

PARTICIPANT CONSENT FORM

- **Read the patient information sheet.** I confirm that I have read the patient information sheet for the Light The Way study. I understand the information and have had the opportunity to ask questions for clarification. These have been answered satisfactorily.
- **Read the privacy notice** <[here](#)>. I confirm that I have read the privacy notice.
- I understand that my participation is voluntary and that I am free to withdraw from the study at any time. I do not need to give a reason and my medical care or rights will be unaffected.
- I understand that if I choose to withdraw, my information will not be used in any future analysis. However, any analysis or interim results that have included my information prior to withdrawal cannot be undone.
- I agree that any samples that I provide will be analysed to determine genetic factors associated with ALS/FTD and in doing so may return results with uncertain clinical significance and/or variants associated with a risk of Spinocerebellar Ataxia type 2 (SCA2) and that I will be provided with the results of these analyses if I choose to receive them.
- I understand that my sample can be sent for a confirmatory test under the supervision of the genetic consultant.
- I understand that my sample and relevant data will be transferred to the United States for genetic testing and storage for up to 5 years.
- I understand that data collected during the study will be looked at by individuals from the study Sponsor (Sano Genetics) and that my de-identified/pseudonymized data may be shared with third parties including academic researchers, non-profit researchers, and for-profit companies.
- I understand that my project data (the answers that you provide on the screener and your genetic test results) will be combined with those of others participating in the project and summarised in a final report and data package. The final report will be shared with others (including the project sponsor) but will not identify you because the survey is pseudonymized during analysis of the data. This means that personal data is replaced with a unique identifier.
- I agree that my samples may be sent elsewhere in the world to be analysed. My samples will be stored securely and researchers that use my samples will not be able to identify me from my samples.
- I agree to be contacted by the Sano Genetics team about taking part in the study, including by reminder emails.
- I understand that I will not benefit financially if this initial research leads to the development of a new treatment, medical test or other products.
- I understand that I will be invited to take part in optional follow-up surveys to evaluate my experience of undergoing genetic counselling and testing for ALS/MND. If I choose to not participate in the optional study it will not prevent me from accessing genetic testing or genetic counselling services that the Light the Way platform offers at no cost to me.
- [OPTIONAL] I agree to be contacted directly about future ethically approved studies based either on the results of sample analyses (including DNA), on my health status, or on other personal characteristics (for example, age, ethnicity, biological sex). I will not be obliged to take part in any such study once contacted.

Please review each bullet point above carefully. If you agree, please tick the box to continue. If you do not agree, you may close this window.

I agree to take part in the above study and by checking this box I am providing my signature in agreement at the current date and time.	<input type="checkbox"/>
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