LETTER TO THE SCOTTISH INTER-COLLEGIATE GUIDELINES NETWORK

28 Southwood Avenue
Coulsdon
Surrey
CR5 2DT

Dr Keith Brown, Chair
SIGN
Healthcare Improvement Scotland
Gyle Square
1 South Gyle Crescent
Edinburgh EH12 9EB

16 October 2012

Dear Dr Brown
We understand that SIGN's forthcoming guideline on rehabilitation after brain injury does not at present mention the significant risk of post-traumatic hypopituitarism. In our opinion, if the guideline is to be seen as a credible review of the up-to-date literature it should contain pragmatic guidance such as:

> Post-traumatic hypopituitarism is not uncommon after traumatic brain injury and pituitary function tests should be considered in anyone presenting with symptoms which might be indicative of deficits in one or more pituitary hormones. There should be close and expert follow-up after moderate or severe traumatic brain injury as some symptoms can go unrecognized for years.

- Agha A, Thompson CJ. Anterior pituitary dysfunction following traumatic brain injury (TBI) Clinical Endocrinology 2006; 64 (5): 481–488, May 2006 DOI: 10.1111/j.1365-2265.2006.02517.x
http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2265.2006.02517.x/full

- Dusick, JR Wang CT, Cohan P, Swerdloff R, Kelly DF. Pathophysiology of hypopituitarism in the setting of brain injury. Pituitary 2012; 15(1): 2-9. DOI: 10.1007/s11102-008-0130-6

Dr Simon Ashwell, Consultant Endocrinologist, South Tees Hospitals NHS Foundation Trust
Professor Michael Barnes, Chair of UK Acquired Brain Injury Foundation
Dr Michael Beckett, Consultant in Emergency Medicine, West Middlesex University Hospital
Mr Antonio Belli, Consultant Neurosurgeon, Birmingham University Hospitals NHS Trust
Professor Julian F Bion, Professor of Intensive Care Medicine, University of Birmingham
Dr Peter Brambleby, FFPH, FRCP(Edin), Independent Public Health Consultant
Dr Maria Bredow, Community Paediatrician, North Bristol NHS Trust
Dr Robert Brenner, Neurologist, The Royal Free London NHS Foundation Trust
Miss Jennifer Brown, Consultant Neurosurgeon, Institute of Neurological Sciences, and Royal Hospital for Sick Children, Glasgow
Child Brain Injury Trust
Dr Andrew Coe, Paediatrician, University Hospitals Coventry and Warwickshire
Dr Andrew Curran, Paediatric Neurologist, Alder Hey Children's Hospital
Dr Nikolaos Daskas, Paediatrician and Paediatric Endocrinology Research Fellow, Royal Hospital for Children, Bristol
Dr Richard Fitzgerald, Consultant Radiologist, Royal Wolverhampton Hospitals NHS Trust
Professor Peter Fleming, Consultant Paediatrician, Royal Hospital for Children, Bristol
Professor Clare Fowler, Consultant Uro-neurologist, National Hospital for Neurology and Neurosurgery
Dr Andrew Gallagher, Consultant Paediatrician, Worcestershire Acute Hospitals NHS Trust
Dr Tom Goodfellow, Consultant Radiologist, University Hospitals Coventry and Warwickshire NHS Trust
Mr Richard Grunewald, Consultant Neurologist, Sheffield Teaching Hospitals NHS Foundation
Professor Julian P Hamilton-Shield, Consultant Paediatrician, Royal Hospital for Children, Bristol
Headway – the Brain Injury Association, Chief Executive Officer Peter McCabe
Professor Peter Hindmarsh, Paediatric Endocrinologist, Great Ormond Street Hospital, London
Dr Zilla Huma, Paediatric Endocrinologist, Heatherwood and Wexham Park Hospitals NHS Trust
Dr Partha Kar, Consultant Endocrinologist, Portsmouth Hospitals NHS Trust
Dr Tara Kearney, Consultant Endocrinologist, Salford Royal Hospital

Professor Christopher Kelnar, Honorary Professor of Paediatric Endocrinology, University of Edinburgh
Dr Tim Kenny, Consultant Editor and Lead Author, Patient UK
Professor Jai Kulkarni, Rehabilitation Consultant, University Hospitals of South Manchester
Dr Raman Lakshman, Consultant Paediatrician, West Suffolk Hospital
Mr Bruce Mathew, Consultant Neurosurgeon, Hull Royal Infirmary
Professor John Monson, Consultant Physician and Emeritus Professor Clinical Endocrinology, St Bartholomew's and the Royal London Hospitals
Miss Anne Moore, Consultant Neurosurgeon, Derriford Hospital, Plymouth, President of the Society of British Neurological Surgeons
Miss Lynn Myles, Consultant Neurosurgeon, Western General Hospital, Edinburgh
Dr Paul Newrick, Consultant Physician and Endocrinologist, Worcestershire Acute Hospitals NHS Trust
Professor David Nutt, Neuropsychopharmacologist, Imperial College, London
Dr Charles O'Donnell, Consultant in Emergency and Intensive Care Medicine, Whipps Cross University Hospital
Professor Michael Oddy, Director of Rehabilitation Services, Brain Injury Rehabilitation Trust
The Pituitary Foundation, Chief Executive Officer, Ms Menai Owen-Jones*
Dr Fey Probst, Consultant in Emergency Medicine, Charing Cross Hospital
Dr Harpal Randeva, Consultant Endocrinologist, University Hospitals Coventry and Warwickshire NHS Trust
Society of British Neurological Surgeons
Dr David Shakespeare, Consultant in Neurological Rehabilitation Medicine, Lancashire Teaching Hospitals Foundation Trust
Mr Patrick Statham, Consultant Neurosurgeon, Western General Hospital, Edinburgh
Mr Jerome St George, Consultant Neurosurgeon, Western General Hospital, Edinburgh
Mr James Steers, Consultant Neurosurgeon (Retired) Edinburgh, Past President
Ms Lisa Turan, Chief Executive Officer of the Child Brain Injury Trust
UK Acquired Brain Injury Foundation
Dr Krystyna Walton, Neurorehabilitation Consultant, Salford Royal NHS Foundation Trust
Dr Jane Young, Consultant Radiologist, Whittington NHS Trust
Mr and Mrs J B Lane, parents
*The Pituitary Foundation supports the inclusion of PTHP in the guideline but does not wish to commit on the degree of risk.
Cc: Dr Roberta James, Dr Moray Nairn, Dr Sara Twaddle, Ms Gaynor Rattray

SIGN'S FIRST REFUSAL

SIGN
Scottish Intercollegiate Guidelines Network

Mrs Joanna Lane
28 Southwodd Avenue
Coulsdon
Surrey
CR5 2DT

26 October 2012

Dear Mrs Lane

**SIGN Guideline on Brain Injury Rehabilitation in Adults**

Thank you for your letters of 15 and 6 October concerning the above guideline.

SIGN agrees that post-traumatic hypopituitarism is a condition that would benefit from greater public and clinical recognition. However, a clinical guideline is not about raising the profile of particular conditions, but about presenting the clinical community with the best evidence to diagnose and treat. Brain injury is an extremely wide reaching topic and, as such, it would never be possible to encompass all possible areas of investigation. Through consulting with clinicians, we believe that the priorities for people suffering from brain injury are effective referral from acute or primary care to specialist services, management of patients beyond the first 72 hours and assessment of their rehabilitation needs. Given this broad remit, it has not been possible to single out specific patient subgroups. So although we are not focusing on post-traumatic hypopituitarism, the needs of people with this condition, like people with the many other conditions that may result from a brain injury, would fall within the remit of the guideline.

The guideline is due to be published in the spring of 2013.

With kind regards
Yours sincerely

Dr K W Brown
Chair, SIGN

**Gyle Square**
1 South Gyle Crescent
Edinburgh
EH12 9EB
**0131 623 4720**
**www.sign.ac.uk**

SIGN'S SECOND REFUSAL A OFFERING SEPARATE GUIDELINE WHICH NEVER MATERIALISED

SIGN
Scottish Intercollegiate Guidelines Network

Joanna Lane
28 Southwood Avenue
Coulsdon
Surrey
CR5 2DT
13 February 2013

Dear Ms Lane,

Thank you for your letter of 4 February 2013. My understanding is that although you appreciate that it was the decision of the guideline development group not to include the suggested sentences about alerting healthcare professionals to the risk of post-traumatic hypopituitarism after brain injury, there remained two questions that you wished to pose to the guideline development group:

**What steps you have taken to ensure that the guideline will enable the numerous potential PTHP patients to be referred to the right people (i.e. endocrinologists), when many of those responsible for the referral will have no idea that PTHP exists?**

**Am I right in assuming that the group would support any reasonable steps which would assist in the diagnosis of a known potential problem, where the condition is treatable? Or, to put it more simply, does the group want PTHP patients to be diagnosed?**

In response I forwarded your letter to the guideline development group and received several responses either by telephone or email.

The guideline development group chair and other group members were comfortable that the issue had been discussed by the group and it wasn't possible to add it into the guideline without literature searching. One member stated that the topic was not one which was generated by the initial process of question-setting, either by the group or by the wider canvassing of the professional brain injury rehabilitation community. For example, endocrinology colleagues of one member confirmed they were are aware of this condition and ask hypopituitary patients if they have had a head injury but neither had ever come across a case. Another group member suspected that even were the issue to have been suggested at the start and then included as a key question it is distinctly possible or even likely (given our experience of the sketchy/poor quality evidence base on other pressing clinical issues in the Guideline) that there would not have been sufficient, and/or sufficiently robust, evidence to make a clear recommendation on this issue using the SIGN approach. The chair also felt this required a much more detailed level of investigation than the rest of the guideline was recommending.

**Gyle Square**
1 South Gyle Crescent
Edinburgh
EH12 9EB

**0131 623 4720**
**www.sign.ac.uk**

Two group members looked at the Fernandez-Gonzalez paper and one also saw a rapid response from you to a paper about suicide prevention in the BMJ dated 22nd January 2013. One member pointed out that although the Fernandez-Gonzalez paper raises a potentially significant clinical issue that may occur in some patients, it is a non-systematic review with no clear methodology for selection of studies and would not be a sufficient basis for any SIGN recommendation. Both group members had concerns about the accuracy of the incidence estimate in the concluding section of the Fernandez-Gonzalez paper, which is based on a body of hand-picked studies quoted in the paper with a very wide range of estimates. They felt that the study did not reflect the true incidence and prevalence of the condition and one member stated that that the figure of 50/100,000 could overstate the issue based on his reading the studies quoted. They agreed in fact, there was a suggestion that the true epidemiology was not well understood, which would be the pre-requisite for any further evidence based recommendations. One member also revealed that research proposals were in planning in NHS Lothian to understand and quantify the condition more accurately. Another group member wondered if there is any scope to make a brief general statement about the issue in the recommendations for further research that would remain consistent with the SIGN process and approach and I think that this is something we could do.

The group members acknowledged that you were asking for greater awareness of the possibility of this condition amongst clinicians dealing with patients some time after moderate or severe TBI.. They think that is a reasonable aim to have and the Fernandez-Gonzalez paper provides some justification for raising such awareness of the possibility of PTPH with clinicians. They did point out that perhaps the SIGN guideline process isn't the best way to raise that awareness

As the issue therefore is mainly about awareness raising, one group member asked if there are any other suggestions we can offer to you by which you could raise awareness of the possibility of this condition as a late sequelae in some head injury patients, and perhaps stimulate more research on the epidemiology, identification, and clinical management of this issue.

As it is now the basis for a separate submission to Healthcare Improvement Scotland for a stand-alone guideline on PTHP, the chair felt this to be the most appropriate way of taking this topic forward and accurately reflecting the evidence base. Additionally, Moray Nairn has been in communication with the Scottish Acquired Brain Injury Network (SABIN). SABIN has suggested that it can take a lead on raising awareness of PTHP in the following ways:

- Supporting research proposals to accurately measure incidence and prevalence of the condition in Scotland
- Provide a summary of the current evidence based knowledge to assist healthcare professionals
- Liaise with the Scottish Government to find routes to highlight what is known about the condition to GPs

- Link to the SIGN guidelines (#110 and #130) so that people with a brain injury are managed most effectively through collaboration between national guidelines and managed care network paradigms.

These steps are likely to take several months, but it was felt results could be achieved in the first half of 2013.

In summary, I hope that you are satisfied that the SIGN executive is reflecting the views and wishes of the guideline development group regarding the forthcoming guideline while remaining within the boundaries of our methodology. I also hope that you feel heartened that although the group is constrained by working within existing evidence base, there is support for raising awareness, although not driven directly by SIGN, of PTHP after a brain injury and agreement that it is a topic in need of further research.

Yours Sincerely,

Keith Brown

Chair of SIGN

QUESTION AND ANSWER IN SCOTTISH PARLIAMENT



The Scottish Parliament
Parlamaid na h-Alba



## Motions, Questions and Answers Search

New Search | Refine Search

**Question S4W-10187: Jackie Baillie, Dumbarton, Scottish Labour, Date Lodged: 11/10/2012**

To ask the Scottish Government whether the March 2013 Scottish Intercollegiate Guidelines Network (SIGN) guideline on head injury will refer to post traumatic hypopituitarism (PTHP).

**Answered by Alex Neil (01/11/2012):**

While recognising that post traumatic hypopituitarism is an important topic, SIGN is unable to include it in the remit of this guideline. A proposal to develop a separate guideline on this topic has been received and it is currently being assessed for inclusion in the future Healthcare Improvement Scotland work programme.

**Current Status:** Answered by Alex Neil on 01/11/2012

New Search | Refine Search

**Search help**

• Motions and Questions search help