YOUR BRAIN HEALTH REPORT

DATE: December 4, 2025

Thank you for participating in the Program Name. You are helping to advance our understanding and treatment of Alzheimer's disease and related dementias in people with Down syndrome, offering hope to so many.

As part of our study, you get feedback from experts on the research tests and measures we perform. This brain health report, created for you, puts this information back in your hands.

UNDERSTANDING YOUR REPORT

The results in this report were obtained for research purposes for the Brain Health and Down Syndrome Cohort study. Although these research tests alone don't give a full view of your brain health, they are helping us to understand more about the brain. Remember, we're still piecing together the puzzle of brain science, and your role is essential in this. Some research findings may indicate a higher dementia risk. If you have cognitive symptoms, this information may be helpful in understanding and managing them.

SHARING YOUR RESULTS

Discussing these research results with your doctor may be beneficial, especially for initiating discussions on memory changes. However, you may want to be cautious about having your research results sent directly to your physicians, as this typically results in them becoming a part of your medical record. Including these types of results in your medical record could have future implications for insurance or medical care.

Consider your family's feelings before revealing any risk information, as it might directly affect them. We're here to address any concerns about sharing your report.

UNDERSTANDING THE LIMITATIONS OF THESE RESULTS

These results come from tests that may still be in the research stage and may not yet be approved for general medical use. This means that sometimes the results might show higher or lower levels of the markers than a true result. It's important to remember that these tests cannot, on their own, diagnose any condition. They should always be discussed with your research team, who can help interpret what they may mean in the context of your overall health.

SUMMARY OF YOUR STUDY VISIT

Physician Assessment and Note

Each time you are seen, we have a team of clinicians review your cognitive assessments, questionnaires your study partner answered, and clinical information. Below is the clinician's feedback from your last visit.

Name: Age: 5 Years

Last Visit: May 15, 2024

Doing well overall

MEMORY AND THINKING TEST SCORES

Down Syndrome Mental Status Exam (DSMSE)

The Down Syndrome Mental State Exam is a cognitive assessment we administer at each visit. It is designed to evaluate an individual's current mental functioning.

While lower percentile scores are generally interpreted as indicating lower cognitive ability, these scores do not take into consideration level of intellectual functioning and other important clinical factors including medical history. Please note, we generally look for change over time to help indicate whether a change in cognitive status is happening.

Below is a brief description of what categories the DSMSE test evaluates.

1. **Visual-Spatial** refers to the skill to be able to interpret what we see and where we are.
2. **Memory** refers to the ability to remember information, people, or experiences
3. **Language** refers to the use of words in order to share information or communicate with others.

Date	Total Score	Visual Spatial	Memory	Language
05/15/2024	28	24	48	22

Max Score: 103

Modified Cued Recall Test

This test assesses learning and your ability to remember a set of pictures during a free recall trial or cued recall trial (i.e., either freely recalled or recalling after being given a cue). Lower scores may suggest difficulties with learning or memory; however, a single low score does not necessarily indicate impairment. Clinicians typically examine changes in performance over time to determine whether a meaningful shift in cognitive status is occurring.

Date	Total Recall	Free Recall	Cued Recall
05/15/2024	27	15	12

Max Score: 36

INTERPRETING MEMORY AND THINKING TESTS IS COMPLEX

Scores can vary based on how you feel, what you are thinking about, and even how well you slept. Some people are naturally good in some aspects of thinking. There is some evidence you can practice and improve in the aspects you aren't as strong in.

Caregiver Questionnaire

The National Task Group-Early Detection for Dementia (NTG-EDSD) is a questionnaire your study partner answers at each timepoint. This questionnaire is used to record observations of changes in function and a screening tool for dementia symptoms.

A greater number of concerns indicates the potential for cognitive impairment in adults with Down syndrome. Clinicians will review your medical history to rule out other underlying medical conditions that may impact your score.

National Task Group - Early Detection for Dementia (NTG-EDSD)

Category	**05/15/2024**
Total Score	63
Activities of Daily Living	7
Language & Communication	6
Sleep–Wake Change Patterns	8
Ambulation	4
Memory	9
Behavior & Affect	17
Adult's Self-Report Problems	6
Significant Changes Observed by Others	6

IMAGING SCANS

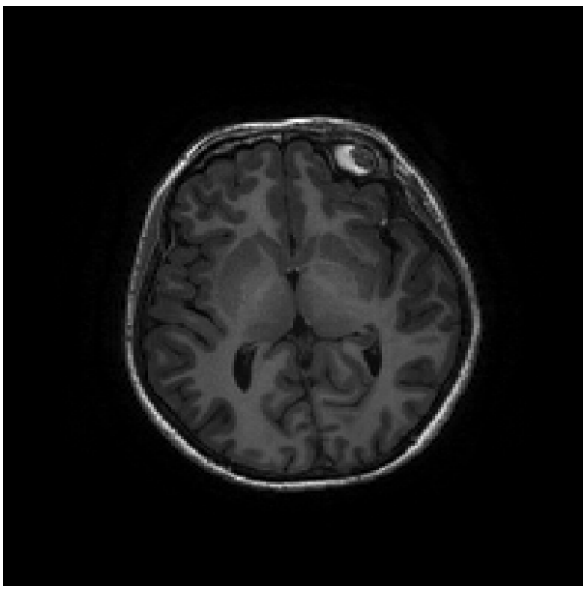
MRI Structural Findings

The MRI scan used in this study is reviewed by a radiologist, below are the radiologist's findings. However, this is not a standard clinical or diagnostic scan and is intended for research purposes only. If there is an incidental finding that is detected on your scan that could potentially be relevant for your medical care, you will be notified, so that you may follow up with your health care provider.

BELOW ARE IMAGES OF THE INSIDE OF YOUR BRAIN

Date of Scan: June 01, 2020

Front



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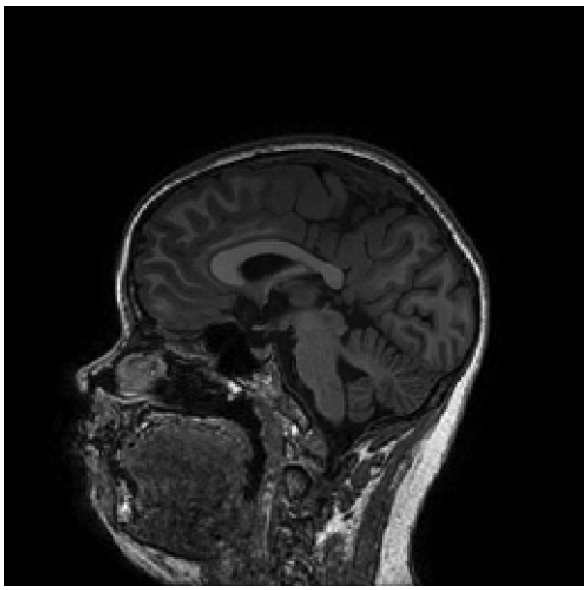
Axial view

Front



Back

Sagittal view

Radiology Read: No significant findings

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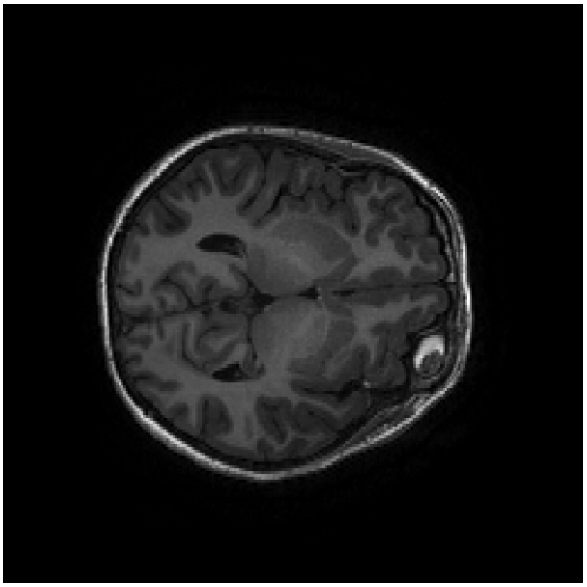

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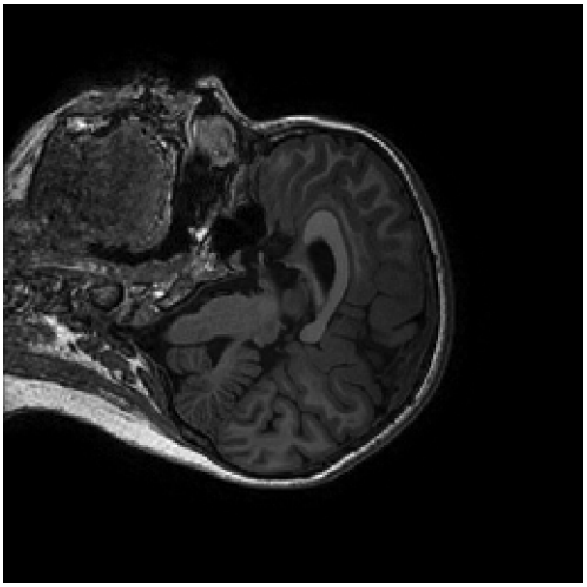
Axial view

Front



Back

Sagittal view

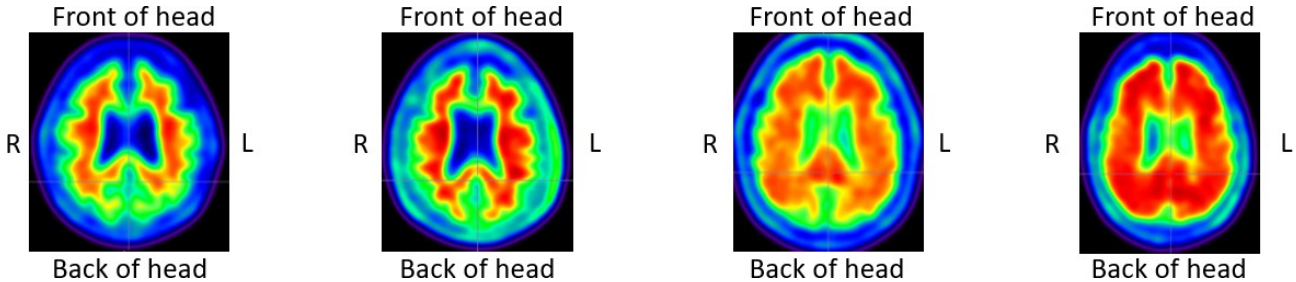
Radiology Read: No significant findings

Your Brain Amyloid PET Scan

Researchers and clinicians can use positron emission tomography (PET) to measure your brain amyloid level in something called centiloids. Centiloids are a unit of measurement ranging from 0 to 100. Everyone has some amyloid in their brain, but having high levels means you have a high risk of developing memory changes. In individuals with Down syndrome a centiloid value of 18 or higher is considered high, meaning someone has a higher risk of developing memory changes.

These pictures are not your PET scan, these are examples of people with different levels of amyloid in their brain. The red areas show the most amyloid close together, and yellow is amyloid spread out.

Low Levels of Amyloid → High Levels of Amyloid



Your centiloid value is: 22

Your Amyloid PET scan results showed that your amyloid level is high.

What do my results mean?

Taken together with your memory and thinking tests, this means:

Your amyloid is high and there are some changes in your memory and thinking.

UNDERSTANDING YOUR ALZHEIMER'S DISEASE RISK

Alzheimer's disease-related proteins

When we're born, the levels of two proteins in our brain, called β-amyloid and tau, are normal. As we age, these levels can change. β-amyloid protein changes happen first, sometimes even 10-20 years before any noticeable problems with thinking or memory start. However, it is important to know that not everyone with changes in β-amyloid levels will develop memory issues.

Tau protein changes usually occur after β-amyloid changes and are more closely linked to actual symptoms of memory and thinking difficulties. As the levels of both β-amyloid and tau change over time, the likelihood of experiencing memory changes generally increases.

Plasma 217 Results and Interpretation

Date	pTau 217	Category	Interpretation
05/30/2020	0.55	Intermediate	Intermediate: Alzheimer's disease pathology possible

pTau 217 is measured in pg/ml

pTau217: This is a blood measure that can reflect both amyloid and tau related changes in the brain. An increase in pTau217 levels, especially above 0.40 pg/mL, suggest microscopic Alzheimer's related change may be present in the brain. This is not a diagnostic test but in patients with memory changes this test can suggest that memory problems may be related to Alzheimer's changes in the brain. In those without memory problems, we are still studying if an abnormal test result can be used to predict long term risk. False positive and false negative test results can occur.

Genetic blood tests regarding Down syndrome – Karyotyping

Full Trisomy 21: When there are 3 copies of chromosome 21 in every cell of the body. Approximately 95% of people with Down syndrome have Full Trisomy 21.

Mosaicism: When some of the cells in the body do not have trisomy 21 and some cells have trisomy 21. Approximately 1-2% of people with Down syndrome have Mosaic Down syndrome.

Translocation: When the long arm of chromosome 21 is attached to the long arm of another chromosome. Approximately 4.5% of people with Down syndrome have Translocation Down syndrome.

Karyotype Result: Trisomy 21

Genetic blood tests regarding Alzheimer's disease risk

From past research, we know a version of the APOE gene, known as APOE4, increases a person's risk for developing Alzheimer's disease. We are still learning about how APOE4 impacts someone with Down syndrome's risk of developing Alzheimer's disease, but current research suggest people with APOE4 may develop signs of Alzheimer's disease earlier then people without it.

We inherit the APOE genes from our parents. Each parent passes one copy on to us, resulting in each of us having two copies of every gene, one copy from our dad, and one from our mom. If you carry the APOE4 gene, it means either your mom, your dad, or both (a rarer scenario) passed it on to you.

YOUR APOE RESULT: E3/E4

LIFESTYLE AND DISEASE RISK

We assessed various measures that can affect your overall brain health. Recent research suggests that a healthy lifestyle is a key components of brain health.

Blood Pressure

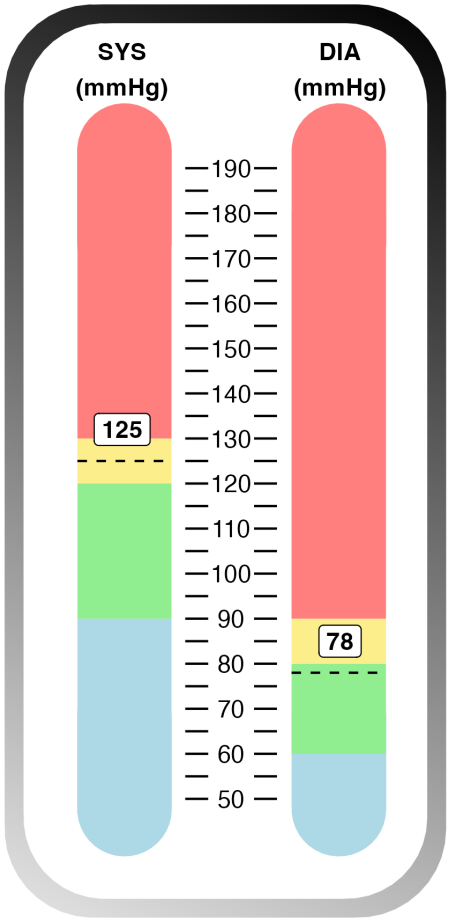
Blood pressure is the force exerted on the walls of your arteries by your heart. Systolic measures the force while your heart is contracting and diastolic measures the force while your heart is relaxed. Individuals with Down syndrome tend to have lower systolic blood pressure, if you are concerned talk to your doctor.

Blood Pressure History

Date	Systolic	Diastolic	Cateogry
05/15/2024	125	78	Elevated

High
Elevated
Normal
Low BP

BP Placeholder



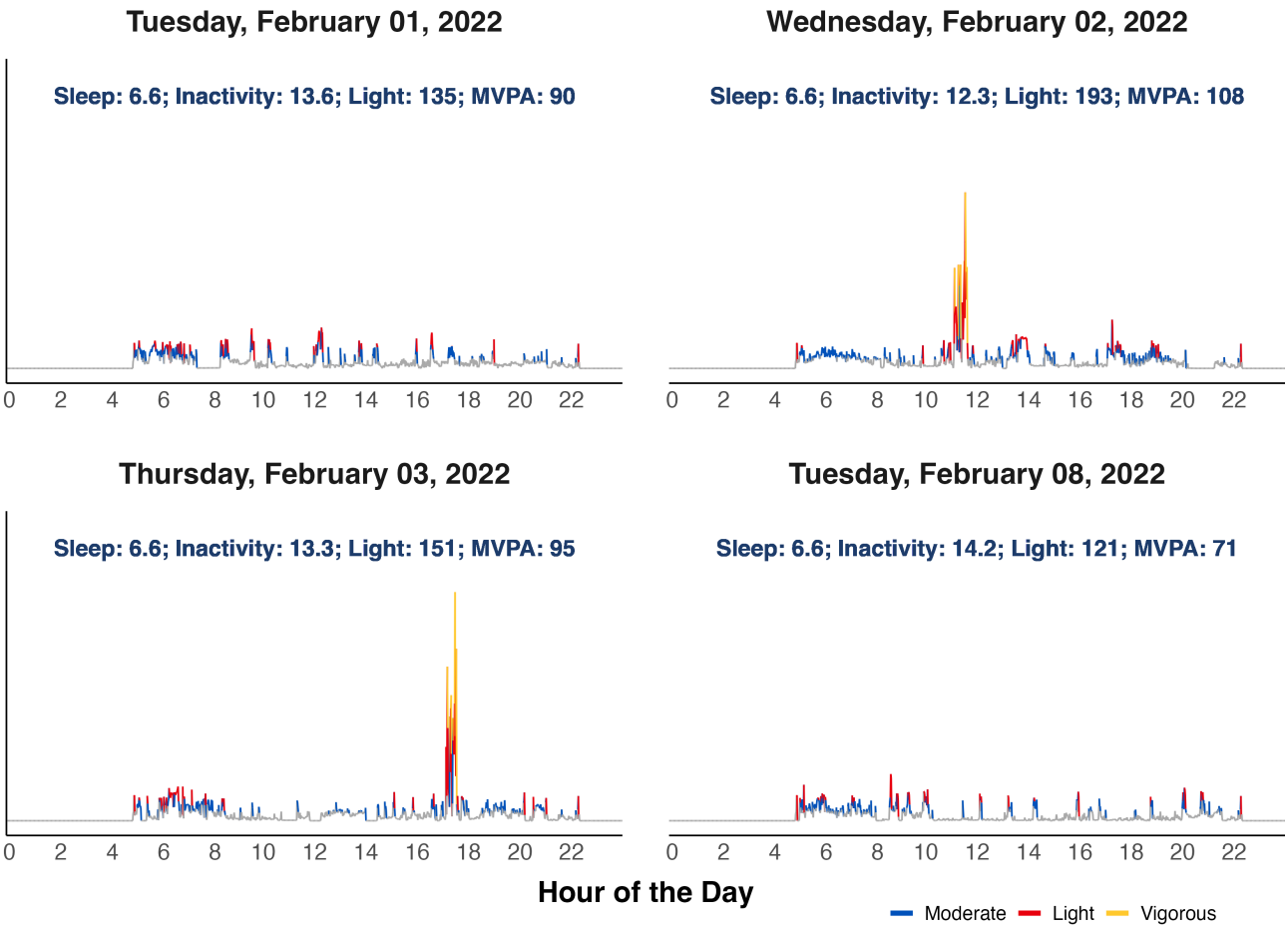
Physical Activity and Sleep

Exercise really is the best medicine! We encourage you to do at least 30 minutes a day of activity that significantly raises your heart rate and breathing rate. For significant health benefits, adults need at least:

1. 150 minutes of brisk walking or similar each week
2. Two days of strengthening activities for all major muscle groups

Sleep also helps improve our memory and focus on our daily tasks. At least 8 hours of sleep is important for our brains. It looks like you achieved the physical activity and sleep recommendations on **0** of the **4** days you were monitored with the accelerometer.

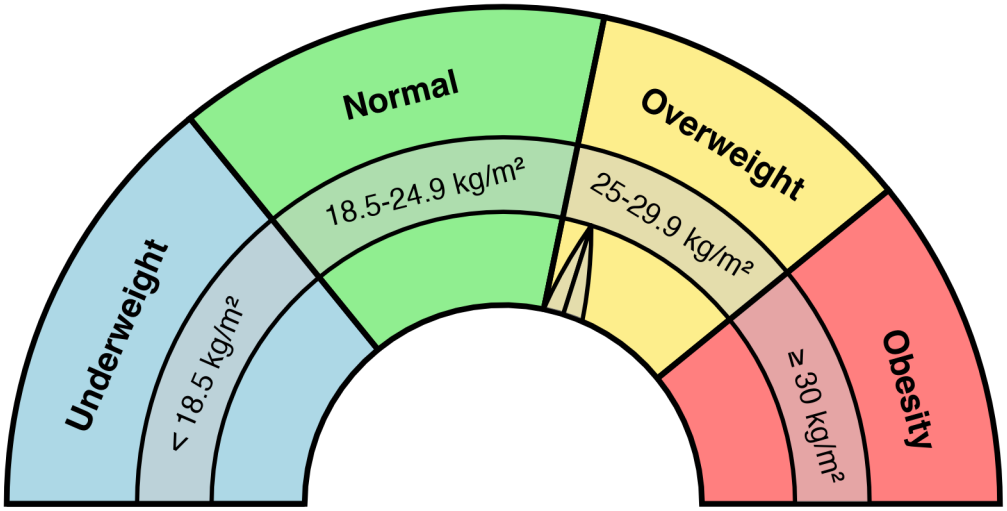
Here are your sleep (hours/day), inactivity (hours/day), light activity (minutes/day), and moderate-to-vigrous physical activity (minutes/day) levels across the week that you wore the accelerometer and the patterns of activity for each day.

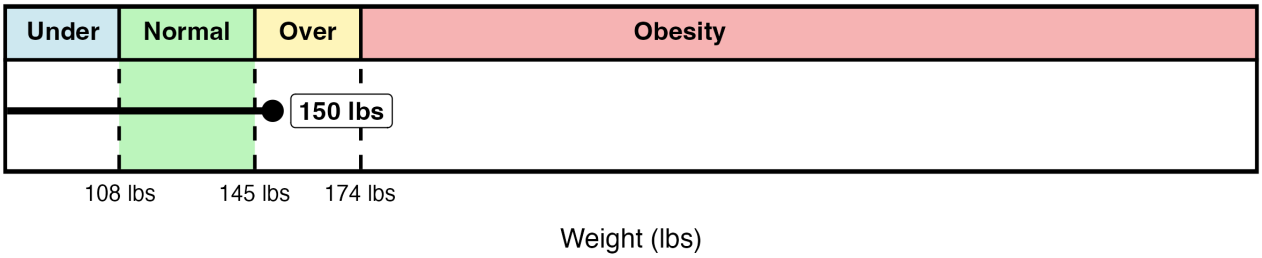


Body Mass Index

BMI is a standard measure of healthy body weight based on your height. A healthy BMI is anywhere between 18.5 and 24.9. If your BMI is too high or too low, it can increase your risk for some diseases. Maintaining a healthy weight with a healthy diet and exercise can bring your number into a healthy range and reduce your risk for diseases like diabetes, heart disease stroke and dementia.

Body Mass Index: $25.7\ kg/m^2$



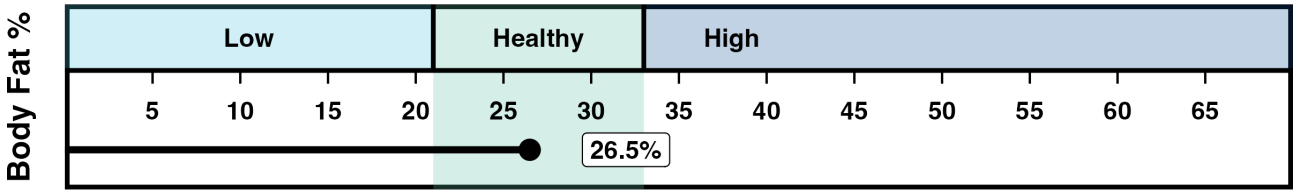


Dual Energy X-Ray Absorptiometry

This scan helps determine your body composition which includes levels of body fat, lean tissue (muscles and organs), and bone density. Your body composition is affected by age, gender, genetics, physical fitness, and diet. A higher amount of lean tissue and a lower amount of fat tissue can help you not get sick as often. The best way to improve your lean tissue is through healthy eating and regular exercise.

Date	Weight	Lean Tissue	Fat Tissue	Fat (%)	BMD
05/25/2020	149.9	94.8	39.7	26.5	-0.2

Weight, Lean Tissue, and Fat Tissue Measured in Pounds
BMD: Bone Mineral Density (Z-score)



A BMD Z-score less than 0 indicates bone mineral density below the average for someone of the same age and sex. A Z-score below -2.0 is considered below the expected range and may suggest an increased risk for fractures or other musculoskeletal complications, especially when accompanied by other risk factors.

Remember, everybody has a different body and will have a different body composition. Be happy with your body no matter what shape or size!

BRAIN HEALTHY HABITS

THE SUPER SIX

Keep Learning

Learning is fun! Read a book, try a puzzle, or learn something new each day.

Manage Stress

It is important to relax! Try yoga or have quiet time to recharge your body and brain.

Get Moving

Movement is great for your brain and body! Aim for 150 minutes of exercise each week.

Eat Well

Eating healthy helps your brain and body! Aim for 5 servings of fruits and vegetables each day.

Stay Connected

Spending time with others can help your brain! Share a meal, volunteer, or talk with your friends and neighbors.

Sleep Tight

Sleep clears harmful waste from our brain. Create a calming bedtime routine that you can do each night.

ADDITIONAL RESOURCES

National Task Group – Early Detection and Screen for Dementia (NTG-EDSD)

https://www.the-ntg.org/ntg-edsd

Alzheimer's Association information about Down syndrome and Alzheimer's Disease

https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome

NIH Information about Alzheimer's Disease in People with Down syndrome

https://www.nia.nih.gov/health/alzheimers-causes-and-risk-factors/alzheimers-disease-people-down-syndrome

National Down Syndrome Society information about the different types of Down syndrome

https://ndss.org/about#p_336

Special Olympics Fit 5 Fitness Resources

https://resources.specialolympics.org/health/fitness/fit-5

KU ADRC Brain Health in Down Syndrome webpage

https://www.kumc.edu/research/alzheimers-disease-research-center/community-outreach/brain-health-in-down-syndrome.html

KU V-Fit Fitness Program

https://myclinicshop.com/ku-weight-management/product-category/ku-v-fit-program

KU ADRC Caregiver Support Services

We offer support services where you can talk with a social worker or care navigator about memory changes or a dementia diagnosis for yourself or a loved one. Contact Amy Yeager at 913-945-7663 or email ayeager3@kumc.edu