

The VOICE of FTD

SUMMER 2022

Poked & Scanned:

Learn about procedures used in FTD research studies

Persons who enroll in research and undergo the various procedures needed can help advance science and bring us closer to the day when these diseases are in the past.

Biological samples are gathered and used to develop **biomarkers** that guide diagnosis and treatment for frontotemporal degeneration (FTD).

Nupur Ghoshal, MD, Ph.D., of Washington University in St. Louis explained these procedures, including what they are and why they are important during a Perspectives in Research webinar, earlier this year co-hosted by the Associations for Frontotemporal Degeneration and the FTD Disorders Registry.

Additionally, Drew, a research participant, shared his experiences of what it was like for him to participate in these procedures.

View the entire webinar: [FTD Biology and Testing: Why do you need my samples?](#)

BIOMARKERS

Biological markers, or biomarkers for short, measure an aspect of health or disease. They measure what is

happening inside a living body, as seen by the results of laboratory and imaging tests.

In FTD, these biomarkers are in the blood, spinal fluid, levels of aggregated [GN1] protein pathology in the brain, and patterns of brain activity on **structural MRI** or **PET scans**. When measured, biomarkers tell researchers information about normal and not normal functions of the body or disease state.

“Technology is all coming together so we can become more savvy about identifying the correctly diagnosed people and determine which pathologies are involved,” Dr. Ghoshal said, “and making sure we're recruiting the right people for the right trials.”

Whether you are a person diagnosed with FTD, a family member, or a caregiver, there are research studies in which you may be eligible to enroll. View studies that are currently recruiting on the [Registry's Find A Study page](#).

Please note that [this glossary](#) is available to help you understand the scientific terms used in this article. Glossary terms are shown in bold the first time they appear.

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PROCEDURES FOR FTD CLINICAL TRIALS

Most clinical trials require at least the basic blood draw, but many also need participants to undergo brain imaging, lumbar punctures (or spinal taps), or possibly a skin biopsy.

Learn about these tests from Dr. Ghoshal, and hear one research participant's thoughts on each one.

THE BLOOD DRAW

The blood draw for research is similar to what is done for a regular doctor's visit or hospital admission. A needle is used to take blood out of the forearm or the crease of the arm.

"The difference may be the quantity that we collect," Dr. Ghoshal said. "There's a lot of bits and pieces that we're separating out from the blood: the fluid component, the cell component, and specifically the cells that contain DNA."

Some of this blood is analyzed immediately. However, as more is learned about FTD, scientists can test earlier blood samples using future knowledge.

What can be learned from the blood?

One test measures a protein called **neurofilament light chain (NfL)**. An NfL score at or above a baseline range can help researchers measure disease intensity. [Research has shown](#) that NfL concentrations are higher in persons with **behavioral FTD (bvFTD)** and **primary progressive aphasia (PPA)**.

"We measure this particular protein in your blood," Dr. Ghoshal said. "We can begin to predict whether

you are likely to go from being someone who has no symptoms ... to some symptoms ... to the full FTD clinical picture."

This and other blood tests are being used to find an accurate diagnosis and track FTD as it progresses. Unfortunately, FTD seems to take a different time course for each person, she noted.

"Because of those who've already contributed blood work to our studies, we now can start thinking about what those numbers tell us on day one, that then inform us about what we can expect in years one and two," she said.

Drew: "I never liked needles myself except for tattoos, but ..."

[Listen to Drew's experiences giving blood.](#)

BRAIN IMAGING - THE MRI

Researchers want to get good quality pictures of the brain because that is where FTD acts. While CAT scans use X-ray technology, which is good in an emergency, **MRI** scans provide fine-tuned details of the brain.

The skull holds the brain and **spinal fluid**. When MRIs show more black space than gray, that means there's more spinal fluid there and less brain tissue, Dr. Ghoshal explained.

Drew: "Claustrophobia is terrible for me. So I had to ask the doctors ..."

[Listen to Drew's experiences doing MRIs.](#)

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BRAIN IMAGING - FTD PET AND TAU PET

There are a couple of different kinds of **PET** images used in research for FTD. An FDG PET scan shows how your brain uses glucose, also called sugar.

“We need to control the amount of sugar already flowing in your system. We may ask you to monitor your diet for a day before,” Dr. Ghoshal said, including “fasting for a period of time before the study itself.”

Requirements can vary from one study to another, so research participants are given specific details of what to do beforehand. Sugar levels are checked by a blood draw before the test. Then a known amount of glucose is injected and allowed to move through your body for an hour.

“It is a little radioactive, a safe amount that has been approved by institutional review boards, and can be seen in the FDG PET scanner,” the researcher explained. “We let that flow in your system for about an hour. We're looking to see how your brain is using that glucose.”

Another protein that is looked for is tau. It is a good protein that goes bad in persons with Alzheimer’s disease and FTD. Similar to looking for glucose levels, a person is given an injection that flows through the body before they undergo a PET scan. The results allow researchers to measure tau deposits.

Drew: *“You get a little sensation when it goes in ...”*

[Listen to Drew's experiences doing PET scans.](#)



THE LUMBAR PUNCTURE (LP)

Spinal fluid coats the brain and spinal cord and acts like a shock absorber. It also tells researchers what the brain is doing without opening the skull to look directly inside.

By looking at the NfL in the spinal fluid, researchers can tell the difference between people who have early onset Alzheimer’s, FTD, or no disease, Dr. Ghoshal said.

“It’s a tool already that helps us separate out the two different populations. We have patients who are similar in age and potentially clinically look very similar or at least overlap,” she said. “We want to make sure that we’re recruiting the right folks for the right studies, developing the appropriate therapies that we know moving forward will be addressing the appropriate problem.”

When taking a sample, doctors draw fluid from the lower back below the level of the spinal cord, Dr. Ghoshal emphasized. Persons either lay on their side or sit and lean forward. The area is numbered using lidocaine or Xylocaine.

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“It is similar to the Novocaine you might have at the dentist’s office,” she said. “It doesn’t deaden all the way down to your toes, but it does numb up that area that we’re about to work in.”

To collect the spinal fluid, a needle is placed between two “pointy parts” of the lower back, which become prominent when you arch your back. Between 15 and 30 ccs is collected, depending on the study.

“You have about 150 sugar cubes worth of spinal fluid running around. For our studies, it depends, we’ll collect between 15 and 30,” she said. “It’s a fluid that you are constantly making as a filtered version of your blood. You make it back in just a few hours.”

Drew: *“It’s all about comfortability and making yourself prepared ...”*

[Listen to Drew’s comments about undergoing lumbar punctures.](#)

SKIN BIOPSY

A new up-and-coming procedure that research participants may be asked to do is a skin biopsy.

A local numbing medication is used on an area of the buttocks. A punch tool is used to take skin tissue from the upper hip area.

“It’s cosmetically very minimally invasive,” Dr. Ghoshal noted.

The sample of tissue is placed in a bottle and sent to the lab to be tested. The skin cells show what is going on in the participant’s body. They can also be used to learn multiple things about the person, including:

- see what the disease looks like in that person
- push skin cells towards becoming neurons
- try to normalize the cells or make them better functioning
- screen possible drugs to see what might work for that person
- develop unique treatments for each person
- screen for new opportunities, new therapies, and new ways of thinking about the disease

While the tests are separate, the results are combined with information collected through paper and pencil testing, family history, the clinical exam, and a neurological exam.

“It’s a huge database of information that we can put together to make sure that moving forward we understand the disease mechanism, understand the disease itself better, and then fine-tune the next steps towards drug development with therapies,” Dr. Ghoshal said.

Drew: *“It was probably the weirdest part ...”*

[Listen to Drew’s experience with the skin biopsy.](#)

CLOSING THOUGHTS

There are different types of FTD research studies, and each has its own requirements, tests, and outcome measures. Only volunteers who meet certain criteria are recruited.

Some participants may be asked to undergo multiple procedures, and others may just do a blood draw. But whatever is asked, it is to advance the science by learning more about FTD.

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“These are all the reasons we poke and prod you,” Dr. Ghoshal said, “because we collect a great wealth of information.”

Drew:

“I think the first time you go into the hardest time. It's a mental game. But each year it got easier and easier for me,” he said.

“I want to figure this out. It might not save me down the road, right, but it might save my kids if they end up getting it. If somebody else's family members have it, it's going to help down the road, generation after generation. If we could find some type of way to stop this or at least curb it for a little bit longer, that's why I'm doing it.”

“I would definitely suggest you do it.”

[Listen to all of Drew's closing thoughts about participating in clinical trials and undergoing these procedures.](#)

FIND A STUDY

Whether you are a person diagnosed with FTD, a family member, or a caregiver, there are research studies in which you may be eligible to enroll.

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**Join the Registry.
Tell Your Story.
Advance the Science.**

“Together, we can make a difference!”

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