



MERRY CHRISTMAS FROM THE TONiC TEAM

It is Christmas time and we wanted to say a big “thank you” to all our participants and carers who have contributed to the TONiC study! We appreciate that the questionnaire is long but this has helped us identify factors which affect quality of life in people with MND.

December 2022



TONiC_MND



TONiC
Trajectories of Outcome in Neurological Conditions
www.finders-study.org/tonic

Winter Greetings!

On behalf of all the TONiC investigators from around the UK, I would like to thank you for the time and effort you have put into completing and returning questionnaires. You have provided a wealth of detailed information which we are analysing to help us understand more about your life with MND. You have done your part, so enjoy the holiday season and we will let you know more about the follow up questionnaires in the next newsletter. More from us in 2023!



Would you like to contribute further to TONiC?

Genetic and Biomarker Research

As part of the TONiC study, we are joining forces with researchers in King's College London and University College London (UCL) to identify genetic and biological factors that affect MND.

What is involved?

We are asking you to donate samples which can be collected at home. Samples which are being collected are:

- King's College London: **saliva**
- UCL: **cheek swab, a finger-prick blood spot, a urine sample, and if possible, a stool sample** (you can choose which samples to provide and do not have to provide all samples).

‘Can I Take Part?’

If you have already completed a phase 3 TONiC questionnaire, you are eligible to take part in the London studies! We will first ask you to give us permission to link your sample results (Phase 5) to your completed TONiC questionnaire using your TONiC number.



Phase 3 Questionnaire

If you would like to take part in **Genetic and Biomarker Research** please contact the TONiC team, at wcft.tonic@nhs.net or 0151 556 3693, who will make sure you have a Phase 5 consent before sending you an email for you to forward to the London Research Teams. Due to Data Protection Regulations, we must ask you to directly contact London yourself (by forwarding the email or by phone). You will be asked to provide the London teams with the following information about yourself:

- Name
- Your TONiC Number—this will be provided by the TONiC team
- Postal Address
- Telephone Number



TONiC Recruitment so far:

MND patients recruited to Phase 2 and Phase 3 = 1,610

MND carers recruited to Phase 3 = 1,174

MND patients recruited to Phase 4 longitudinal study = 540

MND patients recruited to Phase 5 = 69

Findings

Thanks to all our MND participants and their carers who have very kindly taken the time to complete the TONiC questionnaires. TONiC findings are regularly updated on our website: <https://www.finders-study.org/research-papers>.

Where can I get more information about TONiC?

www.finders-study.org

wcf.tonic@nhs.net

Phone: 0151 556 3693

