Health Inequalities - Early Years

Haemophilia Scotland

1. About Haemophilia Scotland
1.1 Haemophilia Scotland is a registered charity (No. SC044298) based in Scotland for people who have haemophilia, von Willebrands and other bleeding disorders. We are an organisation for anyone who has these blood-related conditions so we can talk to each other; and we provides a united representative voice when speaking with the medical profession, with government, with the rest of Scottish society, and when connecting with people like us throughout the world.

2. What health inequalities effect people with bleeding disorders?
2.1 Once diagnosed, most people in Scotland have access to world class Haemophilia Services. Haemophilia Scotland recognises the high levels of expertise and dedication of those who provide Scottish Haemophilia Services and their commitment to continual improvement in particular. We would also like to highlight to the committee the efforts being made by all providers of Haemophilia Services across services to improve health outcome monitoring and ensure equal access to services. This work is being generously supported and facilitated by National Services Division (NDS). However, despite these advantages and efforts we believe that health inequalities continue to exist is specific situations.

2.1.1 Geography: We remain concerned that it is more difficult for individuals and families affected by bleeding disorders living in remote communities to access the comprehensive care package when compared to those living in more urban locations. Scotland’s largest Haemophilia Centres are in Glasgow and Edinburgh. There are also Haemophilia Centres in Aberdeen, Dundee and Inverness. However, this means that for some patients their nearest Centre is many hours travel from their home.

2.1.2 Diagnosis: The rarity of all bleeding disorders can delay diagnosis, particularly where the condition is less severe and where there is no family history to guide clinicians. In these cases diagnosis is often linked to a bleeding episode, either spontaneous or traumatic. As well as being extremely painful, every bleed into joints causes permanent and irreversible damage. As with most rare conditions the low prevalence make bleeding disorders poor candidates for screening programs. However, we believe that more could be done to promote simple clotting time tests, such as the Partial Thromboplastin Time (PTT)) test, in primary healthcare settings. Furthermore, undiagnosed children with bleeding disorders often present to healthcare services with unexplained bruising. This can, understandably, lead to child protection concerns and interventions. These interventions are highly distressing to parents who know that no abuse has occurred and that their baby is unwell. There is a danger that they can also further delay diagnosis.
2.1.3 **Gender:** Although understanding has improved in recent years, and is well understood within the specialism, there remains a perception in the wider healthcare environment that bleeding disorders can only affect men. Haemophilia is often used as an example of a genetic condition which mothers carry and son’s experience. This characterisation can lead to late diagnosis or difficulties accessing services for symptomatic carriers of bleeding disorder and a failure to consider a diagnosis of von Willebrand’s Disease in women with bleeding problems. Von Willebrand’s is through to affect 1% of the population which would equate to 27,000 women in Scotland. Thanks to the efforts of healthcare professionals in the specialism, diagnosis rates for von Willebrand’s in women have improved significantly, particularly for those most severely affected. However, we estimate that only 600 women in Scotland have a von Willebrand’s diagnosis which suggests further work in this area is needed.

2.1.4 **Education:** Frequent admissions in childhood restricted the access of older people with bleeding disorders to education. While modern treatments have vastly reduced the need for regular admissions for most patients, those with inhibitors which prevent standard treatments from being effective, can still be affected in this way. Reduced access to education as a child can have serious and long-term impacts of the life chances of patients.

3 **Where are the opportunities for early intervention for people with bleeding disorders?**

3.1.1 We respectfully invite the committee to consider encouraging the following forms of early intervention in relation to bleeding disorders.

3.1.2 **Tele-Health:**
3.1.2.1 This has the potential to improve access for those in remote communities to the full range of comprehensive care services. It also could be used to provide more specialist support in primary healthcare settings to increase understanding and aid early diagnosis.

3.1.3 **Diagnosis:**
3.1.3.1 Clotting time tests to be promoted in primary healthcare settings where a bleeding disorder is a possibility.
3.1.3.2 Professionals working in child protection should also be made aware that bleeding disorders are a potential explanation for unexplained bruising and have rapid access to appropriate tests.
3.1.3.3 All those in primary healthcare environments dealing with menorrhagia should be aware of the potential for a bleeding disorder diagnosis including von Willebrands or a symptomatic carrier of Haemophilia.
Conclusion
Early interventions in bleeding disorders offer the prospect of earlier diagnosis and more equal access to comprehensive care for some patients. While the vast majority of patients in Scotland already have access to Haemophilia Service which stand up well to international comparisons, Haemophilia Scotland are concerned that some groups of patients remain disadvantaged. These groups are:

- Those living in remote communities.
- Patients with milder forms of the conditions, especially where there is no diagnoses family history.
- Undiagnosed women with bleeding disorders.

As well as improving the health and wellbeing of patients, early intervention in bleeding disorders reduces the lifetime costs of treatment. Earlier diagnosis can prevent bleeds which cause longer-damage through the use of preventative treatment plans. When diagnosis is made during a trauma or childbirth then there are increased risks to patients and increased costs to the NHS.

In addition, we would like to support the submission from The Genetic Alliance UK / Rare Diseases UK.

Haemophilia Scotland
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