

SPSO decision report

Case: 202001107, Lothian NHS Board - Acute Division
Sector: Health
Subject: Clinical treatment / diagnosis
Decision: upheld, recommendations

Summary

C complained that the board failed to provide their child (A) with reasonable care and treatment. C understood that A had a condition known as paediatric acute-onset neuropsychiatric syndrome (PANS) or paediatric autoimmune neuropsychiatric disorder associated with streptococcus (PANDAS, infection-induced autoimmune conditions that disrupt children's normal neurologic functioning). A had been given intravenous immunoglobulin (IVIG, the use of a mixture of antibodies to treat a number of health conditions) treatment but this had been discontinued and stopped suddenly. C stated that the treatment should not have been stopped and wanted this treatment to be available to A in the future if A needed it.

We took independent advice from a consultant neurologist (a specialist in the diagnosis and treatment of disorders of the nervous system). We found that the treatment was not suitable for A and the possible diagnoses for A's condition. We considered that it was appropriate the treatment stopped. However, we noted that it should never have been given as a treatment at any stage. We also found that the board sent spinal fluid for testing to a laboratory in England that did not arrive there. While this was not the outcome C was seeking, we upheld the complaint on the basis that IVIG should not have not have been given to A at all.

Recommendations

What we asked the organisation to do in this case:

- Apologise to A for putting in place a treatment plan for intravenous immunoglobulin (IVIG) when this was not an appropriate treatment. The apology should meet the standards set out in the SPSO guidelines on apology available at www.spsso.org.uk/information-leaflets.

What we said should change to put things right in future:

- Ensure clinical staff are aware of the circumstances in which IVIG is an appropriate treatment.
- Ensure insofar as possible, that a similar situation with fluid sent for testing does not arise in future.

We have asked the organisation to provide us with evidence that they have implemented the recommendations we have made on this case by the deadline we set.