

SPSO decision report

Case: 201508637, Highland NHS Board
Sector: health
Subject: clinical treatment / diagnosis
Outcome: upheld, recommendations

Summary

Ms C, and advocacy and support worker, complained on behalf of Ms B about the care and treatment received by Ms B's daughter (Miss A). In particular, that there was an unreasonable delay by the board in diagnosing Miss A's genetic condition. Ms C also complained that Ms B was wrongly advised during the new-born period that Miss A, who was born at Raigmore Hospital, did not have the genetic condition. Finally, Ms C complained that the board's replies to her complaints were unreasonable.

We took independent medical advice. We found that there was an unreasonable delay in diagnosing that Miss A had the genetic condition. We also found that Miss A should have been referred for a paediatric cardiology opinion. In addition, the advice we received was that had Miss A been appropriately followed up, the genetic test that became available three years later could have been performed at that time, rather than 12 years after her birth when Miss A was referred to a consultant in clinical genetics.

The board said that they now have an IT database which enables them to identify patients who might benefit from changes in genetic testing, but that due to staffing and workload constraints, they were unable to contact all relevant patients. We found that were patients triaged and followed up appropriately, such a database should not be necessary. We therefore upheld Ms C's complaint that there had been a delay in diagnosing the genetic condition.

We also found that while Ms B was given an assurance during the new-born period that Miss A did not have the genetic condition at birth, it was not possible to exclude a diagnosis at that time. When responding to Ms C's complaints, the board explained they were unable to say why this assurance had been given. We therefore upheld this aspect of Ms C's complaint.

Finally, while the board responded to Ms C's complaints in line with the timescales detailed in their complaints process, we were concerned that they had failed to adequately address all the issues raised. In light of this we upheld this aspect of Ms C's complaint.

Recommendations

We recommended that the board:

- apologise for the delay in diagnosing that Miss A had the genetic condition;
- review their policy with respect to checking patients with suspected inherited conditions, to ensure they are appropriately reviewed by a specialist with an interest in inherited conditions;
- consider the adviser's comments regarding the current database and report back on any action taken; and
- ensure that a full response is provided to a complaint and that this addresses all the points in line with their complaints procedure.