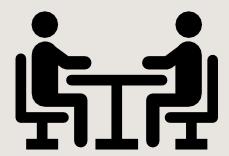


Someone expresses a concern



Brief medical and neurological exam

Interviews and Cognitive Testing



Some Blood Tests

Some Other Tests



# **Asking Two Questions**

### **DEMENTIA**

General term for decline in thinking ability

Affect day to day function

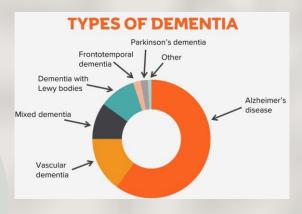
MILD COGNITIVE IMPAIRMENT

General term for decline in thinking ability

Does NOT affect day to day function







DOES THE INDIVIDUAL HAVE A COGNITIVE DISORDER?

WHAT DO WE THINK IS CAUSING IT?



# Treatment Developments

- Very effective in removing amyloid protein from the brain
- Effect on day-to-day outcomes more modest
- Don't have data yet on long-term effects
- Administered by infusion (immunotherapies)
  - Still difficult to access
  - Complications with treatment
- FDA approved: lecanemab (Leqembi) and donanemab (Kisunla)
- Treatments seem to work better if administered early in disease stages – before symptoms

# On Nyote? a · ka Core Values

Kalihwi yó (Galeeh-wee-yo)

The Use of the Good Words About Ourselves, Our Nation and Our Future.

Twahwahtsilay (Dwah-wah-jee-leye)
All of Us Are Family.

Yukwatsistay (You-gwa-jees-stai)
Our Fire, Our Spirit Within Each One of Us.

Kahletsyalúsla (Gahlay-ja-loo-sla)
The Heart Felt Encouragement of the Best in Each of Us.

Kanolukhwásla (Gano-loo-kwa-sla)
Compassion, Caring, Identity, and Joy of Being.

Ka<sup>9</sup>nikuhli yó (Ga-nee-goo-hlee-yo)
The Openness of the Good Spirit and Mind.

Ka<sup>9</sup>shatst\(\delta\)sla (Ga-stat-stuh-sla)
The Strength of Belief and Vision as a People.

# Yawiko

Questions, More Information, Comments:

Comprehensive Health Division - Administration

ohc\_admin@oneidanation.org (920) 869-2711 ext. 0