



# Behçet's Syndrome Society

Registered Charity No: 326679

Caring for those with a rare, complex and lifelong illness

[www.behcets.org.uk](http://www.behcets.org.uk)

## **So you have Behçet's Syndrome? A patient's guide by patients.**

So you've just received a diagnosis or a 'potential diagnosis' of Behçet's Syndrome? You're probably feeling a mixture of emotions now but this will include relief at receiving a diagnosis and also fear about what this illness is and how it's going to affect you and potentially your family.

Firstly, congratulations on finding us. We are the UK Charity supporting people with Behçet's Syndrome and their families. We were established in 1983 and have a great deal of experience in helping people with this condition. By finding us, you've also found a wealth of information about Behçet's Syndrome which is medically validated and not available anywhere else.

Also, receiving a diagnosis or a suspected diagnosis of Behçet's Syndrome is also a real step forwards. This means you must have found a medical person who could recognise the symptoms and was aware of this rare illness. This is not something to take lightly as many of our members have waited several years to obtain a diagnosis.

### **So what is Behçet's Syndrome and how is it pronounced?**

You will hear many different pronunciations of the illness, but the most popular tend to be either "Betjet" or "Baychet". To add further complication, it is also referred to as both Behçet's Syndrome and Behçet's Disease. The two are the same and are used interchangeably.

The syndrome is named after a Turkish Professor of Dermatology who described the **main** features of the condition in 1937. It had previously been described as long ago as the 5<sup>th</sup> century BC by Hippocrates, by a Chinese physician in the 5<sup>th</sup> century AD and by a number of European physicians in the late 19<sup>th</sup> and early 20<sup>th</sup> century.

The cause of the condition is not known. It's been proved there is a disturbance of the immune system but this isn't thought to cause the illness. Current theories are that it is potentially a genetic weakness that is triggered by an infection or virus but this has still to be proved. It tends to be diagnosed when the patient is in their 20s or 30s, but it can be diagnosed outside of these age brackets.

It is known that the illness is most prevalent in Turkey, North Africa, the Middle East and in South East Asia – the old Silk Route, which is another name for the condition – The Silk Route Disease. In Western Europe it is rare, with an estimated 1000 people in the UK having a diagnosis. It seems to be more common in women in Europe, but men are

more frequently affected in other regions and men also tend to have more severe disease activity.

### **How is it diagnosed?**

There is no diagnostic test for Behçet's Syndrome which is partially the reason for the elongated diagnosis period. A clinician who has experience of Behçet's Syndrome would be able to make a diagnosis based on a collection of the following symptoms presenting themselves. Other clinicians may have a high index of suspicion and refer you to an expert:

- Ulcers – both in the mouth and genital region
- Skin lesions – acne-like or red tender swellings known as *erythema nodosum*
- Eye involvement – including inflammation of the front or back of the eye (*uveitis*) or around the retina (*retinal vasculitis*)
- Arthritis or arthralgia (joint pain) – particularly in the knees, hands and wrists.
- Thrombophlebitis – inflammation of veins, usually in the lower legs resembling deep vein thrombosis.
- Pulmonary lesions – arising from inflammation around the heart
- Central Nervous System involvement – arising from inflammation around the brain
- Gastrointestinal ulceration – affecting the small intestine or the colon.
- Pathergy reaction – a red lump appearing 48 hours following a sterile needle pricking the skin.
- Chronic fatigue

This list is long and affects different areas of the body but you would be very unlucky to suffer with each of these symptoms. Behçet's Syndrome seems to affect patients differently both in the symptoms you first present with and also in what may develop later. It is best to be aware of the various areas it can affect so that you can discuss any concerns you have with your consultant.

### **Appointments and your Doctors**

It may well have been that up to the symptoms of Behçet's Syndrome presenting themselves you didn't have a need to visit your GP and the hospital very much. Unfortunately, that is likely to change and you will need to build relationships with the medical professionals who are providing your care.

Depending on what symptoms you have, you may just be seeing one consultant and your GP or you may have several consultants concentrating on different areas of your illness. When the symptoms flare, it is very important to seek prompt medical advice. If you have built up a relationship with your clinician, this is far easier.

You will also be having regular medical appointments either in hospital or with your GP. These can become exhausting, particularly when you're unwell but it is important you attend all of these or let the clinician know if you are too unwell.

It is important to see a clinician who has experience of Behçet's Syndrome as it is rare and complex. This is something the Society can help you with as we keep a list of the consultants we're aware of who are currently attending to our members. We're unable to make a recommendation but we can provide you with the names of consultants in your locality.

## **The future**

Behçet's Syndrome is currently incurable but that doesn't mean it is untreatable. Many drugs are on the market which, although not licensed specifically for Behçet's Syndrome can have a positive effect on controlling the symptoms.

The course of the illness tends to be that it 'flares up' and then subsides. During these flare-ups, the symptoms you already have may become more of a problem or you may present with new ones. It is at this point that your medication may be increased or new drugs added to your prescription. However, during times when your disease activity is minimal, you will still need to take this medication to prevent any inflammation.

There are different drugs you may be prescribed depending on your symptoms. Steroids are often used to dampen down the immune system but immunosuppressants may also be required, together with topical treatments for other symptoms.

Unfortunately, Behçet's Syndrome doesn't qualify you for free prescriptions from the NHS. If you do not qualify for free prescriptions due to another condition or your financial circumstances, it may be beneficial to consider a Prepayment Certificate for your prescriptions. These can be bought quarterly or annually and can work out more economical depending on how many medicines you take regularly.

## **Helping yourself**

The medical professionals will provide the best care they can for you but you can take some simple, practical steps to help yourself too.

- Pace yourself. Getting overtired or over stressed should be avoided wherever possible.
- Take regular, gentle exercise to keep yourself as fit as possible.
- Eat a healthy, well balanced diet including your 5 fruit and vegetables every day.
- Take the medicines you're prescribed correctly. If you don't think it's suiting you, speak to your clinician rather than just stopping it.
- Keep all your medical appointments including any blood tests you need.
- During times of flare-ups, keep a diary of your symptoms and how you're feeling. This will help your consultant when you next see them.
- Join the Society – it will mean there's always someone to talk to who understands what you're going through.

## **What the Society can do for you**

The Behçet's Syndrome Society offers a large number of services including:

- Helpline (0845 130 7329) – operated by volunteers who either have Behçet's Syndrome themselves or have a relative with it. They offer a confidential service and will listen to your concerns and do their best to answer any questions you have.
- Website ([www.behcets.org.uk](http://www.behcets.org.uk)) – our website provides a wealth of information to both patients and medical professionals alike. It has a chat forum available for members to share tips and seek help from other members. It is also used to keep our members informed of what the Society is doing and the events you may be interested in.
- Factsheets – these provide medical information on all the different areas affected by Behçet's Syndrome. They are written by our medical experts and are aimed at both the patient and their medical carers.

- Support Groups – having a rare illness can be isolating. Support groups help to overcome that feeling. We are currently developing a network of groups throughout the country. Please get in touch to see if there's one in your area.
- Newsletter – our members receive a quarterly newsletter keeping them informed of both what the Society is doing on their behalf but also what research is taking place.
- Annual Conference – this is an opportunity for our members to meet other people with Behçet's Syndrome. We also invite prominent medical experts to discuss advances in the treatment of the illness.
- Carry card – our members can receive a carry card which is the size of a credit card. This card is designed to contain valuable information about your medical carers, the medicines you take and the illness in general should you need it in an emergency.
- Benefits help – we can provide information for those that need to claim benefits due to Behçet's Syndrome.
- Grant awards – if there are cases of severe financial hardship due to Behçet's Syndrome, we can award small grants to alleviate the suffering based on our current guidelines.
- Supporting research – as a small charity we are unable to conduct research ourselves, but provide support where we can to research projects which are aiming to benefit Behçet's Syndrome patients.

### **Can you help the Society?**

You may think that you're new to this illness and that you have nothing to offer a support group but you will be best placed to let us know what services are most needed. A fresh viewpoint is always welcomed.

You can help in many ways whether this be joining the committee or volunteering for the helpline or whether you'd like to help with fundraising. This can involve selling our Christmas cards or encouraging friends and family to help. Maybe they'd like to jump out of a plane, run a marathon or even undertaking a challenge event such as walking the Great Wall of China!