

Briefing for the Public Petitions Committee

Petition Number: [PE01682](#)

Main Petitioner: James Jamieson

Subject: Access to specialist support for hidradenitis suppurativa sufferers in Scotland

Calls on the Parliament to urge the Scottish Government to establish a specialist clinic for hidradenitis suppurativa sufferers in Scotland.

Background

According to the [British Association of Dermatologists](#), Hidradenitis suppurativa (HS) (sometimes called 'acne inversa') is a long term, recurrent, and painful disease in which there is inflammation (redness, tenderness and swelling) in areas of skin containing a specific type of sweat gland. These glands are found mainly in the armpits, breasts and groin. Within HS there is a blockage of the hair follicles, which causes the inflammation. This in turn causes a mixture of boil-like lumps, areas leaking pus, and leads to scarring once the lumps heal. Hidradenitis suppurativa tends to begin around puberty, and is more common in women. It is estimated to affect about 1% of the population¹.

Hidradenitis suppurativa is a distressing condition and it can have a severe psychological effect. It can also sometimes be associated with inflammation of the joints (arthritis) causing chronic pain. The lesions can last for up to two weeks and can severely affect a sufferer's quality of life.

It is classified as a discrete condition – a 'follicular disorder' in the International Classification of Diseases (ICD 10) - [2018 ICD-10-CM Diagnosis Code L73.2](#).

Causes

It is not known what causes HS, but it can be hereditary, running in the families of about a third of sufferers. It is possibly an abnormal immune response and is possibly linked to hormonal activity. Smoking and excess weight may also be factors.

¹ See Revuz JE, Canoui-Poitrine F, Wolkenstein P, et al. Prevalence and factors associated with hidradenitis suppurativa: results from two case-control studies. J Am Acad Dermatol 2008;59:596- 601. Cited in: [European Dermatology Forum Guideline for HS](#)

There is no cure, and the condition can persist for many years. For some it can eventually become inactive.

[NHS UK](#) also has information on the condition, symptoms and treatment

Treatment

Treatment comprises:

- antibiotics,
- antiseptic washes,
- retinoids (Vitamin A - based medications)
- and for some women, the combined contraceptive pill;
- immunosuppressive treatments such as Infliximab and adalimumab might also be prescribed by a dermatologist when other treatments have not worked;
- corticosteroids;
- surgery

Specialist Treatment

[Guy's and St Thomas' NHS Foundation Trust](#) in London has a specialist clinic for HS, comprising two consultant dermatologists and a clinical nurse specialist. It is clear from their site how referrals can be made. Patients from Scotland can apply for a referral directly through their health board. However, if it is deemed by the board that equivalent treatment is available locally, the referral to the specialist clinic would not be approved.

Research and guidelines

The HS Trust compiles [annual lists and links to scientific and medical research on HS](#).

The [European Dermatology Forum](#) has produced a [detailed guideline on HS](#) based on the work of clinicians and dermatologists active in supporting and treating sufferers. This is not an EU body, but a non-profit professional organisation dedicated to improving the healthcare needs of dermatology patients in Europe, established in 1997.

NICE (National Institute for Health and Care Excellence) guidance is limited to the use of adalimumab for HS.

NICE is also a source for finding [further evidence and research on HS](#).

[Further guidance](#) was published in the Journal of the European Academy of Dermatology and Venereology in 2015

Scottish Government Action

No guideline on the condition has been published by the Scottish Intercollegiate Guideline Network (part of NHS Healthcare Improvement Scotland).

There is no specific reference to the condition on Scottish Government or NHS Scotland sites, although there is some evidence that data has been collected: <https://hidradenitissuppurativaawareness.org/hs/nhs-scotland-number-of-patients-diagnosed-with-hidradenitis-suppurativa-hs/>. This was obtained via an [FOI request in 2015](#) to NHS NSS. The data supplied is not routinely available.

Dermatologists in Scotland

Most health boards in Scotland provide dermatology services. As at 30 September 2017, there were [126.8 whole time equivalent dermatologists](#) working across the 14 NHS health boards.

Scottish Parliament Action

None to date

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