

**PE1682/B**

The Hidradenitis Suppurativa Trust submission of 14 June 2019

Having examined the petition put forward by Mr Jamieson, I agree that there are no specialist centres that we are aware of within the Scottish borders, with the closest clinic most likely to be Newcastle.

There are now approximately 30 HS clinics within England, which we refer to as Tertiary Treatment Centres, which are authorised to by NHS England to administer the only licenced medication for HS, most of which being in the Midlands and Southern England. Most of these clinics take on a multi-disciplinary approach to a patient's treatment plan, involving discussions from clinicians from different departments and specialities, and it is this in our opinion, that leads to better overall care for our patients.

However, as Mr Jamieson has rightly pointed out, currently the only way that patients north of the border can benefit from this multi-disciplinary specialist approach, is via lengthy referrals to clinics within England. This in turn can cause lengthy delays in obtaining specialist treatments, care plans and access to vital pain management. Unfortunately, delays in attending these specialist clinics can very often lead to further advancement of the condition which often is irreversible, and can cause unnecessary stress, which itself is a common trigger of HS flares.

The HS Trust is dedicated to raising awareness and support across the UK, and have exhibited in both Edinburgh and Glasgow recently during 2018, speaking to both Dermatologists and GPs in Scotland regarding the condition. We firmly believe that Mr Jamieson is correct to say that further awareness and patient support is vital in Scotland, and we feel that a specialist multi-disciplinary clinic north of the border would give faster, less stressful access for local patients, and would also ease the huge financial burden on the patient when travel and accommodation into England is also considered.

In response to the statement made by Johann Lamont, in regards to the number of people who are suffering with the condition, we estimate that to be approximately 1% of the Scottish population, which could amount to around 54,000 people, which in our opinion would highly justify a dedicated specialist clinic in Scotland.

We at the HS Trust are working on forming new community support groups within the Scottish borders, and are actively looking for new facilitators to help do so. We have also recently began offering a telephone based service to offer emotional support and a listening ear to patients needing that support (0300 123 0870). We would also assist and encourage any work that is planned in Scotland for new clinics and facilities for support, and hope to be able to compliment any services that are made available.