JOHNS HOPKINS MEDICINE

Approved June 14, 2023

Please Read About ARIC PYP Study-Heart Scan

Thank you for participating in ARIC!

ARIC-PYP aims to identify approaches for early detection of transthyretin cardiac amyloidosis, an important and treatable cause of heart failure.

As part of ARIC-PYP, you may have the opportunity to take part in a special heart scan. This study will help us understand what changes happen in the hearts of people with transthyretin cardiac amyloidosis and how these changes are associated with heart failure. To do this, we will be conducting a heart scan.

Is ARIC confidential?

Yes. All the information you give us is confidential and will only be used for research purposes. Information collected about you will not be associated with your name.

If I decide to participate, what are my next steps?

Similar to previous visits, all imaging studies will be discussed with you over the phone or in person.

You may be asked questions to help us determine if you are eligible for this study.

If you are eligible, we will schedule you for a heart scan, imaging appointments and questionnaires.

An ARIC staff member will accompany you for the duration of the appointment. The visit for the heart scan will take about 3 hours.

This imaging scan is separate from the regular ARIC clinic visits, and we still hope you will continue to participate in regular clinic visits.

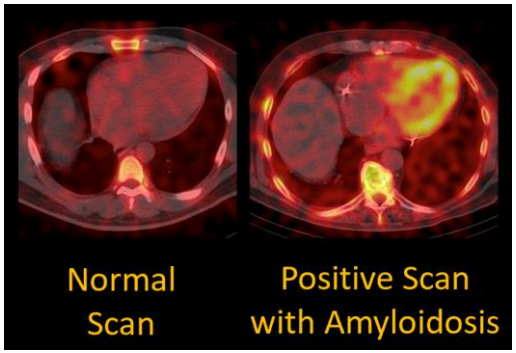
We are happy to answer any questions!

612-626-4056

SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF MINNESOTA

ARIC-PYP Study

HEART SCAN



A research study conducted at the University of Minnesota

ARIC

Atherosclerosis Risk in Communities Study

JHM sIRB PI: Josef Coresh; UMN PI: Pamela Lutsey

sIRB Protocol: IRB00311999

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Purpose

The purpose of the **ARIC-PYP research study** is to study approaches for early detection of transthyretin cardiac amyloidosis. This is an important cause of heart failure and is due to deposition of transthyretin protein in the heart muscle. Medications exist to treat transthyretin cardiac amyloidosis. However, diagnosis and treatment are often delayed. We are examining if early changes in heart size and function and in blood proteins can help identify this condition early.

How will we accomplish this? What is a heart scan?

Participants will be asked to complete a heart scan and questionnaires.

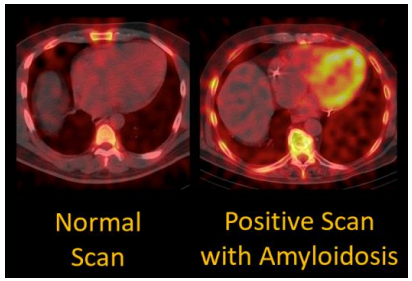
A **heart scan** is a photo of your heart using a special camera. In this study, a SPECT machine will take photos as you lie flat within the machine. The heart scan takes about 30 minutes.

SPECT Machine

Prior to the heart scan, a small amount of a radioactive tracer (technetium-99m-pyrophosphate, PYP, or oxydronate, HDP) will be injected into a vein in your arm. Your total time at the imaging facility may be 3 hours, however, the heart scan process takes approximately 30 minutes.

What is the use of this heart scan?

A scan is an image of the heart that is obtained by injecting a small amount of FDA approved radioactive tracer into your arm.
This scan is used in the diagnosis of transthyretin cardiac amyloidosis.



Why participate in the ARIC-PYP Study?

This heart scan may identify early transthyretin cardiac amyloidosis in your heart. If cardiac amyloid is found:

(1) There are specific medicines that can help the heart, ease symptoms, and increase lifespan.

(2) Your doctor may perform genetic testing which could identify a genetic predisposition to cardiac amyloidosis. If present, this could allow for earlier screening, detection and treatment of affected family members.

(3) By combining this data with information we've collected from you over the past 30 years, this study might allow researchers to create new and better ways to screen for early amyloidosis and thereby allow for early treatment.

For more information call: 612-626-4056

ARIC-PYP Study
University of Minnesota

Who is eligible?

Approximately 900 people across all four ARIC locations will participate in the heart imaging study. This will include people with heart failure and other abnormal heart findings. The ARIC staff will work with you to determine if you are eligible to take part in this study.

Who are good candidates for a heart scan?

Persons with Heart Failure: Among older adults, **cardiac amyloidosis may cause greater than 1 in 10 cases of heart failure.** If heart failure is due to cardiac amyloidosis, there are specific medicines that can slow the progression of heart failure that are not used in heart failure without cardiac amyloidosis.

Genetic Variation: Persons with **certain genetic variations** appear to be at higher risk for developing **cardiac amyloidosis**. However, the frequency with which they develop cardiac amyloidosis is not known. **Your family members may require an evaluation to enable early diagnosis if you have this condition.**

Abnormal heart size and function: In older adults**, up to 10% of the time cardiac amyloid may be the cause of certain abnormalities in heart size or function**.

Men: Cardiac amyloidosis is more common in men than in women. In older men, heart failure or certain abnormalities in heart size or function may signify cardiac amyloid burden.

Women: Studies suggest that cardiac amyloidosis may be underdiagnosed in women. **We do not know how common this is in women because mostly men have been studied.**

Black Race: Studies suggest that **cardiac amyloidosis is even more underdiagnosed in Black Americans**, particularly in specific regions of the country including the Southeastern U.S.