About Behçet's UK

Behçet's UK cares for all those affected by Behçet's including patients and their carers. We promote research into the condition and our ultimate aim is to find a cure but in the meantime we will strive to obtain the best care for all Behçet's patients.

How we help:

- We were instrumental in establishing Specialist Centres for Behçet's in NHS England and we now lobby for equivalent care in Wales, Scotland and Northern Ireland.
- Hold an Annual General Meeting and Conference, allowing those affected by Behçet's to hear from Behçet's specialists and patients, ask questions and meet others with this rare condition.
- Publish a quarterly newsletter keeping our members up to date with the Society's activities including lobbying on rare diseases along with our work with researchers.
- Maintain an active Medical Advisory Panel with eminent representatives from each of the medical disciplines involved in Behçet's to whom questions can be directed.
- Manage a website which includes factsheets written by lead Behçet's clinicians on each of the areas affected by Behçet's.
- Provide a Helpline which is run by volunteers who have an understanding of Behçet's.
- Facilitate peer to peer support groups to minimise the isolation experienced by patients.
- Award small personal grants for items which will help members manage their Behçet's day to day.
- Host an annual event for members to have fun with their friends, family and carers and get to know others affected by Behçet's.

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Projects and plans

Our future projects and plans include:

- Continue to lobby for comprehensive care for everyone across the UK.
- Create a Patient Registry to establish accurate, valid, reliable and timely information for the Behçet's UK patient group, including family members, which is critical underpinning to improve healthcare outcomes through research.
- Charting the natural history of Behçet's in the UK; a prerequisite for designing studies that assess the impact of interventions.
- Embrace the Genomics Medicine initiative, in addition to forming a Priority Setting Partnership to secure agreed research questions that need addressing, allowing us to support the most appropriate research projects to benefit our members.
- Encourage patron support and develop a fundraising strategy to sustain the lifespan of these projects.

Join, donate and get more information at

behcetsuk.org

Follow us @behcetsuk

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Registered Charity No. 326679

Registered with FUNDRAISING REGULATOR

Behçet's UK

Caring for all affected by this rare, complex and lifelong condition; promoting research into the cause, effects, treatment and management of Behçet's

Helping Behçet's patients since 1983

We represent all Behçet's patients, their carers and those who have not yet been diagnosed

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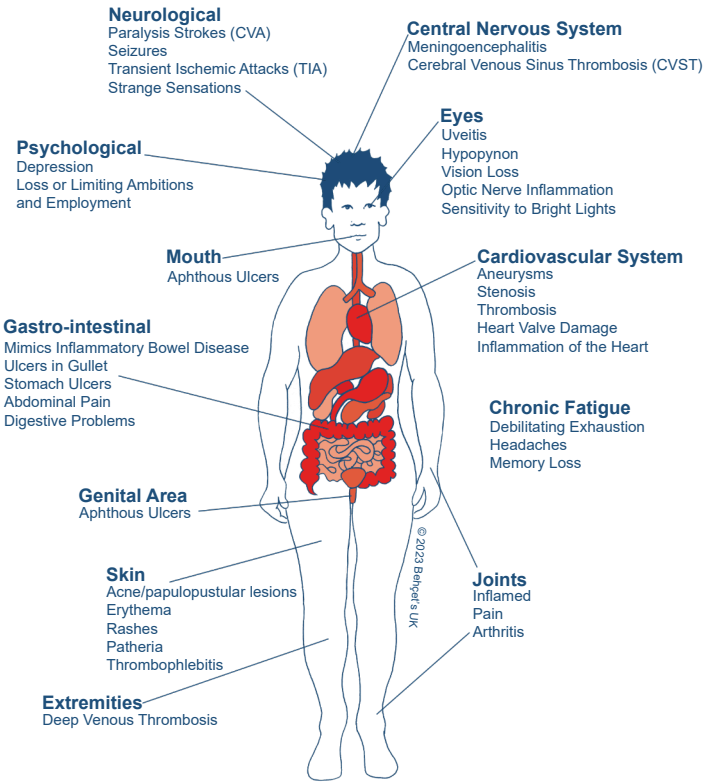
What is Behçet's?

Behçet's Syndrome (also known as Behçet's Disease or, simply, Behçet's) is a rare, chronic, debilitating, lifelong, multi-system auto-inflammatory disorder which can potentially involve any organ in the body. All age groups can be affected by Behçet's but it tends to present in patients in their 20s onwards.

Symptoms can occur anywhere there is a blood supply, from the brain down to the feet. They include recurring oral and genital ulcers, in conjunction with (but not exclusively) eye inflammation, skin lesions, sore joints, thrombophlebitis, and gastrointestinal ulceration. Involvement of the central nervous system is a major concern, including memory loss, impaired speech and problems with balance and movement. Blindness can result, as well as stroke and swelling of the spinal cord. Headaches and extreme fatigue are commonly experienced.

There are no blood tests to diagnose Behçet's. Diagnosis is based on a combination of positive clinical features, whilst excluding other conditions.

Behçet's is treatable, to a degree, but not currently curable. By suppressing the immune system, inflammation can be reduced and symptoms relieved. Behçet's tends to come and go in a series of attacks ('flares') throughout life. The condition does not 'burn itself out', but over time, flares can become less aggressive and less regular.



Working Together

- **The rare disease patient is the orphan of health systems, often experiencing a lengthy journey to diagnosis, contradictory experiences, and varying levels of treatment and indeed understanding about their symptoms.**
- **A rare disease is defined as affecting fewer than 1 in 2,000 people. Behçet's UK therefore works with others so that its 'collective voice' can be heard - strength in numbers.**
- **Behçet's UK is a member of National Voices, The Neurological Alliance, Genetic Alliance (Rare Disease UK), EURORDIS and International Society for Behçet's Disease.**
- **Clinical diagnosis requires multi-disciplinary assessment and GPs are advised to refer patients to the National Behçet's Syndrome Centres of Excellence, to assist with diagnosis. These Centres are optimally placed to provide these assessments and lead treatment.**

When to suspect Behçet's?

When a patient presents with two or three of the following symptoms:

- Painful recurrent mouth ulcers
- Painful recurrent genital ulcers
- Recurrent eye inflammation
- Recurrent skin lesions
- Thrombophlebitis

Key patient concerns

The following are the main concerns of Behçet's patients:

Diagnosis is difficult as there are many unusual symptoms, which do not necessarily appear together

Most GPs have never dealt with a patient with Behçet's, so they don't automatically recognise the symptoms. An average GP would have to practise for 5 lifetimes before seeing a Behçet's patient. There is no diagnostic test for Behçet's.

The patient does not always look ill

However, the person can be suffering with a variety of debilitating symptoms including ulcers of the mouth, legs and genitals, swollen joints, severe and continuous headaches and overwhelming fatigue. They find it difficult to function normally on a day to day basis.

Patients can very quickly feel isolated and lonely when dealing with this illness

They can lose their confidence, their job, their income and any relationship they had; they can become dependent on benefits that are difficult to obtain because of the intermittent nature of the flare-ups. "Your whole way of life for you and your family is disrupted and changed forever".

There is currently no cure (but it can be treated)

When diagnosed, depending on the severity, a patient may be given powerful drugs for the rest of their life; which may control their symptoms but can have serious side effects. What one patient's body can tolerate and feel better using, another patient's body might reject.