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## The tip of the iceberg in idiopathic intracranial hypertension

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Running title: Tip of the IIH iceberg

## **The tip of the iceberg in idiopathic intracranial hypertension**

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Running title: Tip of the IIH iceberg

Lumbar puncture (LP) is a critical part of the diagnostic algorithm to measure opening pressure and contents in all those presenting with raised intracranial pressure (ICP).[1-4] The diagnosis of IIH is one of exclusion, and at the point of initial presentation, there is no clinically recognised sign that can diagnose IIH above other causes of raised ICP.[1-4] Gates *et al.* [5] raise an interesting discussion regarding the utility of needle tip type for the lumbar puncture (LP) procedure in those who are diagnosed subsequently with idiopathic intracranial hypertension (IIH).[5] Whilst the first guidelines in IIH [1] and the European IIH guidelines [2] have recommended that therapeutic serial LPs are not advocated as a long-term treatment strategy for IIH due to the lack of high-quality peer reviewed evidence [1,2], to which the authors agree, we accept that there are centres that continue this practice.

There are established complications of LPs which include local discomfort, low pressure headaches and more rarely infection or local haemorrhage.[6] Although LP induces a transient reduction of CSF pressure the effect is typically short lived with pressures found to rise rapidly after the procedure, despite the amount of CSF drained.[7] Therapeutic LP has limited application for managing headache, as headache improves in 71%, but the improvement is small (1 point on the verbal rating score 0-10) and there is also a 64% chance of a significant headache exacerbation in the week following LP in IIH patients.[8] More importantly, those with IIH frequently report high pain scores and a very negative emotional experience when they undergo a LP.[9]. IIH is associated with poor quality of life and the impact of LP needle type utilised (atraumatic versus cutting needle) have not been evaluated to consider the long term pros and cons for the patient.[10]

Running title: Tip of the IIH iceberg

As the incidence of IIH has been documented to rise, with an unexpected increase in unsolicited hospital admissions [11], it is important that the natural history of the condition is considered, as relapse is common, even in those who appear to initially have a rapid improvement post LP. [12] Expert clinical experience, as cited by Gates *et al.*[5], provides important insights to inform hypothesis driven research.

Within the United Kingdom the authors have occasionally seen the phenomenon of IIH resolution post LP, we have tended to observe that these patients seen may be on a mild spectrum of the disease. We have not seen patients with moderate to severe IIH go into prolonged remission immediately following an LP. So, before the call for a change to clinical practice without clear evidence [5], more robust research is needed to evaluate the extent of resolution of IIH post LP, the role of needle type, the baseline disease severity in these patients, and the duration of the remission following LP. Our experience of following patient's long term, is that the disease can fluctuate and in those that settle following an LP, without further intervention, they typically re-present with recurrent disease further down the line. With the emergence of telemetric ICP monitoring in IIH we are gaining fascinating insight into the relationship between ICP and clinical signs and the dramatic changes in ICP seen over the course of progressing disease. We have noted that ICP varies widely in IIH with progression from diagnosis, to fulminant disease with declining vision, until ICP was temporarily controlled with lumbar drainage (which did not reverse the disease process) and ultimately the ICP settled following a definitive CSF shunt [12]. The lumbar puncture needle choice may be the tip of the iceberg in managing and understanding raised ICP in IIH.

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## Declarations or Conflicts of Interest

No authors contributing have a conflict of interest in the subject matter.

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## Contributor Statement

All authors have read and approved the final manuscript.