

Message from Dr. Jennifer O'Brien, PACT Study Principal Investigator

Since the **PACT** Study started in 2021, there have been many changes in the world. Together, we have made our way through a pandemic and some rough hurricane seasons. Many of us (study staff and participants) have changed addresses or relocated to totally new areas. **PACT** has also experienced some study site changes. Both the University of North Florida (UNF) in Jacksonville, FL, and the Roskamp Institute in Sarasota, FL, closed as study sites in 2024 and the beginning of 2025. However, **PACT** has weathered these changes well. The University of Florida (UF) opened an additional study site in Jacksonville to work with all the UNF participants. The University of South Florida (USF) is serving all the Roskamp Institute participants with its location in Sarasota.

As time moves forward and life takes you in different directions, we hope you continue your **PACT** study journey. Almost 2000 participants have completed the 3-year follow-up visit and we anticipate completing another 5000+ between now and January 2028. If life's disruptions have slowed down or halted your brain training, your completion of the 3-year visit remains vital to the study's success. If you have moved, know that we will happily see you for your 3-year visit at other study locations. Every single participant's contribution is invaluable and together we are making an im**PACT**.

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Research Matters

The Value of Blood Tests in Alzheimer's and Dementia Research

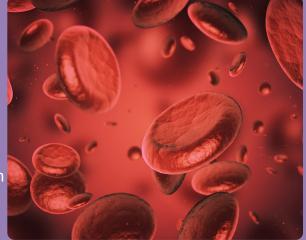
Blood tests are becoming an exciting tool in Alzheimer's and dementia research. They can reveal valuable information about brain health and are quicker, safer, and less invasive than other procedures. By studying blood, researchers can learn more about risk, track changes over time, and test new treatments that may one day help prevent and/or cure cognitive impairment and dementia.

"Your blood sample today could help unlock answers for tomorrow."

Understanding APOE

One focus of this research is a gene called APOE. Everyone has it, but some versions raise

the risk of developing Alzheimer's while others may lower it. Learning about APOE helps explain why some people are more vulnerable to the disease than others. Check out the <u>National Institute of Health's Alzheimer's Disease Genetics Fact Sheet</u> for more information.



What are Biomarkers?

Another focus is on blood-based biomarkers, which are proteins and other substances in blood that provide clues about what is happening in the body and brain. Certain biomarkers indicate the buildup of harmful proteins and can be detected before

observable symptoms appear. Dementia-specific biomarkers can be used to (1) determine if a person is at high risk of developing Alzheimer's or a related dementia, (2) help properly identify the cause of observable cognitive symptoms such as memory loss, and (3) determine if a person may benefit from specific types of treatment. Check out this video, Biomarkers and How they Help Diagnose Dementia, by the National Institute on Aging (Only available in English).

How PACT Participants are Contributing

Through the PACT study and in partnership with the **National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD)**, participants are asked to give a blood sample at or after their first visit and again at the 3-year visit. These samples are used to study Alzheimer's-associated blood-based biomarkers and to determine APOE genotype. These deidentified samples are also stored for future research, paving the way for innovative discoveries—perhaps even a cure!

Your participation in PACT helps researchers move closer to earlier detection, better treatments, and, ultimately, prevention.

Is there content you would like to see featured in our next newsletter? Please send to MCOM-SAGEmarketing@usf.edu with subject line "Newsletter Ideas"

Common Questions

Will I see the results of biomarker blood tests?

The blood draw is an important part of research studying the early detection of Alzheimer's disease and related dementia. While we cannot provide the results to you, we hope this will contribute to knowledge to help future individuals. The blood samples will not be connected to your name and will be processed after all samples are collected at the end of the five-year project period. The blood tests we are completing are in development. There is not yet a sufficient amount of conclusive, generalizable data to tell us what the numbers or results from these blood tests mean. The data we collect will help scientists to determine if these blood tests may be indicators of health that could be used in the future. You will be contributing to this science. We will share with you the results of the study overall which will be available in about 7-10 years from study start (approximately 2028-2030).

Will I see the results of APOE genetic tests?

We will not be providing individual APOE genotype results as this information is being collected strictly for research purposes within the context of the PACT clinical trial. If you would like to know your genetic risk for Alzheimer's disease, consider speaking with your health care provider who can discuss with you the clinical benefit of this information and answer any questions you have. Persons with certain genes are at higher risk for Alzheimer's disease. However, if you have the gene, it does not mean that you will get Alzheimer's disease, just that your risk is greater. For more information, check out the Mayo Clinic's Alzheimer's genes: Are you at risk? (Only available in English).

I am not sure that I am comfortable with NIH and/or NCRAD having my biological samples. Is it secure?

We understand that it may be uncomfortable sharing your biological samples with the study, but we follow procedures to ensure your identifying information is strictly concealed. Samples are identified solely by your participant study number. No identifying information such as name or DOB are sent to NCRAD with the provided sample. Once the samples are received at NCRAD, access to the deidentified study samples is tightly controlled.

Stakeholder Spotlight



Meet the Team - Tarneisha Hundell, Jacksonville, Florida

Meet Tarneisha Hudnell, Project Manager I, who serves as the PACT study site supervisor at both University of Florida sites in Jacksonville, FL, one on each side of the St. John's River - Downtown and East Jacksonville near Kernan and J. Turner Butler Blvd. She is a Jacksonville native who bleeds DUUVVAAAL. She remembers a Jacksonville, the largest city by land area in the contiguous United States, with only two-lane highways running through it instead of the 6-8 lanes today. She has traversed the seven bridges of the St. John's River countless times.

With a Bachelor of Science in Health Science form Florida A&M as well as a Master of Science in Health Informatics from Jacksonville University, Tarneisha is passionate about healthcare. She loves how research helps move forward the quality of healthcare. Tarneisha enjoys being a part of the PACT study and running clinical trial sites that serve participants across seven counties in Northeast Florida as well as other participants who travel down from Georgia. She sees how well UF Health is positioned throughout the region, which accommodates two study sites in Jacksonville. She knows that the diverse community of Northeast Florida is better represented in the PACT study because study team members can see people at the site that works better for them. Better representation means that what we learn from clinical trials, like the PACT study, is more broadly applicable across the entire population. Better science for all improves healthcare for all and Tarneisha is proud to be a part of such science.

Participant Perspective

Don't simply sit on the shore of your life; get busy jumping into the waves! That is both a core memory from youth and a lifelong philosophy of Dianne, a PACT study participant in Northeast Florida, who recently completed her 3-year study visit.

Dianne joined the PACT study 3 years ago after seeing an advertisement and deciding

that this research was worth her time. Dianne had seen what losing one's memory was like from time she had spent volunteering in nursing homes. She made a promise to herself to do what she can to age well. She does not want to lose her memory as she ages.

Just as the ocean has a powerful pull, staying busy can be a force that draws you into productive activities. Embracing that pull allows you to achieve great things. As Dianne moved into her retirement years, she was aware that she would have a lot of free time and did not want that to take a toll on her well-being. She has made a promise to herself to stay engaged. Staying occupied with her volunteer work with a local hospital twice a week keeps her connected with the community and provides her the opportunity to help others. Dianne's participation in the PACT study has also been a welcomed addition to her daily activities. She made a personal commitment to herself to do some of



the brain training exercises every single day over the last 3 years--much more than the expected 2-3 times a week for about an hour during the initial, 1-year, and 2-year training periods. Dianne trusted that such an undertaking would help preserve her brain health and strengthen her memory. She is proud that she missed very few days over the 3 years. In fact, she found the training so valuable that she intends to keep doing the brain training as long as she has access. She is also looking at adding new activities, like Mahjong, that she finds interesting and challenging into her daily routine. She fully embraces being busy with meaningful and impactful pursuits.

PACT is the first research study in which Dianne has chosen to participate, but she does not think it will be her last! She is open to participating in other university-based research once she completes the PACT study. She believes that the commitment that you have to your health is key to your overall happiness. She will continue to live her life looking for waves to jump in!

Thank you for your contribution and commitment to the fight against dementia, such as Alzheimer's disease.

For updates on the PACT study, visit www.PACTstudy.org or follow us on Facebook