

CSF LEAK ASSOCIATION Patient Representative Appointment

This biography has been prepared for the Annual General Meeting on 19 November 2020.

Patient Representative

Our patient representative is not a member of the Board of Trustees and does not have a formal decision-making role within the charity. Their remit is to represent our membership and patients more generally within the organisation and, in particular, on the Medical Advisory Committee.

Patient Representatives are appointed for a set term and anyone within the membership of the CSF Leak Association may apply for the position, after which their application will be considered by the Board who make appointments. The patient representative will normally be a current or former CSF leak sufferer.

The Board of Trustees has received one expression of interest for the position of patient representative, from Sarah Med. Sarah is the current patient rep and has played an active role on the MAC. The Board is very pleased to support her reappointment.

Sarah Mead

Sarah lives in a market town near Cambridge and worked as a Botanical Illustrator until illness made this no longer possible. Sarah's CSF her leak started spontaneously in January 2010. She has been treated in various UK hospitals and her final treatment in Germany in 2015 appears to have worked, but she is now being treated for rebound high pressure issues. Sarah, like many leakers, has also been diagnosed with Ehlers Danlos III (an inter-connective tissue disorder. When she is able, Sarah runs a small design company from home and is also a classically trained singer. Sarah was a co-founder of the charity and is out current patient representative.