

Strictly private and confidential

7th February 2022

To whom it may concern,

I started in my role as haematology consultant at the Royal Infirmary of Edinburgh in August 2019 and then as Director of the Edinburgh Haemophilia Centre in January 2020. W2080's statement is dated 14th November 2018, when Dr Ryan Rodgers was Director of the Edinburgh Haemophilia Centre, which is before I took up these roles. I have therefore reviewed the medical notes and am answering to the best of my ability in this context.

The questions I am asked to address are as follows:

6. At paragraphs 28, 29 and 32, witness W2080 states that her son no longer trusts the doctors at the RIE and has fallen out of contact with them. Witness W2080 further states that the RIE they have not bothered to keep in touch with him or monitor his condition. She states that her son is frightened of what the RIE will "throw at him next" and in avoiding the hospital, he suffers more than he needs to. Please comment on this.

7. At paragraph 33, witness W2080 states that due to the lack of contact from the RIE, her son has not been offered any new treatments that may have become available. Please comment on this.

In my reply to these questions, I refer to several letters sent from the Royal Infirmary to **GRO-B** (referred to as Letters 1 to 6). Copies of these are attached for your information. Please note that Letter 5 was written after a switch to an electronic clinical notes system and no original paper copy was kept on file as a result. Thus, the copy is dated as being printed on 7th February 2022. All of the other letters pre-date this switch, and copies are taken from the contemporaneous paper notes.

Regarding question 6, at the time that this statement was given, **GRO-B** was not being followed up on a routine basis in the Edinburgh Haemophilia Centre. The last routine review appointment that he had attended was on 27th February 2015, with an attendance in the Emergency Department of the Royal Infirmary on 18th September 2015 at which time he was reviewed by a member of the haematology team.

An appointment in September 2015, one in October 2015 and a further one in January 2016 were rearranged, although I cannot see any documentation of whether these rearrangements were at **GRO-B** or the Haemophilia Centre team's request. Subsequent to this, **GRO-B** did not attend an appointment arranged for 3rd February 2016. A letter with a new appointment for 30th March 2016 was sent out (Letter 1). A further letter was sent out on 3rd March 2016 from Dr Dennis, Associate Specialist in the Haemophilia Centre, with an offer to arrange a review by Professor Hayes, Consultant Hepatologist, on the same day as this appointment for the purpose of discussing

newer treatments for hepatitis C infection (Letter 2). [GRO-B] did not attend the appointment of 30th March 2016.

At that time, the practice in the Haemophilia Centre was to write to patients who had missed two consecutive review appointments to ask that they arrange an appointment at their own convenience, but not to arrange further routine appointments. Dr Rodgers, consultant haematologist, wrote a letter to this effect which was sent to [GRO-B] on 12th April 2016 (Letter 3).

A follow up letter was sent to [GRO-B]'s GP on 13th October 2016 by Dr Dennis, explaining that [GRO-B] had not attended two appointments in the preceding year and that the clinical team had been hoping to discuss new treatments for hepatitis C with him (Letter 4). [GRO-B] GP was asked to mention these new treatments and to explain that [GRO-B] could arrange to come to the Haemophilia Centre or to be put directly in contact with the hepatology team. No response appears to have been received to this letter, and certainly no corresponding appointment was arranged.

In the time since W2080's witness statement was written, [GRO-B] attended the Haemophilia Centre on 17th May 2019 with an injury to his hand. There does not appear to have been any contact from the Royal Infirmary with [GRO-B] or his GP in the intervening period. In May 2019, he received a period of treatment for this injury and routine follow up in the Haemophilia Centre was arranged after that. In addition, he was referred back to the hepatology team of the Royal Infirmary of Edinburgh for consideration of treatment for hepatitis C with the agents that had become available since treatment had last been attempted.

He was reviewed at the hepatology clinic on 1st July 2019. It is documented in a letter summarising this appointment that [GRO-B] stated that he had not taken up Dr Dennis' offer of discussion of further treatment options for hepatitis C in 2016 as it was not a good time for him to consider further treatment at that stage (Letter 5). Following this hepatology review in 2019, he was treated for his hepatitis C infection with one of the newer treatments for hepatitis C infection. At his last appointment with hepatology on 10th February 2020, he had no evidence of cirrhosis or active hepatitis C infection and had evidence of sustained response to antiviral treatment, so was discharged from their follow up.

Since this time, he has remained under regular follow up from the Haemophilia Centre team, although he did not attend appointments with either the orthopaedic or special care dental teams in April 2021.

The only documentation of reasons for [GRO-B] to have not attended appointments in the Haemophilia Centre precede the time when he was not under regular review at the Haemophilia Centre. On several occasions practical difficulties with attending from Fife are documented, such as adverse weather conditions making travelling difficult.

The documentation from a clinic review on 5th September 2005 states that [GRO-B] was upset at receiving notification of a possible risk of vCJD infection and that he was angry that this was yet another thing that he was having to deal with (Letter 6). I cannot see that this was explored further at subsequent appointments and cannot see any documentation of conversations about his fear of further problems relating to his previous treatment being revealed, or of this acting as a barrier to

his attending. This was not something that he has raised on the occasions that I have seen him. I would be happy to address this with **GRO-B** at future appointments should he wish to discuss it, and to offer any support that the Haemophilia Centre team can in making it easier for him to attend appointments in future, including support from the Centre's clinical psychologist. I cannot say whether he now feels that he can trust the clinical team in the Haemophilia Centre, but would aim to build this trust, if possible, going forwards.

I would agree that **GRO-B** is very likely to experience symptoms which could be better managed had he been able to attend the appointments offered, and to suffer as a result. Specifically, he is at risk of dental pain owing to the state of his dentition, and he has pain in his knee which may be amenable to further orthopaedic intervention. Unfortunately, he did not attend his most recent appointments to address these issues, but I will endeavour to support him in this regard.

In summary, there is documentation demonstrating that the Haemophilia Centre team of the Royal Infirmary made multiple efforts to ensure that **GRO-B** was offered appropriate follow up. Our current approach would be to try to explore barriers to his attending appointments and to offer support, in particular from our clinical psychologist, in this regard.

Regarding question 7 of the rule 9 request, from W2080's statement, this appears to refer to newer treatments for hepatitis C infection. As detailed above, efforts were made to offer these to **GRO-B** in 2016 but, as he did not respond to these attempts, there was a period of delay from 2016 to 2019 where treatment options were available that **GRO-B** did not receive. Since the time of W2080's statement, he has been successfully treated with one of these newer treatments. Fortunately, there is no evidence of long-term harm to **GRO-B** liver as a result of this delay in his receiving this treatment.

Yours faithfully

GRO-C

Dr Andrew Page

Consultant Haematologist

Royal Infirmary of Edinburgh