FTD DISORDERS
REGISTRY®

Questions to Ask When Participating in Research

Research can be a powerful way to contribute to the understanding and treatment of FTD disorders, but it is important to be fully informed before you decide to participate. Here are some essential questions to consider asking the research team before joining any FTD disorder study.

Understanding the Study's Purpose and Impact

What is the purpose of this study?
Understanding the goals can help you determine if the study aligns with your values and interests.
How will this study contribute to the field of FTD disorders research?
Knowing the study's potential impact on the understanding or treatment of FTD disorders might increase your comfort and sense of purpose.
Has this research been reviewed and approved by an ethics committee or Institutional Review Board (IRB)?
This ensures the study adheres to safety and ethical standards.

Your Role and Participation

What will I need to do if I participate?
This can include specific tasks, tests, or schedules, helping you assess if the requirements are manageable.
How long will the study last?
Ask about the study duration, frequency of visits, or time commitment needed.
Can I leave the study if I change my mind?
Many studies allow participants to withdraw at any time without penalty, but it's good to confirm.

Potential Risks and Benefits

What are the potential risks of participating in this study?
Risks can vary and might include physical, emotional, or privacy-related concerns. Understanding these can help you make an informed decision.
What are the possible benefits of participating?
Ask about any potential personal or broader benefits, such as contributing to research that may benefit future FTD disorder patients.
What steps are taken to protect my health and safety?
Knowing the precautions and safeguards in place can provide reassurance.

Privacy and Data Usage

How will my information be kept private?
Privacy practices can vary between studies, so ensure you understand who will have access to your data and how it will be protected.
Will my data be used in other studies or shared with other researchers?
If data-sharing is part of the study, ask about the measures to protect your identity.
What happens to my data if I withdraw from the study?
Clarify whether your data will be retained or removed if you decide to leave.

Costs and Reimbursement

Are there any costs to participate?
Some studies might have associated costs, like travel or specific procedures not covered by insurance. Knowing these upfront can help you budget.
Will I be reimbursed for expenses?
Some studies may offer compensation for time, travel, or other related expenses.
Are there any incentives for participation?
Compensation or incentives might be offered to help offset costs or to acknowledge your time and effort.

Results and Follow-Up

Will I receive any results or updates from the study?
Some studies provide participants with information about their study test results and/or general findings, while others may not. Ask if you will be informed about the results or study progress.
Who can I contact if I have questions during the study?
Make sure you have the contact information for someone involved in the study, in case you have questions or concerns later on.
Are there any follow-up procedures after the study concludes?
Some studies may require follow-up or provide additional care; it’s important to understand any expectations for after the study ends.

By asking these questions, you’ll be better prepared to make an informed decision about participating in FTD disorders research. Understanding the scope, purpose, risks, and benefits allows you to contribute meaningfully while prioritizing your well-being.