

# How about I come to you? Recruiting and Studying Diverse Research Samples in their Community

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UNIVERSITY OF MIAMI  
MILLER SCHOOL OF MEDICINE

COMPREHENSIVE CENTER  
for BRAIN HEALTH

# 1 Florida ADRC ORE Core



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Disparities reach beyond clinical care to include uneven representation of **Black, Latinx, Asian, and indigenous Americans** in Alzheimer's research in clinical trials

**Race, ethnicity, and socioeconomic status** are known to affect several aspects of the patient journey including:



Stigma



Cultural differences



Disease awareness and understanding



Ability to obtain a diagnosis



Disease management



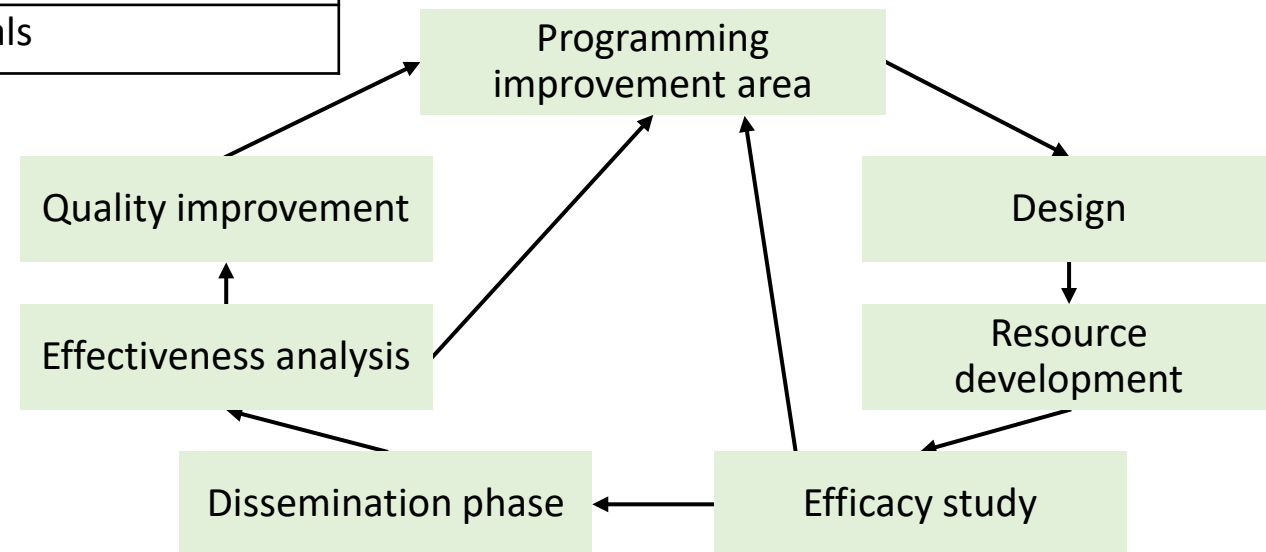
Access to care and support services

# Research Readiness and Partnering with Communities

Community Readiness Model: Stages and Goals	
Readiness stage	Goal to achieve for movement to next stage
No awareness	Raise awareness of the issue
Denial	Raise awareness of the relevance of this issue
Vague awareness	Raise awareness that something can be done
Preplanning	Raise awareness with concrete ideas to address the issue
Preparation	Gather existing information to help plan strategies
Initiation	Provide community with specific information
Stabilization	Stabilize efforts /program
Confirmation/expansion	Expand and enhance service
Professionalism	Maintain momentum and continue goals

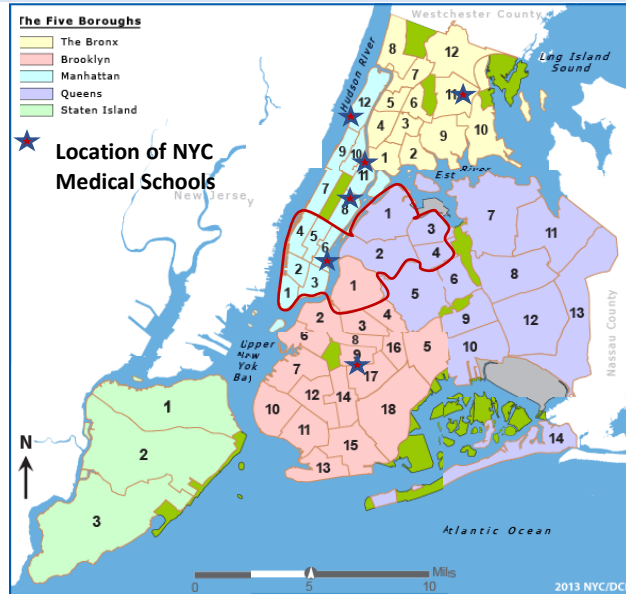
## Community-based participatory research framework

- Promote co-learning
- Iterative process
- Ecological perspective
- Disseminate information
- Long term commitment



# Engage the Community

## Know your community



**Race (%):** White=63.8; Black=6.4; Asian=21.6; Other=8.2

**Ethnicity (%):** Hispanic=28.4

**Age (%):** over 65=11.4

## Recruit your community

**These collective efforts increased overall under-represented group participation from 11.5% in 2004 to 17.5% in 2009 to 22.8% in 2014**

## Educate your community



## Engage your community





# Dementia Literacy Assessment (DELA)

## STORY

### Grandma's [Adapt] Story

I can clearly recall the first time I became worried about Grandma's [Adapt] memory. We were watching TV and she asked, "Who is that actor?" That was strange because this was our favorite program that we had been watching every Sunday night for years. What worried me even more was that after I told her the actor's name, she asked me the same thing over and over again.

My Grandma [Adapt] is 78 years old but lately has just seemed older than she used to. I used to think that being forgetful was just part of growing old. I now know that memory changes can be the first sign of dementia. After I noticed that she was forgetting names, I became aware of other things about Grandma [Adapt]. She forgot to go to the beauty parlor [Adapt], even though she never ever missed her hair appointment [Adapt] in the past. She quit making coffee [Adapt] that she had been making for years. When we asked her, she said "I just decided I don't want to drink coffee [Adapt] anymore." The truth was that she had trouble operating the coffee maker [Adapt]. She rarely cooked on her own, and if she did, she would just heat up soup from a can [Adapt]. She sometimes forgot to wear a coat on colder days or would put on a sweater in the heat of summer. She used to laugh and smile all the time, but now she often looked sad. She lost interest in knitting [Adapt] and playing cards [Adapt] with her friends.

We took Grandma [Adapt] to see the doctor for the first time in years. The doctor talked to Grandma [Adapt] for a little while and then asked her a bunch of questions, like remembering three words and asking her to make change from three dollars [Adapt]. I was really surprised when she remembered only one of the words and couldn't do math problems. She used to help me with my math homework. The doctor said that we should have brought her in sooner because he could have checked on her memory. He gave her a medicine that he said could slow down the symptoms. He talked about her diet, which wasn't the healthiest. Grandma has always been a little on the heavy side, and she did like her fried foods [Adapt]. The doctor told us that being obese increased the chance of getting dementia. He also said that eating healthy foods like fruits and vegetables could decrease the chance of getting dementia. The doctor helped us make plans about how we would take care of Grandma [Adapt] going forward. Before we left, I asked him if my mom [Adapt] and me would get dementia because Grandma [Adapt] had it, but he said that most times it happens because old age is a big risk factor, not because of our genes. I am happy to help take care of my Grandma [Adapt] because she would do the same for me.

### Readability Statistics

- **Flesch Reading Ease score:** 80.1 (text scale)  
Flesch Reading Ease scored your text: [easy to read](#).
- **Gunning Fog:** 8.5 (text scale)  
Gunning Fog scored your text: [fairly easy to read](#).
- **Flesch-Kincaid Grade Level:** 6.2  
Grade level: [Sixth Grade](#).
- **The Coleman-Liau Index:** 7  
Grade level: [Seventh Grade](#)
- **The SMOG Index:** 5.3  
Grade level: [Fifth Grade](#)
- **Automated Readability Index:** 6.4  
Grade level: [10-11 yrs. olds \(Fifth and Sixth graders\)](#)
- **Linsear Write Formula:** 8.1  
Grade level: [Eighth Grade](#)

Readability Consensus, Based on (7) readability formulas:

- **Grade Level:** 6
- **Reading Level:** [easy to read](#).
- **Reader's Age:** 10-11 yrs. olds (Fifth and Sixth graders)

## PRE/POST TEST

### DEMENTIA LITERACY ASSESSMENT

1. Forgetfulness is a normal part of aging  
True      False
2. Which of the following is NOT a risk factor for dementia?
  - a. Stroke
  - b. High blood pressure
  - c. Arthritis
  - d. Diabetes
  - e. Obesity
3. Changes in personality, behavior or mood may be an early sign of dementia  
True      False
4. Which of the following MAY reduce the risk of dementia?
  - a. Exercise
  - b. Eating healthy
  - c. Socializing
  - d. Keeping mentally active
  - e. All of the above
5. Dementia usually runs in the genes of families  
True      False
6. Which of the following is NOT an early sign of dementia?
  - a. Repeating the same questions over and over
  - b. Getting lost while driving in familiar places
  - c. Trouble making decisions and figuring things out
  - d. Loss of vision
  - e. Loss of interest in hobbies
7. Doctors can check for memory during an office visit  
True      False
8. Which of the following is the GREATEST risk factor for dementia?
  - a. Family history
  - b. Smoking
  - c. Age
  - d. Air pollution
  - e. Aluminum pots
9. There are treatments that can reduce the symptoms of dementia  
True      False
10. Dementia is the same thing as Alzheimer's Disease  
True      False
11. Which of the following is NOT associated with dementia?
  - a. Trouble finding the right word
  - b. Difficulty moving arms or legs
  - c. Difficulty operating household items
  - d. Forgetting appointments
  - e. History of head injury and concussions
12. Getting an early diagnosis can help me, my doctor, and my family better plan for the future  
True      False

# Outreach



## BOOST YOUR BRAIN HEALTH IN A BOOK CLUB

Join in the fun!  
Deerfield Center for Active Aging  
227 NW Eller St,  
Deerfield Beach, FL 33441  
Space is limited. Register at 954-480-4449.



Book Club Meets on Tuesdays  
1/10, 1/17, 1/24, 1/31 at 1:00 - 2:00 PM

Hosted by Rebecca Smither, MS, CHES  
UNIVERSITY OF MIAMI  
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for BRAIN HEALTH

**Nourish your Brain  
with the Art of Origami**  
Free workshop for adults 50 years old and older.  
Join us at the library for a beginner workshop in paper folding.  
Learn how origami supports your brain health, it's history,  
fold types and techniques, and construct models.

Have fun and learn something new!

Wed, 5/10/23 10:00-11:00 AM  
at Boynton Beach City Library  
In the Florida room.  
100 E. Ocean Ave  
Boynton Beach, FL 33432



REGISTRATION is required with library.  
Space is limited.  
Register by phone or web.  
Library Phone: 561-742-6390  
Web: <https://bbfpl.libcal.com/event/10565769>

WORKSHOP PRESENTED BY:

UM Comprehensive Center for Brain Health  
7700 W. Camino Real, Suite 200,  
Boca Raton, FL 33433  
561-869-6808

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Music connects us all!  
Experience the benefits of drumming, enhance cognition, regulate mood, reduce stress, release emotion, and release physical energy.

**'Feel Good Drumming'**  
with  
**Mind & Melody**  
Instructed by Eric Guffan, Program Director

Tuesday, October 17th @ 10:30 - 11:30 AM  
at Volen Senior Center  
1515 W. Palmetto Park Rd, Boca Raton, FL 33486

Workshop is for adults 50+ years old. No cost. No experience required.  
Registration is required. Space is limited.  
Register directly with the Volen Center, call 561-395-8920

Join a fun workshop of rhythm and beats including drumming meditation and activities to brighten your day, connect with others, and learn a new self-care activity for coping with day-to-day stress and emotion.

Workshop contact is Rebecca Smither, CCBH Outreach Coordinator  
Phone: 561-869-6823 | Email: [rxs1947@miami.edu](mailto:rxs1947@miami.edu)

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**Learn the Art of Zentangle**  
Monday, Nov 13, 2023 @ 3:00 - 4:00 PM  
A free art workshop for adults 50+ years old.

Experience a relaxing and fun drawing technique to create beautiful, unreplicated, abstract images with structured patterns.  
Draw with black ink on miniature white paper tiles.  
Express your creativity, and the possibilities are endless!

Zentangle benefits include improved focus, imagination, fine motor skills, and increased personal well-being. Zentangle is not about sketches that are right or wrong. Instead, it is the process that matters.

Zen - state of mind where emotion or thought does not bind you.  
Tangle - patterns of dots, lines, basic curves, S-curves, and orbs.  
Instructor: Robert Eng

Workshop hosted by  
**MIND & MOBILITY**  
Home Care Centers  
Workshop Address: 6018 SW 18th St, Boca Raton, FL 33443

Registration is required.  
Contact Rebecca Smither, Outreach Coordinator  
Comprehensive Center for Brain Health  
561-869-6823 | [rxs1947@miami.edu](mailto:rxs1947@miami.edu)

Building A Better Brain

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**Ageless Grace®**  
A Seated Exercise Class With  
**POMPEY PARK SENIOR CLUB**

DATE: Wednesday, September 20, 2023 @ 10:30 - 11:30 AM  
LOCATION: Pompey Recreation Center  
ADDRESS: 1101 NW 2nd St., Delray Beach, FL 33444  
PHONE: 561-243-7356

Ageless Grace® is a brain fitness program based on neuroplasticity by activating 5 functions of the brain - strategic planning, memory/recall, analytical thinking, creativity and imagination, and kinesthetic learning. It simultaneously addresses 21 physical skills needed for lifelong optimal functions.

REGISTRATION REQUIRED  
Contact: Rebecca Smither, Outreach Coordinator  
Comprehensive Center for Brain Health

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**NEUROGRAPHIC ART**  
A NEW LINE. A NEW NEURAL PATHWAY

NEUROGRAPHIC ART CREATES A MINDFUL, MEDITATIVE, EXPERIENCE THROUGH THE CREATION OF NEW NEURAL CONNECTIONS WHEN ENGAGING IN THIS ART. ITS TECHNIQUES LOOSEN AND REDIRECT THE HABITUAL THOUGHT PATTERNS AND NEUROPLASTICITY MEETS A NEW WAY OF THINKING.

Join our workshop to experience vast creative freedom, new artistic expression, and positive changes due to neurographic art's simple but positively impactful technique that requires no previous art experience. Workshop is at no charge and offered to adults 50+ years old.

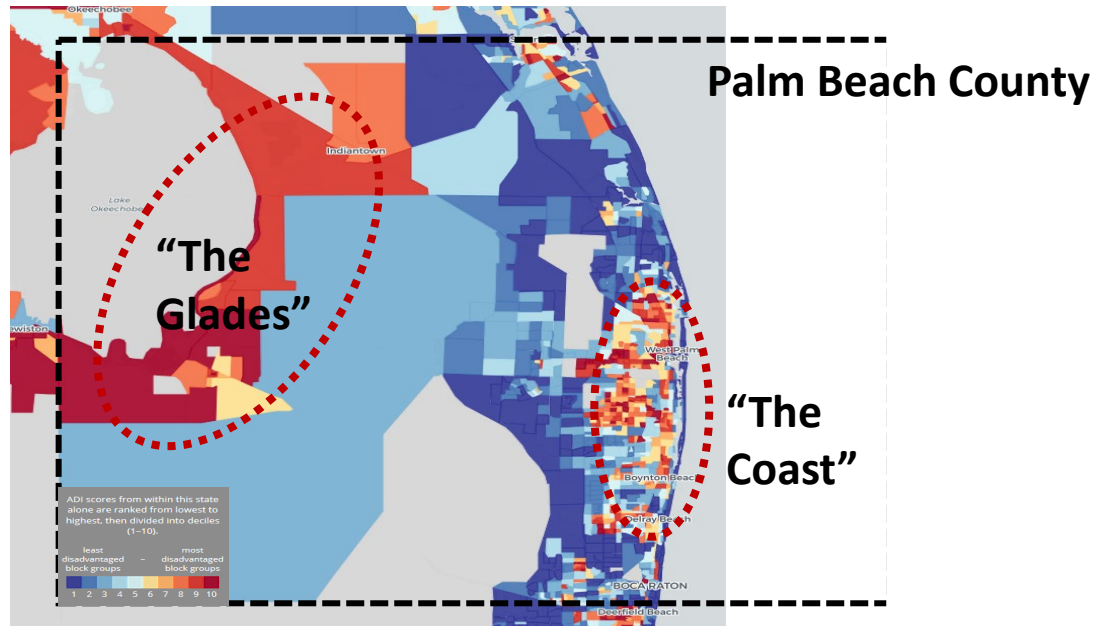
Friday, Nov. 10th @ 11:00 - 12:00  
In-Person or Virtual by Zoom

Registration required. Contact: Rebecca Smither, Outreach Coordinator  
Phone: 561-869-6823 | Email: [rxs1947@miami.edu](mailto:rxs1947@miami.edu)  
Workshop location: Comprehensive Center for Brain Health  
Address: 7700 W. Camino Real, Suite 200, Boca Raton, FL 33433  
Instructor: Lindsey Weaver, ATR-BC, Art Therapist University of Miami Sylvester Cancer Support Services

Building A Better Brain



# Detecting VCID and ADRD in Rural Florida



- To date, >350 individuals enrolled
  - Dementia Screening
  - UDS “Lite” assessment
  - GWAS
- Mean age  $73.1 \pm 9.7$
- 71.1% Female
- 55.3% Black, 9.6% Hispanic
- Mean AD8 score  $2.7 \pm 4.7$
- Mean QDRS score  $1.6 \pm 2.4$

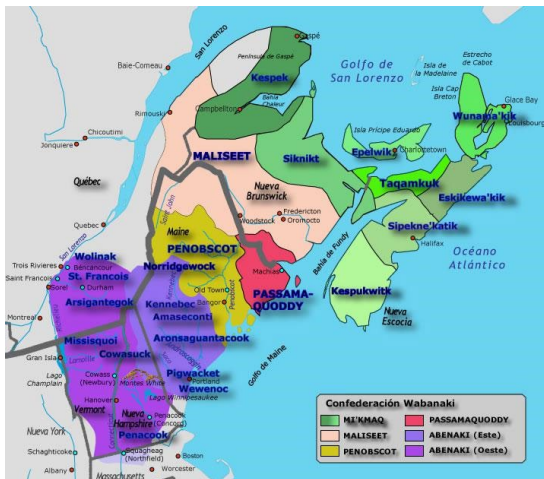
# Reaching Indigenous Populations



- First Program Project grant to focus on Indigenous populations
  - American Indian
  - Alaskan Native
  - Native Hawaiian and Pacific Islanders
- Three clinical trials
  - Clinic education
  - CPAP adherence in OSA
  - Hula for SCI
- Genetics



- Situated in the heart of the South Pacific, American Samoa is the only U.S. territory located south of the equator.
- First population-based ADRD assessment
  - 46,366 residents
  - 11,025 (23.8%) age 50 and over
- Dementia Literacy
- Dementia Screening
- UDS Gold Standard
- Genetics
- Plasma ADRD Biomarkers



- Native American Research Center for Health
- Wabanaki Confederation in Main
- Community Needs Assessment
- Dementia Screening
- UDS Gold Standard



# Engagement Event: Brain Train

- All-day event with presentation, discussion, hands-on activities and interactive stations
- Informed consent and biospecimen use
  - Learn about *APOE* and collect saliva samples for DNA
- Learn about ADRD
  - Videos
  - Examine whole brains and coronal slices from normal and ADRD brains
  - View slides stained for amyloid and tau from normal and ADRD brains
- Healthy Body, Healthy Brain event
  - Body mass index, Blood pressure, Grip strength, Gait and Balance
- Cognitive Assessment
- Culturally tailored information on ADRD research
- Receive “Native Brain Expert” certificate

Participant Name: \_\_\_\_\_ Date: \_\_\_\_\_

Height: \_\_\_\_\_ Weight: \_\_\_\_\_ Body Mass Index (BMI): \_\_\_\_\_  Low  Normal  High

Blood Pressure: \_\_\_\_\_  Low  Normal  High Pulse: \_\_\_\_\_  Low  Normal  High

**Cognitive Performance:**

Your performance today is consistent with: \_\_\_\_\_

**Domains Affected:**

- Learning and Memory (free recall, cued recall, recognition memory, autobiographical long-term memory)
- Attention & Concentration (sustained, divided, and selective attention, processing speed)
- Executive Function (planning, decision-making, working memory, inhibition, flexibility, responding to feedback)
- Language (object naming, word finding, fluency, grammar and syntax, receptive language)
- Perceptual-motor control (visual perception, visuo-constructural reasoning, hand-eye coordination)

Test	Normal Range	Score Today	Test	Range of Scores	Score Today
<b>Tests of Memory</b>			<i>Higher Scores Are Better:</i>		
AD8 – Subjective	Less than 2		Applied Mindfulness Scale	0-60	
Montreal Cognitive Assessment	24 or greater		MIND Diet	0-15	
Hopkins Delayed Recall	8 or greater		Quick Physical Activity Rating	0-153	
<b>Tests of Language</b>			Cognitive & Leisure Activity Scale	0-80	
Animal Naming	20 or greater				
Multilingual Naming Test	29 or greater		<i>Higher Scores in these categories helps build a stronger brain by staying physically fit, mentally active, socially engaged, practicing mindfulness, and eating a brain and heart healthy diet.</i>		
<b>Tests of Attention and Executive Function</b>					
Trail Making B	Less than 70				
Number Symbol Coding Test	44 or greater				

Test	Normal Range	Score Today	Performance	Findings
<b>Tests of Physical Performance</b>			Walking Speed	<input type="checkbox"/> Normal <input type="checkbox"/> Slow
Timed Up and Go	Less than 10		Strength (Grip)	<input type="checkbox"/> Weak <input type="checkbox"/> Normal <input type="checkbox"/> Strong
Mini Physical Performance	12 or greater		Lean Muscle Mass	<input type="checkbox"/> Normal <input type="checkbox"/> Low
<b>Tests of Mood</b>			% Body Fat	<input type="checkbox"/> Normal <input type="checkbox"/> High
HADS-Anxiety	Less than 11		Falls Risk	<input type="checkbox"/> Low <input type="checkbox"/> High
HADS-Depression	Less than 11		Frailty	<input type="checkbox"/> Present <input type="checkbox"/> Absent

**Results/Reports to Pick Up** (pick up at next visit, or at least 2 weeks from today)

Only results listed below will be shared with you

- WatchPat Sleep Study  Labs- Blood work  Audiometry- Hearing Test

We recommend that you share these results with your primary care doctor for further management.

Thank you for your participation!

Discussant: \_\_\_\_\_ Signature: \_\_\_\_\_

**REFERRALS**

- \_\_\_\_\_ Comprehensive Center for Brain Health: 561-869-6808
- \_\_\_\_\_ Division of Cognitive Neurology, University of Miami: 305-243-1664
- \_\_\_\_\_ Florida Memory Disorders Clinic (<https://elderaffairs.org/wp-content/uploads/2022-MDC-Map.pdf>)

**PRIMARY CARE OPTIONS**

- |   |  |  |
|---|--|--|
| _____ UHealth at Boca Raton<br>3848 FAU Blvd, Suite 305<br>Boca Raton, FL<br>561-455-3627     | _____ UHealth at Fort Lauderdale<br>4800 NE 20 <sup>th</sup> Terrace, Suite 201<br>Ft Lauderdale, FL<br>954-772-2200 | _____ UHealth at Plantation<br>8100 SE 10 <sup>th</sup> Street<br>Plantation, FL<br>305-243-4000 |
| _____ Delray Beach Health Center<br>225 S Congress Avenue<br>Delray Beach, FL<br>561-274-3100 | _____ Edgar Mills Health Center<br>900 NW 31 <sup>st</sup> Avenue<br>Ft Lauderdale, FL<br>954-467-4700               |  |

**RECOMMENDATIONS/RESOURCES**

**Nutrition:**

- \_\_\_\_\_ Heart healthy diets such as Mediterranean or MIND diet
- \_\_\_\_\_ [www.usda.gov/topics/food-and-nutrition](http://www.usda.gov/topics/food-and-nutrition)
- \_\_\_\_\_ [www.cdc.gov/nutrition/index.html](http://www.cdc.gov/nutrition/index.html)
- \_\_\_\_\_ Examples of healthy recipes can be found at [www.platejoy.com](http://www.platejoy.com)

**Activity:**

- \_\_\_\_\_ Physical Activity (daily walking, stretching, pool exercises)
- \_\_\_\_\_ Cognitive stimulation (puzzles, books, hobbies, sudoku, crosswords)
- \_\_\_\_\_ Re-visit an activity you liked in the past (painting, drawing, music, dancing, gardening)
- \_\_\_\_\_ Silver sneakers (<https://tools.silversneakers.com>)
- \_\_\_\_\_ YMCA (<https://www.ymca.org>)
- \_\_\_\_\_ Join local Community Center(s)

**Computerized Cognitive Activities:**

- \_\_\_\_\_ BrainHQ ([www.brainhq.com](http://www.brainhq.com)), Lumosity ([www.lumosity.com](http://www.lumosity.com)), NeuroNation ([www.neuronation.com](http://www.neuronation.com)), Brain Metrix ([www.brainmetrix.com](http://www.brainmetrix.com))

**Mindfulness and Wellness Activities:**

- \_\_\_\_\_ Try Yoga, Meditation, Deep Breathing Exercises, or Tai chi
- \_\_\_\_\_ Acupuncture or acupressure
- \_\_\_\_\_ Phone apps: Healthy Minds Program, UCLA Mindful, Smiling Mind
- \_\_\_\_\_ Websites: Headspace ([www.headspace.com](http://www.headspace.com)) or Zenfie ([www.zenfie.com](http://www.zenfie.com))
- \_\_\_\_\_ A free on-line mindfulness-based stress reduction course is available at [www.palousemindfulness.com](http://www.palousemindfulness.com).

**Sleep:**

- \_\_\_\_\_ On-line resources include [www.aurahealth.io](http://www.aurahealth.io), [www.calm.com](http://www.calm.com), and [www.thesleepreset.com](http://www.thesleepreset.com).

**Legal and Safety:**

- \_\_\_\_\_ Advance Care Planning
- \_\_\_\_\_ Durable Power of Attorney/Guardianship

**Educational and Support:**

- \_\_\_\_\_ Alzheimer's Association Southeast Florida Chapter: Palm Beach (561) 967-0047; Broward (954)786-1533; Miami Dade (305)835-2451; <http://www.alz.org/seflorida/>
- \_\_\_\_\_ Alzheimer's Community Care: (561)683-2700; <http://www.alzcare.org>
- \_\_\_\_\_ Alzheimer's Foundation of America: (866) 232-8484; <http://www.alzfdn.org/>
- \_\_\_\_\_ Alzheimer's Disease Education and Referral Center: <http://www.nia.nih.gov/alzheimers>
- \_\_\_\_\_ Lewy Body Dementia Association: (800) 539-9767; <http://www.LBDA.org>
- \_\_\_\_\_ Lewy Body Dementia Resource Center: (516) 218-2026; <http://www.lewybodyresourcecenter.org>
- \_\_\_\_\_ Association for Frontotemporal Degeneration: (866) 507-7222; <http://www.theaftd.org>

# Other Ways of Giving Back

Procedure	Reimbursement
Nasal Swab	\$25
Saliva	\$25
Blood Donation	\$50
Brain MRI	\$75
PET scan	\$125
DAT/SPECT scan	\$125
MIBG Cardiac Scintigraphy	\$125
Skin Biopsy	\$150
Lumbar Puncture (LP)	\$200

## Bring a Friend Incentive

- \$20 per referral that enrolls

## Provide Food and Giveaways

- The power of “Breaking Bread”

## Compensate Collateral Sources

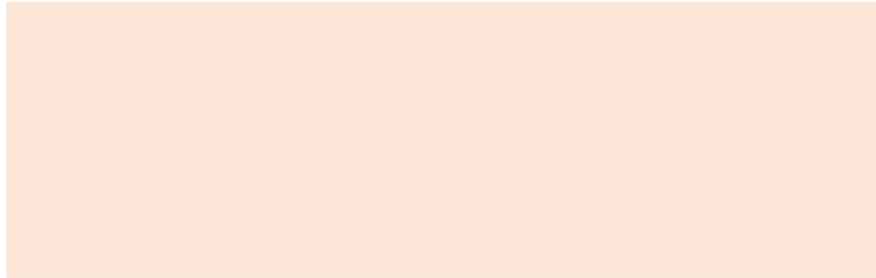
- \$25 for completing assessment

## Offer Tours of Research Center

- Invite “anyone and everyone”



# Cross-Cultural Manual



Manual: Cross-Cultural Considerations



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# Summary

- Participants from all backgrounds are willing to participate in research, if offered the opportunity
- Through a multi-pronged approach, we have been able to engage, educate and recruit a diverse multicultural cohort into our studies
- Taking a “Healthy Body, Healthy Brain” approach is an attractive option across different cultures and communities
- Important to:
  - Go to communities
  - Give back to communities