

Short Title: Hereditary Sensory Neuropathy Serine trial (SENSE trial) Sponsor Code: XX/XXX



University College London Hospitals
NHS Foundation Trust

Study Title: Hereditary Sensory Neuropathy Serine trial (SENSE trial)

Dear X

Date

GP
Practice
Address

Commented [LM1]: Do we need to add the GP?

RE: Hereditary Sensory Neuropathy Serine trial (SENSE trial)

We are contacting you because you have been diagnosed with hereditary sensory neuropathy type 1 (HSN1) which is due to a mutation in either the SPTLC1 or SPTLC2 gene.

We would like to inform you that we are starting a clinical research drug trial at the National Hospital for Neurology & Neurosurgery specifically investigating a possible treatment for HSN1 called L-Serine. This will be called the SENSE trial (Hereditary Sensory Neuropathy Serine trial). We would like to discuss more about this with you in case you would like to participate.

We would like to invite you to attend an online patient information day where further details about the trial will be provided and you will have the opportunity to ask the research team any questions. The meeting will be chaired by Professor Mary M Reilly who will be leading the trial and Dr Matilde Laura. The meeting will also be attended by other patients with your condition and their family members.

This meeting will be held online on Tuesday 18th April 2023 3-5pm via Microsoft teams.

All the information you need to register and join the meeting is included further in this letter.

The **agenda** for the patient information day 18th April at 3pm will include:

15.00-15.05: Introduction
Professor Mary M Reilly

15.05-15.30 What is HSN1?
Professor Mary M Reilly

15.30-16.00: HSN1 Natural History Study
Dr Umaiyal Kugathan

16.00-16.30: Trial protocol including: drug treatment and placebo, trial assessments and participant requirements
Dr Matilde Laura and Dr Caroline Kramarz

16.30-17.00: Q & A
Prof. Mary M Reilly, Dr Matilde Laura, and Ms Maria Brezitski



UCLH is an NHS Foundation Trust comprising: University College Hospital (incorporating the Elizabeth Garrett Anderson Wing, the Macmillan Cancer Centre and University College Hospital at Westmoreland Street), Royal London Hospital for Integrated Medicine, Royal National Throat, Nose and Ear Hospital, National Hospital for Neurology and Neurosurgery at Queen Square and Cleveland Street, Institute of Sport, Exercise and Health, Hospital for Tropical Diseases, The Eastman Dental Hospital.

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You will need to register in advance in order to join the meeting.

This is so that we can maintain the security of the meeting. We ask that you do not forward this link so that we can keep track of who is attending. Relatives, friends and caregivers are welcome to register also.

Your attendance at the patient information day is entirely voluntary. Whether you attend the patient information day and if you later take part in the trial or not will have no effect on the medical care you receive. If you definitely don't want to hear any more about the trial, please let us know so we can update our records.

Meeting details:

We will be using Microsoft Teams to host the Online meeting (Webinar) so you can join using a computer, tablet, mobile phone.

Tuesday 18th April 2023 at 3pm

Duration: 2 hours

Topic: SENSE Trial Patient Information Day

Location: Online via Microsoft Teams

Register in advance for this meeting:

Please email: caroline.kramarz@nhs.net

After your email is received, you will receive a confirmation email containing information about joining the meeting which will include:

- A link to add a calendar invitation
- A link directly into the meeting (no passcode required)

When joining the meeting, you will have several options:

- Listening in from a phone if you do not have a computer/tablet/smartphone or are uncomfortable with those technologies.
- You can just watch and listen if you do not have a webcam or microphone on your computer.
- You can also turn off your webcam and not be seen for privacy.
- You can type any questions into the chat section if you don't have a microphone.

If you want any help or have any questions prior to the meeting, please contact us and we will do our best to help.

We look forward to seeing you on the 18th April 2023.

Yours sincerely,

Dr Caroline Kramarz
Clinical Research Fellow



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Email: caroline.kramarz@nhs.net

On Behalf of:

Professor Mary M Reilly
Professor of Clinical Neurology and Consultant Neurologist



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