

Patient information

Behçet's Syndrome National Centre of Excellence Information and Advice for Newly Referred Patients

Rheumatology Department - Aintree Hospital

This information leaflet is for people who have been referred into the Liverpool Behçet's Centre of Excellence Multi- Disciplinary Clinic.

The Liverpool Centre is one of the three National Behçet's Centres of Excellence. There are also Centres in Birmingham and London.

What is Behçet's Syndrome?

Behçet's Syndrome, or Behçet's Disease as it is also known is rare in the UK, with only about 2,000 people diagnosed.

It is a multi-system inflammatory disorder and can affect any part of the body including the mouth, genitals, skin, eyes, gastro-intestinal tract, joints, major blood vessels and brain.

The exact cause is currently still not certain, but we know that the immune system and certain genetic markers are involved.

If Behçet's Syndrome is left undiagnosed and untreated it can eventually cause irreversible damage to the body such as blindness, stroke and even death.

People with symptoms of Behçet's Syndrome are often without a diagnosis for many years.

Liverpool Behcet's Centre?

You have been referred to the Liverpool National Behcet's Centre by a medical professional such as your GP, Rheumatologist or other hospital consultant, or Dentist.

Because Behçet's can affect many parts of the body, it is likely that you will need to see several different specialist consultants. The purpose of having a multi-disciplinary clinic is to Allow you to be seen by different doctors in as few visits as possible.

- Have any investigations or tests which may help coming to a diagnosis, in one place
- Receive timely confirmation of either having or not having Behçet's Syndrome.
- Have all your symptoms assessed promptly, and treatment initiated if required.

On the day of your appointment

As you may see several specialists your visit may take a few hours.

The Behçet's Nurse Consultant will go through a series of questions to assess how your symptoms have been over the weeks before coming to clinic.

You may have an eye test and possibly need to have your pupils dilated with eye drops to allow more in-depth eye examinations. You may experience blurred vision for 4-6 hours after these tests, so you should not drive during this time (your insurance will be invalidated).

Liverpool Behçet's Team:

- **Professor R. Moots**, Consultant Rheumatologist & Liverpool Behçet's Centre Clinical Lead
- **Dr J. Nair**, Consultant Rheumatologist
- **Dr Nima Ghidiri**, Consultant Medical Ophthalmologist
- **Dr B. Rajliwat**, Consultant in Oral Medicine
- **Dr M. Ghadiri Sani**, Consultant Neurologist (attends monthly)
- **Dr I. Coulson**, Consultant Dermatologist (attends monthly)
- **Dr S Crozier**, Clinical Psychologist
- **Mrs. Sarah Hardy**, Nurse Consultant & Liverpool Behçet's Centre Manager
- **Mrs. Jackie Pooler**, Behçet's Support Coordinator – Behçet's Patient Support Charity (Non NHS)

Liverpool Women's Hospital

- Mr J. Kirwan, Consultant Gynaecologist – Direct referral if required)

Please be aware that there may be appointment delays on the day you visit due to the complexity of some assessments that need to be carried out.

Future Visits:-

The number of times you will need to come to the Centre depends on the findings of our consultation and any further tests you need to have.

As well as Tuesday morning MDT Behçet's Clinic Professor Moots and Nurse Consultant Sarah Hardy have clinics on Wednesday afternoons 13.30 - 16.30 hrs, Clinic F, Ground floor, Aintree University Hospitals.

Once a diagnosis is confirmed Dr Crozier, Clinical Psychologist is available for support and advice once a diagnosis is confirmed and Jackie Pooler, Support Co-Ordinator is also available on Tuesday mornings or by telephone for guidance with Behçet's Syndrome related support.

Each time you visit, please bring with you:

- A list of any medication you currently take
- Your usual glasses if you wear them, and some sunglasses if you have regular eye examination.
- Your shared care diary and most recent blood results (If your GP is monitoring you on any Behçet's treatments).

Getting in touch

The Behçet's secure email address is **behcets@liverpoolft.nhs.uk** if you are asked to send any photographs or documents to us.

The Behçet's secretary phone number is Tel:0151 529 2091.

The Behçet's Nurse Consultant advice line for non-urgent advice about symptoms or treatments is Tel: 0151 529 8123. This is an answer phone and messages will be responded to within two working days. **It is not an emergency line.**

Important note: Aintree Hospitals' policy is to discharge patients who do not attend appointments without prior cancellation.

If you cannot attend your appointment, please call us on Tel: 0151 529 8038 with as much notice as possible so that another patient can be offered your place.

For prescription queries please Tel: 0151 529 3802.

For further information on Behçet's Syndrome please visit the Behçet's Syndrome Society Website www.behcetsuk.org.uk

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

**Department of Rheumatology
Aintree Hospital
Tel: 0151 529 0257**

Websites

For further information on Behçet's Syndrome please visit the Behçet's Syndrome Society Website www.behcetsuk.org.uk

All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل ائتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرق تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والكترونياً.

所有經信托基金批准的患者資訊均可以其它格式提供，包括其它語言、易讀閱讀軟件、大字體、音頻、盲文、穆恩體 (Moon) 盲文和電子格式，敬請索取。

در صورت تمایل می‌توانید کلیه اطلاعات تصویب شده توسط اتحادیه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

زانیاری پیموندیدار بهو نه‌خوشانه‌ی له‌لایمن تراسته‌وه په‌سه‌ند کراون، نه‌گه‌ر داوا بکرنیت له فورماته‌کانی تردا بریتی له زمانه‌کانی تر، نیزی رید (هاسان خویندنه‌وه)، چاپی گه‌وره، شریتی ده‌نگ، هیلی موون و ئلیکترۆنیک‌ی همیه.

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Dhammaan warbixinta bukaanleyda ee Ururka ee la oggol yahay waxaa marka la codsado lagu heli karaa nuskhado kale, sida luqado kale, akhris fudud, far waaweyn, dhegeysi, farta braille ee dadka indhaha la', Moon iyo nidaam eletaroonig ah.