

December 2023

TONiC-MND

MERRY CHRISTMAS

*We hope your holidays are
filled with laughter & love*

Thank you so much for your generous contributions to our TONiC study! We are very grateful for your ongoing partnership!

It is Christmas time once again and we wish you a merry Christmas and a Happy New Year!

Winter Greetings!



This has been an exciting and positive year for MND care and research in the UK, with the creation of the UK MND Research Institute. Integral to the Institute, TONiC is providing the outcome measures which will be offered to every person with MND in future, to study their illness and direct them to the most suitable trial for them.

December 2023

Genetic & Biomarker Research

We have been working with King's College London and University College London (UCL) to identify genetic and biological factors that affect MND.

- King's College need a saliva sample that you provide from home
- UCL would like a cheek swab, a finger-prick blood spot, a urine sample, and if possible, a stool sample (you do these at your home and can choose which samples to provide; you do not have to provide all samples).

You are eligible to take part in the London studies once you complete your Phase 3 questionnaire and consent for Phase 5, which will allow us to link your sample results to your completed TONiC questionnaire. We can then study how your symptoms and health history vary according to your genetics & biomarkers.

If you would like to take part in Genetic and Biomarker research, please contact the TONiC team (contact details on the next page).

If you want to make your previous completion of any TONiC questionnaire more valuable, please contact the team for more information about Phase 5. If you are then happy to sign, we can anonymously use your earlier information more effectively and may use your previous NHS information for research.




TONiC Recruitment updates:

MND patients recruited to Phase 2 and Phase 3 = 1,886
MND carers recruited to Phase 3 = 1,360
MND patients recruited to Phase 4 longitudinal study = 591
MND carers recruited to Phase 4 longitudinal study = 436
MND patients recruited to Phase 5 = 106





Recent TONiC Publications

-  Young CA, Ealing J, McDermott CJ, Williams TL, Al-Chalabi A, Majeed T, Talbot K, Harrower T, Faull C, Malaspina A, Annadale J, Mills RJ, Tennant A; Tonic Study Group. **Prevalence of depression in amyotrophic lateral sclerosis/motor neuron disease: multi-attribute ascertainment and trajectories over 30 months.** Amyotroph Lateral Scler Frontotemporal Degener. 2023;24(1-2):82-90.
-  Young CA, Ealing J, McDermott CJ, Williams TL, Al-Chalabi A, Majeed T, Talbot K, Harrower T, Faull C, Malaspina A, Annadale J, Mills RJ, Tennant A on behalf of the TONiC Study Group. **Measuring disability in amyotrophic lateral sclerosis/motor neuron disease: the WHODAS 2.0-36, WHODAS 2.0-32, and WHODAS 2.0-12.** Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration. 2023;24(1-2):63-70.
-  Young C, Ealing J, McDermott C, Williams T, Al-Chalabi A, Majeed T, Roberts R, Mills R, Tennant A. **Fatigue and anxiety mediate the effect of dyspnea on quality of life in amyotrophic lateral sclerosis.** Amyotroph Lateral Scler Frontotemporal Degener. 2022; 23(5-6):390-8.

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:
<http://www.finders-study.org/research-papers>

For more information, please visit www.finders-study.org (or simply scan the QR code on this page!)

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*Looking forward to hearing from you
in the New Year!*

