NEWSLETTER

SUMMER 2025

COMMUNITY EVENT

Around 90 attendees from our research community gathered to engage with the latest in Alzheimer's science, share questions, and strengthen connections. See highlights and photos. p.2

GENETIC RISK SCORES

Learn what polygenic risk scores are, how they may help assess Alzheimer's risk, and how this emerging science could one day support more personalized care and prevention. p.4

Community, Science, and the Future of AD

Around 90 attendees gathered to explore the latest in Alzheimer's research, brain health, and the power of community participation

COMMUNITY FORUM ON ALZHEIMER'S DISEASE RESEARCH: UNDERSTANDING, DIAGNOSING, AND ADVANCING TOWARD A CURE

Our recent Alzheimer's research community event brought together leading experts, engaged participants, and families affected by dementia to discuss the latest developments in understanding, diagnosing, and treating Alzheimer's disease.

Hosted by the Center for Alzheimer's and Neurodegenerative Diseases (CAND) at Baylor College of Medicine, the May 1 community forum offered attendees both scientific insights as well as up-to-date information on how their participation is helping advance groundbreaking research.

What Is Alzheimer's Disease and How Does It Affect the Brain?

Dr. Alan Levey, a distinguished neurologist from the Emory School of Medicine and national leader in Alzheimer's research, opened the event with an overview of what is currently known about Alzheimer's disease. He explained how the condition leads to progressive loss of memory and thinking abilities, stemming from abnormal changes in the brain, including the accumulation of amyloid plaques and tau tangles. Dr. Levey also highlighted recent therapeutic advances that offer new hope by targeting these disease processes more directly than ever before.

How might precision medicine transform Alzheimer's diagnosis and treatment?

Dr. Joshua Shulman, BCM neurologist and director of CAND, discussed exciting research initiatives to develop a breakthrough, precision medicine approach to Alzheimer's disease, allowing much earlier diagnosis and more targeted therapies. At BCM, the Precision Medicine for Alzheimer's and Related Dementias research study aims to personalize care by looking at each person's genes, brain scans, blood tests, and lifestyle. Researchers are working with Houston's diverse community to better understand both Alzheimer's and Parkinson's, studying people at all stages, from healthy adults to those with memory or movement problems, to find better ways to diagnose and treat these conditions in each individual. Dr. Shulman also introduced the audience to new research platforms that help scientists model the disease using patient-derived cells and robotic testing systems, allowing researchers to both better understand disease development and to screen drugs directly on human neurons in culture.

Why Is Studying Brain Pathology Important?

Dr. Matthew Torre, a neuropathologist, provided an in-depth presentation on the critical role of brain donation in Alzheimer's research. He explained how a definitive diagnosis still relies on microscopic examination of brain tissue after death, and how donated brains are essential for confirming clinical diagnoses, studying disease heterogeneity, and validating findings from laboratory models. Dr. Torre showcased ongoing studies using donated tissue to uncover the complex biology of Alzheimer's and related diseases such as Lewy body dementia and vascular dementia.

Why Your Participation in Research Matters.

Everyone in the room — whether as a research volunteer, a family member, or an advocate — has contributed to the shared mission of ending Alzheimer's disease. Throughout the event, panelists and audience members alike reflected on the profound importance of community involvement in research. Speakers acknowledged common barriers to participation, including fear of learning one's risk of AD, uncertainty about the research process, and even a longstanding mistrust of medical institutions.

Neuropsychologist Dr. Luis Medina emphasized the critical need for researchers and clinicians to listen to underserved communities, close health literacy gaps, and build lasting relationships rooted in trust and respect.

The event concluded with powerful reflections from participants who had contributed to our ongoing studies.

As public support and scientific progress accelerate, your involvement has never been more vital.

By taking part in research, sharing your story, or advocating for continued investment through national and local initiatives, you are helping shape a future with better treatments, earlier diagnosis, and ultimately, prevention.

We are deeply grateful for your ongoing interest and engagement. If you would like to learn more about our research efforts or discuss opportunities to connect with our team, please reach out to the CAND team at Baylor College of Medicine.

Dr. Joshua Shulman, M.D., Director of the Center for Alzheimer's and Neurodegenerative Diseases at BCM, thanked our generous research contributors and shared the latest updates in Alzheimer's research.

An expert panel engaged with the audience, addressing questions on Alzheimer's research, diagnosis, and care.

UNDERSTANDING GENETICS IN ALZHEIMER'S RESEARCH

WHAT GENETIC RISK SCORES CAN TELL US ABOUT ALZHEIMER'S DISEASE

Jamie Fong MS CGC *is a genetic counselor and Assistant Professor in the Department of Molecular and Human Genetics at Baylor College of Medicine. She specializes in helping individuals and families understand and navigate genetic information related to health and disease.*

We are now offering polygenic risk scores (PRS) to participants in the Precision Medicine Study for Alzheimer's Disease. These scores estimate a person's genetic risk for Alzheimer's based on thousands of small genetic changes.

What is a genetic risk score?

A polygenic risk score (or PRS) is a genetic test that estimates the risk of developing complex diseases such as Alzheimer's. A complex disease occurs as a result of many genetic factors, paired with environmental influences (such as diet, sleep, stress, and smoking). The many genetic factors influencing Alzheimer's disease are altogether known as "polygenic", with "poly" meaning many and "genic" involving genes. A change in the DNA sequence that makes up a gene is known as a "variant." A "DNA sequence" refers to the biological code contained in cells, providing instructions for our bodies to grow and develop.

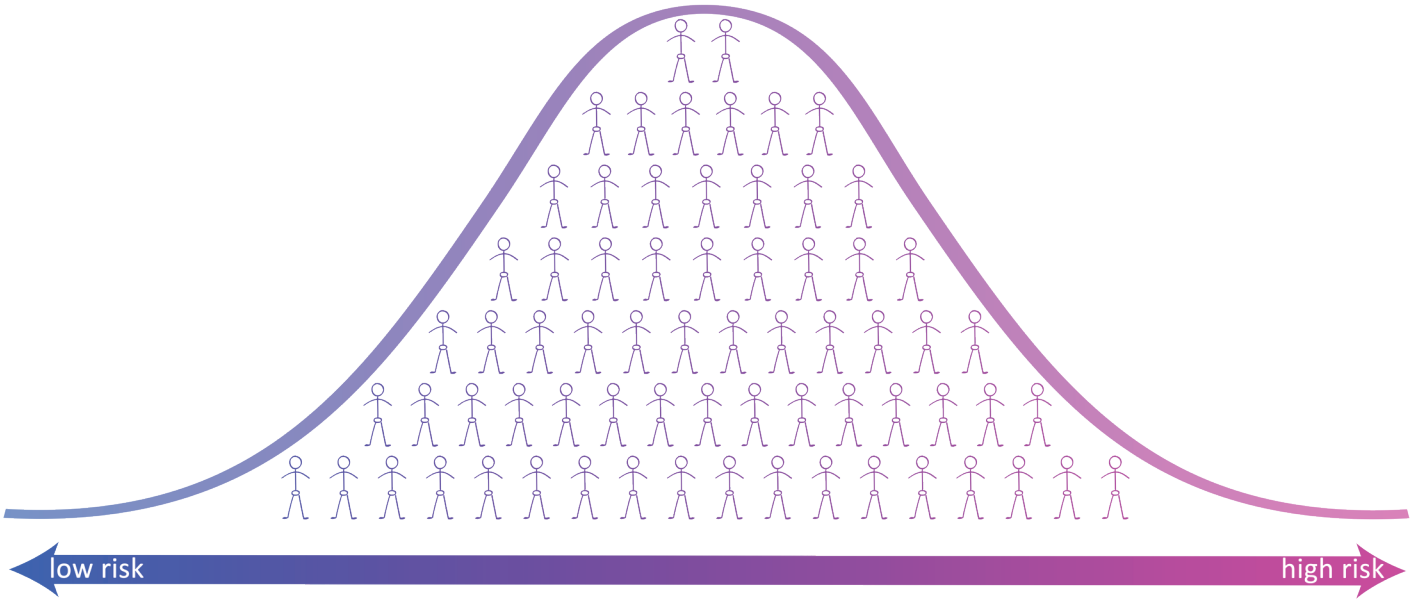
A polygenic risk score for Alzheimer's disease can be calculated by combining risk from more than 100,000 distinct variants in the DNA sequence of a person's sample. Each of these variants by itself contributes a little to the overall risk that a person will develop Alzheimer's, and considering each small-impact variant by itself has limited usefulness. However, when we combine risk from all small-impact variants into a polygenic risk score, we can compare one person's risk to that of other people.

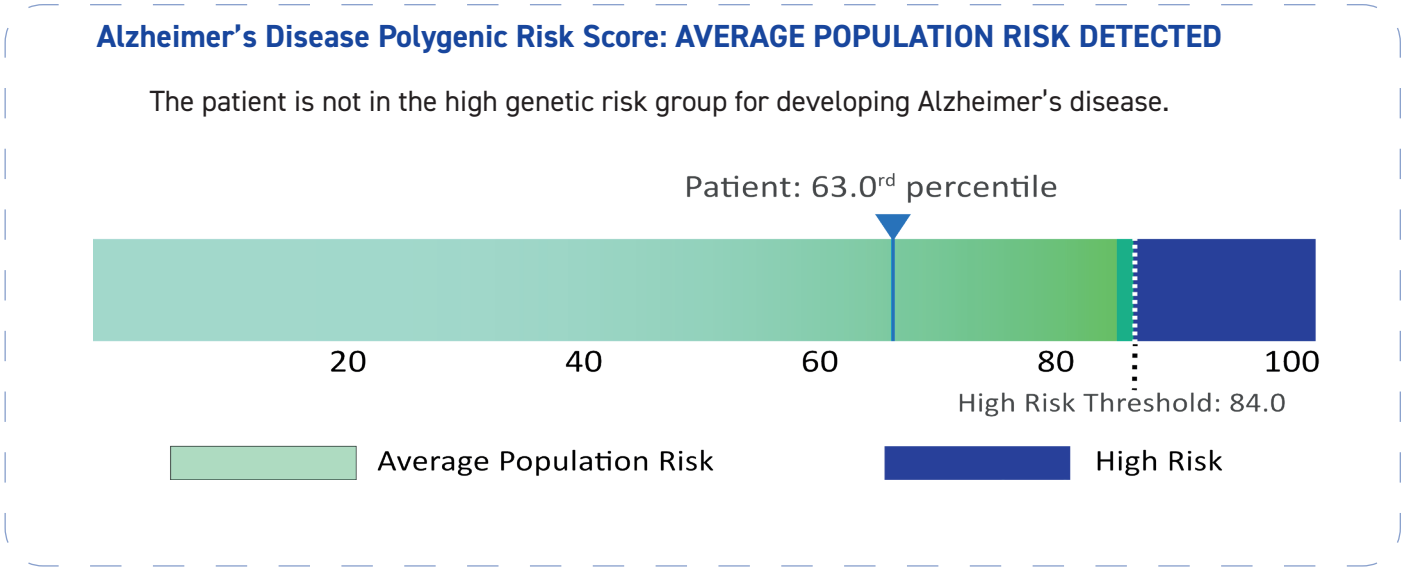
A polygenic risk score can be reported using descriptive categories ("high risk", "average risk"), or as a number, usually "percentile rank", which describes how a person's score compares to other people in the population, or both.

This summer, our "Precision Medicine for Alzheimer's Disease and Related Dementias" research study began computing and disclosing a polygenic risk score to all participants, in addition to the results of more than 200 single-gene tests that we are already returning. All research study participants meet with a genetic counselor to learn about their results and also will receive a "Polygenic Risk Score Report."

If you already received genetic results which did not include your "Polygenic Risk Score Report," you will be contacted soon to schedule an appointment. Please also feel free to contact us at 713-798-9080.

YOUR PRS. LOOKING AT HEALTH RISK THROUGH A GENETIC LENS





A **genetic counselor** is a healthcare professional who helps people understand their genetic information, what it means for their health, and what choices they can make based on it.

Genome sequencing reads all of a person's DNA to look for changes that may affect health, including rare genetic conditions and inherited risk factors.

A **polygenic risk score** estimates a person's chance of developing a disease like Alzheimer's based on many small genetic differences. It reflects genetic risk only, not lifestyle or environment.

A **percentile rank** shows how a person's polygenic risk score compares to others. For example, the 63rd percentile means the score is higher than 63 out of 100 people.