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To: All members of the Clinical Working Group for the 'Optimal Pathway for Adults: TBI'

Viz: Mr Antonio Belli, Dr Shai Betteridge, Professor Alan Carson, Dr Paul Cooper, Dr Mike Dilley, Miranda Gardner, Dr Richard Greenwood, Dr Colette Griffin, Professor Peter Hutchinson, Dr Peter Jenkins, Dr Lucia Li, Dr Clarence Liu, Professor David Sharp, Dr Richard Sylvester, Dr Jacqueline Twelftree, Dr Martha Turner, Professor Mark Wilson, Dr Sancho Wong, Georgina Carr.

5 September 2023

Dear Clinical Working Group Members

While I respect the hard work and scholarship that has gone into the preparation of the TBI Pathway, I am concerned that it does not recognize, nor incorporate, post-traumatic hypopituitarism. The multi-disciplinary group that you advocate does not even include an endocrinologist. I will set out the reasons for my concern under the headings of research, the numbers involved, and the gravity of the symptoms, adding some personal stories of people I have met or corresponded with.

Research

Since four of you were also authors of the 2017 British Neurotrauma Group guidance entitled 'The screening and management of pituitary dysfunction following traumatic brain injury' I imagine you are more familiar with the research than I am. Suffice it to point out that (to quote that guidance)

A meta-analysis of 14 studies reported the pooled prevalence of PTHP to be 27.5%.¹¹ When classified according to the severity of TBI based on the Glasgow Coma Scale (GCS) score, pituitary dysfunction was detected in 16.8% of patients with mild TBI (GCS 13–15), 10.9% with moderate TBI (GCS 9–12) and 35.5% with severe TBI (GCS 3–8).¹¹

I agree there are reasons why the percentage may not be as high as this, but the very possibility that a **quarter** of TBIs of all degrees of severity may result in pituitary damage should guarantee its inclusion in the Pathway.

The numbers involved

The numbers of sufferers are very large indeed. Research* suggests that incidence of PTHP in the total population is 50:100,000 which (to quote the author) 'results in a high number of patients affected.' In fact, taking into account the two decades over which the condition has remained virtually undiagnosed, the likely figure is between half a million and a million, an estimate which the BBC was happy to air on its 'Inside Health' programme.

The gravity of the symptoms

Given the unrecognized nature of this condition, there is possibly an assumption that it cannot be too serious. However, one has only to look at NICE's Technology Appraisal Guidance TA64, to see that deficiency in growth hormone alone - the hormone most commonly compromised -

causes cardiovascular disease, liver disease, osteoporosis, obesity and fatigue. These are indeed serious physical illnesses but arguably worse are the mental effects – depression, anxiety, brain fog, loss of concentration, and suicidal ideation. The suicide rate after head injury is four times the norm.

My experience

My own experience through Headinjuryhypo and more recently Christopher Lane Trust bears this out. Since our son's suicide I have both met and corresponded with many people with hypopituitarism including a 53-year-old musician whose cardiovascular problems over ten years led to long stays in hospital and the insertion of many stents, who was only saved from committing suicide by the test result that showed that he had growth hormone deficiency and gave him hope of at least partial recovery. (I should add here that it was only through his own research and persistence that he had the test at all.) I also met and corresponded with a woman who suffered from cortisol and growth hormone deficiency for 27 years, her fatigue costing her a promising career with British Telecom, before she was diagnosed. She was saved from jumping in front of a car by her husband. Thirdly I should mention a Scottish man who was hit on the head by a golf club when he was ten, suffered from impotence which destroyed his relationship, obesity and liver disease, fatigue which made it impossible for him to work, who made two suicide attempts and remained undiagnosed with growth hormone deficiency for 35 years. He wrote to me once 'I'm not scared of dying just so depressed I didn't get a chance to live' and these words haunt me. I know all these people personally, and could give many more examples of extreme human misery and wasted life. It is appalling to think how many others there undoubtedly are, in the shadows.

The consequences of omitting PTHP from the Pathway

These people suffered as they did because the doctors treating them did not recognize what could be causing their symptoms. And the doctors did not know because they were not told. NICE's head injury guidance was silent about the risk for roughly 20 years.

It is encouraging that NICE's new version now includes it, but if medics focus on your Pathway instead there will be no improvement, because you are perpetuating the silence.

Currently this enormous group of sufferers are 'diagnosed' with chronic fatigue syndrome, fibromyalgia, metabolic syndrome, depression etc. If they are sportspeople they may be told they have chronic traumatic encephalopathy. They are given no hope. It is no wonder that many commit suicide.

Please do your duty as doctors who care for their patients and revise the Pathway!

The CEO of NNAG is included in this letter. I am sending a copy to the CEOs of the eight other organisations who endorsed this pathway, as well as the Royal Colleges and Societies who as stakeholders supported the inclusion of hypopituitarism in the NICE head injury guideline. I also intend to send it to a selection of medical journalists.

Yours sincerely

Joanna Lane

*Fernandez-Rodriguez E et al, Hypopituitarism following traumatic brain injury: determining factors for diagnosis, *Front Endocrinol* 25 August 2011 doi: 10.3389/fendo.2011.00025
http://www.frontiersin.org/Pituitary_Endocrinology/10.3389/fendo.2011.00025/full