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IRB Approved at the
Protocol Level
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Sano

Your guide to supporting **FTD research**

You are being invited to participate in a study aiming to identify people with genes linked to **Frontotemporal Dementia**

In this document you'll find information about

- **Why** this study is happening and what it aims to achieve
- **What** participation involves
- **How** health information will be used and kept private, safe and secure

Where can I direct questions?

We're here to help in any way we can. Call us, email us, or start a live chat via the Sano Genetics website.

contact@sanogenetics.com | sanogenetics.com

Why is this study happening?

- To find people with specific genetic changes linked to FTD
- To better understand the biological mechanisms underlying certain types of FTD
- The future aim is to use this information to support the identification and development of new FTD treatments

This study aims to identify people with Frontotemporal Dementia (FTD) or who are at risk of developing FTD, who have changes in specific genes involved in the development and progression of the disease.

The genes we are testing in this study are GRN, MAPT and C9ORF72. There are instances of other genes being associated with FTD, these are rarer and not covered in this study.

GRN MAPT C9ORF72

Conducted by

Prevail Therapeutics | Sano

Reviewed and approved by

wcg™

Genetic uncertainty

Not all cases of FTD are caused by genetics, and just because someone in your family has FTD (whether or not it has an underlying genetic cause) it doesn't necessarily mean other family members will go on to develop it.

Cases of FTD that do have an underlying genetic cause are the result of changes called genetic variants. A genetic variant is a change in a gene (a part of our DNA, the genetic blueprint which carries the instructions for building our cells and making our bodies work) which varies from the general population.

It's not possible to know if your FTD/suspected FTD (or that of the person you care for) is caused by genetic changes without taking a genetic test (an easy and completely painless process which can be done using a saliva sample from home).

Participating in FTD research

If you join our study, you'll receive a complimentary at-home genetic test to check if you have any of the genetic variants this study is investigating. A positive result could contribute to future FTD research for new treatment options. This study, conducted by Sano Genetics and Prevail Therapeutics, is approved by the WCG Institutional Review Board.

Why was I invited?

You have been invited to participate in this study because you (or the person you care for) either have a confirmed diagnosis of FTD, have symptoms which suggest you may have FTD, or are at an increased risk of developing FTD in the future (for example, due to family history).

What's involved?

- Participate entirely from home
- Take a free, easy-to-use genetic test and return it by post
- Attend two free online genetic counseling appointments. The first to understand if genetic testing is right for you, the second (if you decide to take a test) to explain your results and what they mean for your health.

Step by step process

01
Brief online survey

02
Genetic counseling

03
Genetic testing

04
Review your results with a Genetic Counselor

05
Discover opportunities to participate in research (if eligible)

Your genetic test results will only be used to support this research. They will not appear on your official healthcare records or be used to make decisions about your clinical care.

Taking part

If you or the person you care for agree to join the study, you'll provide personal details and answer medical questions. If eligible, we'll send a link to book a free online genetic counseling session. In this session a genetic counselor will discuss genetic testing and help you decide if it's right for you. Sessions are private and won't be recorded in your healthcare record. You can withdraw from the study at anytime. If you have already had a genetic test for FTD, you can upload your report and find out if you are eligible for genetic counseling.

Have questions about genetic counselling?

Download free guide

Risks and Benefits

Potential Benefits:

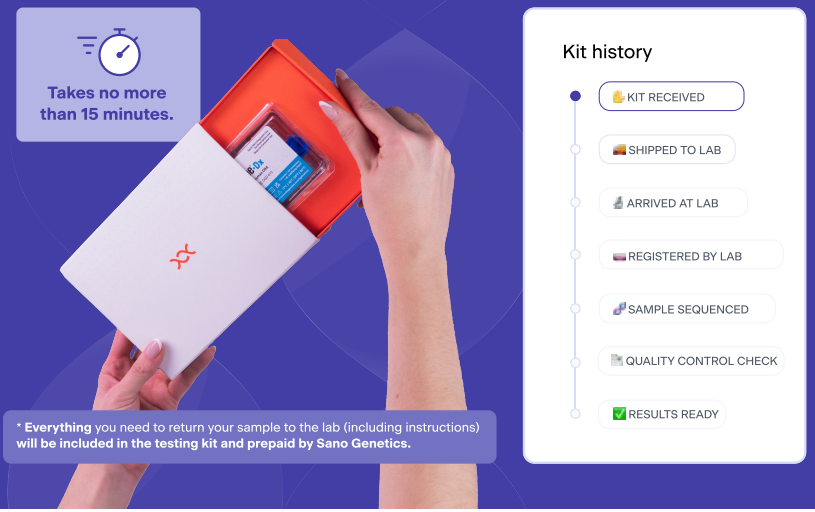
- Participation offers free at-home genetic testing and online genetic counselling services.
- Testing reveals if you carry genetic variants linked to an increased FTD risk, potentially allowing you to support future research for new treatment options.

Potential Risks:

- While we prioritize safeguarding your data, sharing personal information online carries inherent risks.
- Discovering an increased risk of FTD from genetic testing can cause distress for you and your family.
- While our partner labs validate genetic sequencing methods rigorously, there is a small risk of receiving inaccurate results.

Genetic testing

- After your first genetic counseling, you'll receive a free genetic testing kit from Sano Genetics. Follow the instructions to collect and send your DNA sample back to the lab.
- Once your sample reaches the lab, DNA extraction and sequencing will begin.
- We'll keep you updated via email throughout the process.
- Once your results are ready, we'll notify you and provide a link to schedule a follow-up appointment with your genetic counselor. They'll explain the results and help you plan your next steps.
- After the appointment, your results will also be available on your private Sano Dashboard to download at any time. Using your Sano Dashboard, you'll be able to stay up to date as the study progresses, read, listen and learn more about the genetics of FTD, and gain access to a number of exclusive features, services, and further opportunities to contribute.



How is my information used and protected?

- All study information is stored on secure and encrypted servers
- Genetic testing results do not appear on your official healthcare record
- Your anonymised information will be combined with other study participants' to help researchers understand the impact of specific genetic changes on FTD

How will my data be used?

The answers that you provide (either about yourself or on behalf of the person you care for) and your genetic testing results will be used to assess your eligibility for future research studies, which may include clinical trials for potential new treatments.

Your de-identified information may be combined with that of other people participating in the study and summarised in a report about the outcome of the research.

How will my sample be handled?

Your DNA sample will be sent to our third party DNA testing laboratory. The laboratory will extract DNA from your sample and will then perform sequencing on the DNA to see if you (or the person you care for) carry variants associated with an increased risk of FTD in the genes that this study is investigating.

After your genetic counsellor shares your results with you and talks you through the outcome, you'll be able to download a copy of your genetic results from your Sano Account at any time.

We'll be in touch to let you know about any new opportunities we think you might be able to support.

Sano ensures compliance with all applicable data protection laws, including but not limited to: the GDPR in the EU, the Data Protection Act in the UK, the HIPAA in the US and the Australian Privacy Act in Australia

GDPR

Data Protection Act 2018

HIPAA

You can review our full data and privacy policy here:

sanogenetics.com/privacy

Compliance is an effective way to validate trustworthiness. Sano is pleased to provide independent verification that our security and privacy practices comply with the most widely accepted standards such as ISO 27001 and Cybersecurity Essentials.

CYBER ESSENTIALS

ISO 27001

How will my personal information be protected?

The information and genetic sample you provide us with will be stored on secure and encrypted HIPAA and UK-GDPR compliant servers owned by Sano Genetics and located in the UK.

Only de-identified information (where personally identifiable information has been removed and replaced with a unique code) will be sent to our third-party genetic testing laboratory, for the purposes of generating your genetic test results.