

Rolling out adult and paediatric, patient centred Emicizumab education, counselling and administration training: Experience from a Haemophilia commissioned network covering a large catchment area

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Introduction

Since NHS England commissioned the use of emicizumab in patients with severe haemophilia A, with and without inhibitors; there has been growing interest from individuals to switch to this novel, more convenient, subcutaneous treatment. The Southern Haemophilia Network (SHN) with Basingstoke comprehensive care centre (CCC) at its hub, has a large catchment area spanning 3 counties. Therefore we designed a patient centred emicizumab education and counselling provision that could be readily accessed.

What we did

Adult patients

As a network it was decided that eligible patients would have emicizumab offered at local clinic appointments, if interest was shown they would be invited back for an hour appointment with the CCC haemophilia consultant and a member(s) of the nursing team. As there was a significant cohort of interested adult Dorset patients, we set up a satellite group education and counselling session at Royal Bournemouth hospital. This was led by the CCC and local haemophilia consultant with support of haemophilia nurse specialists. All patients verbally consented to participate in the group education and counselling session. Home visits by the CCC consultant and nurse specialist were also carried out in order to provide equal access of emicizumab education and counselling to our elderly patients with mobility problems.

Paediatric patients

Before starting or considering switching prophylaxis, the patient with parents/carers were invited to discuss treatment options at the CCC face to face. This allowed for consolidation of their understanding of living with haemophilia, effective management, discussion of prophylaxis options including novel agents and to help build familiarity with CCC healthcare professionals. If interested in emicizumab, parents/carers and the older children would have a demonstration in the reconstitution and delivery of emicizumab, using a dummy model. Thereafter if emicizumab was chosen, a more detailed training session would take place.

Patients switched to emicuzimab (until July 2020)

	On emicuzimab with an inhibitor	On emicuzimab without an inhibitor	Other prophylaxis	Total patient number
Number of severe haemophilia A adult patients	2	10 (-2#)	46	58
Number of severe haemophilia A paediatric patients	0	2	23	25

During the COVID pandemic in the UK; 2 patients (1 adult , 1 PUP) have been switched to emicuzimab.

2 patients stopped emicuzimab treatment 1 patient died (not emicuzimab related), 1 patient chose to go onto an EHL FVIII product and discontinued treatment

Summary

Emicuzimab up take by patients with severe Haemophilia A will likely continue to increase, as it provides an effective alternative to frequent intravenous prophylaxis. It's important that all patients have access to high quality counselling and nursing support to help make an informed decision. A combination of counselling sessions at the CCC as well as remote haemophilia centres helps facilitate this. Virtual visits have also had a role in initial counselling in order to minimise hospital visits during the pandemic.

References

- Oldenburg J *et al* (2017) Emicuzimab prophylaxis in hemophilia A with inhibitors. *New England Journal of Medicine*, 377, 809- 818
- Young G *et al* (2017) HAVEN 2 updated analysis: multicenter, open-label, phase 3 study to evaluate efficacy, safety and pharmacokinetics of subcutaneous administration of emicuzimab prophylaxis in pediatric patients with Hemophilia A with inhibitors. *Blood*, 130, 85
- Mahlangu J *et al* (2018) Emicuzimab prophylaxis in patients who have Hemophilia A without inhibitors. *New England Journal of Medicine*. 379, 811-822