



The Haemophilia Society
52B Borough High Street
London
SE1 1XN

Tel: 020 7939 0780
Email: info@haemophilia.org.uk
Web: haemophilia.org.uk

27 July 2020

The Newcastle upon Tyne Hospitals NHS Foundation Trust
Freeman Hospital
Freeman Road
High Heaton
Newcastle upon Tyne
NE7 7DN

Dear Dame Jackie,

Re: Newcastle Haemophilia Comprehensive Care Centre

We write on behalf of our members, in anger, frustration and disappointment at the apparent decision to permanently move the haemophilia centre from the Royal Victoria Infirmary. At the outset of the Covid-19 pandemic, the Centre, along with many others across the UK, voluntarily vacated their site to assist in the national effort. To date, we are aware of only one centre who will seemingly not be returning to their original site: Newcastle.

This apparent “land-grab” by the trust, cannot and will not be tolerated by the bleeding disorders community. It has been done without any consultation, despite your apparent values of caring for your patients and being inclusive. We have been contacted by a number of our members who have raised grave concerns about the risk this poses to the quality of their care in the future. As the UK wide patient charity, we share those concerns.

The Newcastle Centre provides a cradle-to-grave service across a very large geographical area. The next closest centres are situated in Leeds or Manchester, several hours travel away. In February 2019, the Haemophilia Centre in Newcastle was reviewed as part of the Quality Review Service’s comprehensive review of all 37 haemophilia centres in the UK. The Review described the service provided as “...an excellent service: safe, innovative, and with plans in place to improve services

For everyone affected by a genetic bleeding disorder

President: Baroness Meacher Registered charity no. 288260. Charity Registered in Scotland No SC039732.

A company registered in England and limited by Guarantee. Registered Company No. 1763614

haemophilia.org.uk

further.” The moving of the centre without consultation can only be seen as a risk to these hopes and aspirations for our community and nullifies the findings of the Quality Review.

Whilst the Centre provides an excellent service, this is despite the environment in which it operates. The QRS report went on to state “The limited space in the Centre posed problems.” This further diminution in space and capacity will only hamper future services. Indeed, what space there currently is has been improved by our own members fundraising efforts for the educational treatment room at the RVI. Carl Sanderson’s efforts can be found here:

<https://www.chroniclive.co.uk/news/north-east-news/washington-dad-kicks-remarkable-tough-9160072>

The current climate for the bleeding disorders community is a very testing one. Novel treatments continue to come to market and provide an increasing challenge for patients in terms of their care. The latest national tender for coagulation products has the potential to save, yet again, significant funds for the NHS provided that staff are able to implement it which requires ‘buy-in’ from those with severe haemophilia in changing treatment products and potentially home delivery services, with the necessary hospital visits to undertake this safely. Alongside this, our community is continuing to grapple with the Infected Blood Inquiry and its psychological impact. Consequently, the need for first class care and support has never been greater. The current changes to care in Newcastle provide an unwelcome distraction to say the least, from what should be the primary focus of health-care professionals at this time.

On behalf of our members and the centres clinical staff, we would ask that an urgent update is given about the short-medium term plans for the haemophilia centre. We would welcome an opportunity to meet with you and discuss them in order that we can provide that reassurance which our members urgently require.

Yours sincerely,

C. Smith

Clive Smith
Chair

For everyone affected by a genetic bleeding disorder

President: Baroness Meacher Registered charity no. 288260. Charity Registered in Scotland No SC039732.

A company registered in England and limited by Guarantee. Registered Company No. 1763614