

December 2013

I am writing to wish you a very Happy Christmas, and to thank you warmly for contributing to the TIME Project, which is in its 10th anniversary year.

The study remains highly active, with continuing recruitment of new patients from around the UK and abroad.

Many of you have contributed to the projects being run by Serge Hoefijzers in Edinburgh and Kathryn Atherton in Oxford (pictured below). Thank you very much for your help with these. Both Kathryn and Serge have interesting findings which will, we hope, soon be published. In brief, both have been investigating the 'accelerated forgetting' that occurs in some people with Transient Epileptic Amnesia (TEA). While the timing of this forgetting may well vary from person to person, the new findings suggest that much of it occurs within hours after learning. We had wondered whether there might be a disproportionate loss of information overnight, during sleep, but this has not, so far, proved to be the case. We will learn from the results of Serge's work, which are still being analysed, whether memory in people with TEA may benefit particularly from rest after learning. Kathryn is analysing the results of brain wave recording and brain scans which may shed further light on the causes of memory loss in TEA. Both Serge and Kathryn will be submitting their PhD theses in the New Year.

We have published three research papers this year. Serge led on a study which shows that accelerated forgetting is unlikely to be due to an initial problem with learning (*Neuropsychologia*, 2013;51:1549-1555). Chris Butler wrote a study of brain imaging in TEA, using a variety of methods, which shows that both areas in the temporal lobes, especially the 'medial temporal lobes', and in the frontal lobes, are involved in TEA, but structural changes in these regions do not appear to explain either accelerated forgetting or the loss of memory for remote events ('autobiographical amnesia') which occurs in TEA (*Epilepsy and Behaviour*, 2013;28:363-369). I coordinated a paper describing the work Fraser Milton, Nils Muhlert, Chris Butler and I have done together since the launch of the TIME project (*Epilepsy and Behaviour*, 2013;26:335-34). We have between us written three chapters or encyclopaedia entries on TEA this year and Chris Butler has published a major review paper on transient amnesic syndromes in *Nature Reviews Neurology* with Torsten Bartsch in Germany (doi:10.1038/nrneuro.2012.264).



Two members of the team have new jobs. Chris Butler, who supervises Kathryn, has been awarded an MRC Clinician Scientist post in Oxford, which will enable him to continue to work on TEA and a related disorder caused by inflammation in the temporal lobes. Michaela Dewar, who supervises Serge, has been appointed a



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Prof Narinder Kapur, London

Prof John Hodges, Sydney
Prof Facundo Manes, Buenos Aires
Dr Nils Muhlert, London
Dr Fraser Milton, Exeter

Research Leader in Psychology at Heriot Watt University, where she will continue her work on how memory is affected by interfering material and improved by rest.

I have remained in close touch with two people with epilepsy in the US who have independently thought and written a lot about memory problems from which they suffer, very similar to those that occur in TEA. I hope that a description of their experiences, including some of their writings, will be published next year. *If anyone would like to join their confidential e-discussion group, to compare experiences and exchange ideas, please send me an email and I will put you in touch with them.*

We are awaiting the outcome of a grant application which would enable us to follow up the folk we saw first in 2003-5, to learn more about the long-term outcome of TEA. This has not been studied previously. The grant would also enable us to find out, for the first time, whether treatment of TEA and TLE improves memory generally (as well, of course, as stopping seizures).

We have updated our website, and are in the process of providing links to, or the manuscripts of, all the papers we have published on TEA, for ease of access.

As before, we are very grateful to the growing number of participants who have agreed to donate their brains to the project, and we will be in touch with new recruits about this in due course. This provides the best opportunity to learn about the changes in the brain that give rise to TEA and the memory problems that occur with it. But we are also glad to say that so far no donation of this kind has reached us.

Once again, we are extremely grateful for your help which has made this project possible. If any of you are keen to help us plan our future work, or have any queries or suggestions, please drop me a line.

The British Medical Journal is building up a database of 'patient reviewers' who would be interested in commenting occasionally on work submitted to the journal, and/or writing short perspectives. If anyone would like me to put them in touch with the BMJ, please let me know.

I will probably be writing again in the New Year, asking participants to give permission to indefinite retention of the information we have gathered in the course of the project. We originally sought permission for a limited period, but as the study is still going strong we need to seek your consent to an extension.

We wish you a very Happy Christmas and New Year



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