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The patient's perspective; follow up Foix-Chavany-Marie syndrome secondary to bilateral traumatic operculum injury (4.1.19 9 pm) [1255 words]

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A novel, unusual case of Foix-Chavany-Marie syndrome (FCMS) was recently reported in this Journal [1]. The paper was written under COPE guidelines, with the patient described as a “62 year-old right-hand-dominant (semi-) retired male academic ...” That patient is one of the authors of this Letter (RT). He cannot help smiling and finding irony in the situation whereby, having written close to 150 scientific papers in his career, near its end a paper has been written about himself. More seriously, he and his Hospital Consultant (AH) are of the view that it provides a valuable opportunity to describe a rare neurological syndrome from a patient's perspective and how recovery from traumatic brain injury with FCMS has evolved in the 30 months since his bike accident. The paucity of patient reports about their own experiences is a current gap in the medical literature, and this Letter might then be useful to neurologists in the future caring for a patient with similar symptoms.

RT believes the accident was a one-in-a-million freak; he has biked for 55 years averaging about 4000 miles a year without accident. There were no other people or vehicles involved, and the weather was good. The front wheel locked in a rutted road in rural Suffolk, the bike spun through 180°, and he was tossed onto the right-hand side of his head. He was wearing a helmet, it cracked badly, but it probably saved his life. He was transferred by Air Ambulance to Ipswich District General Hospital, intubated and CT head scanned. Hours later, he was transferred to Addenbrookes Hospital neurocritical care unit where he spent the next seven weeks. He spent two weeks in intensive care and then three in the High Dependency Ward; he remembers nothing of these weeks. He remembers some details of the final two weeks in the Rehabilitation Ward. It is now clear that a complete absence of swallowing and speech were the main causes of medical concern, and FCMS was only diagnosed after four weeks and many MRI scans. Despite extensive literature searches, the doctors could give no guarantees to RT's family about the eventual outcome: ‘we genuinely do not know’. To everyone's amazement, RT uttered his first words after six weeks: ‘Ben [a fellow patient], don't do that!’ One week later, he was transferred to the Queen Elizabeth Birmingham Hospital close to his home, he spent ten days there, then was discharged. RT saw the Neurology team in Cambridge as an Outpatient four months later, then again after ten months, and had a full assessment day in the Wolfson Brain Unit at Addenbrookes fourteen months after his accident. In many of the Staff's words, ‘one year ago, we would not have put money on this [good] outcome’. He has been undergoing therapy as an Outpatient at the QE for the last two years.

RT has spent hours wondering how he got to his present [good] state: was he unlucky, lucky, or did he make his own luck? Probably all three. Unlucky to have the accident in the first place, lucky to be treated by two superb large hospitals, but once his brain started to ‘engage’ he perhaps helped himself by doing exactly what the medical professionals advised. He has worked over 40 years in academia and been involved with huge numbers of undergraduates and PhD postgraduates. He understands that there are times professionals have to be careful what they say, so he quickly empathised with the Cambridge doctors who did not know what was going to happen. It was the same story with the Birmingham therapists.

To details. Once the nasal feed was withdrawn one week after getting to Birmingham, he drank and ate exactly what the speech therapists advised. Once home, again on advice, for several months he slept most afternoons for 2-3 hours in addition to 12 hours overnight. Luckily, the autumnal weather in October 2016 was superb, so he could walk with support every day, increasing from one quarter to four miles over two months. Early on, he was advised that his balance was not perfect, so he engaged hourly with the gym physiotherapists at the QE twice a week for three months. He took their advice that 'perhaps it was too early to get back on your bike [in January 2017]', and only re-started in April, nine months after the accident. He did not drive a car until May, and only after assessment by a DVLA disability centre. He was lucky that he was (semi-) retired from paid employment, so there was no pressure to 'get back to work as soon as possible' and he had huge love from his wife, three children and many friends. Depression, or 'why me?', never entered his head.

The recovery of speech has been fronted by Speech and Language Therapists at the QE. RT remembers being told early on by a senior person that, in her experience, full recovery was likely to take 5+ years, but not to fight it. At his first full SLT session, the therapist advised 'speaking softly, slowly, using short words, and thinking before you speak'. He has tried to follow this advice ever since, not always successfully! He is now signed off, not because his speech is fully recovered (the 'before' and 'after' clips of his voice in the Supplementary data of the paper are revealing), but because the professionals believe they have done all they can to give appropriate exercises and coping strategies.

Two final points. With an American colleague, Tomas Baer, when the accident happened RT was halfway through preparation of a major review article in one branch of experimental chemical physics. Five months later, he started to concentrate but only for 1 h per day, so he suggested to Tomas that he carry on alone because of RT's health. Tomas would hear nothing of it, 'end of matter, period'. The review was finally submitted about six months late in February 2017 and published in May [2]. RT is eternally grateful; he has no doubt that this process helped enormously his recovery and self-confidence. Finally, RT used to be an accomplished amateur pianist, but found to his dismay that initially he could not coordinate two hands playing together; the brain was not sending correct messages to left and right hands. Again, it was the QE therapists who said not to fight this but try to play for 3-4 minutes every day, and with luck new brain connectivities would be established. It took about 3-6 months, but that is exactly what happened.

RT now cycles the distances he covered before the accident, his swallowing is 99.5% there, and he hopes that full speech may recover in a few more years. If it does not, he will not worry as he can communicate with family / friends and he now can give undergraduate lectures and conference talks (helped by a microphone and lots of water). RT hopes that this Letter may help others patients / neurologists in the future where the former has suspected FCMS. He also wants to say Thank You to the huge number of people involved with him from the start, especially his cycling colleague and the Essex Herts Air Ambulance team who got him to Ipswich within the 'golden hour' and the nursing staff at Addenbrookes who had to deal with 'Restless Richard'. He also appreciates how excellent the National Health Service in the UK is, especially for serious life-threatening cases. A talk about his recovery, made in February 2018 for the Air Ambulance Trust, is on YouTube [3].

[1] Digby R, Wells A, Menon D and Helmy A (2018). Foix-Chavany-Marie syndrome secondary to bilateral traumatic operculum injury. *Acta Neurochirurgica* **160**, 2303–2305.

[2] Baer T and Tuckett RP (2017). Advances in Threshold Photoelectron and Threshold Photoelectron Photoion Coincidence spectroscopies. *Phys Chem Chem Phys* **19**, 9698–9723.

[3] <https://www.youtube.com/watch?v=63-3lLezXfo>