

Behçet's Formerly Behçet's Syndrome Society UK

Caring for all affected by this rare, complex and lifelong condition

Behçet's UK 2022 Conference and AGM

The 2022 edition of the Behçet's UK Conference and Annual General Meeting took place on Saturday 15 October at the Holiday Inn, Stevenage, and online. A total of 193 people registered to attend, of whom 54 attended in person and at least 56 attended online. About half (48%) of those attending in person were members.

Behçet's UK AGM

Tony Thornburn thanked the administrative staff and all the trustees for their work, mentioning Alan Lane's excellent oversight of the accounts. He also thanked the organisers of the various face-to-face and online support groups. The quarterly newsletters reflect another successful year for the charity, with an emphasis on research and the fantastic fundraising by members and supporters.

Looking forward, Tony mentioned the plan to establish a constituent management system to streamline interactions with members. Another aim is to improve outcomes for Behçet's patients in the devolved nations, including establishing a specialist nurse in Scotland to help with coordination of care. Regarding research, following the completion of the Bio-Behçet's trial comparing interferon-alpha and infliximab, Prof Robert Moots has secured £700,000 in funding from Novartis for a major clinical trial of secukinumab, a



From left to right, front row: Steve Higgins, Desmond Kidd, Farida Fortune, Marwan Ghabra, Tony Thornburn. Back row: Azimoon Bibi, Bindi Gokani, Jean Christians, Nardos Wakjira, Sarah Sacoor

biologic drug used effectively in several inflammatory conditions. A study on monogenic mimics of Behçet's, being conducted by Alice Burleigh under the supervision of Prof Paul Brogan at the Institute of Child Health in London, will provide insights into the genetics of Behçet's-like diseases.

Finally, Tony said that the 2022 Friends and Family Day had been a great success. Behçet's UK hopes to extend the opportunity to Scotland, Wales and

Northern Ireland in the future.

Alan Lane, Honorary Treasurer, reported that the membership of the Society has continued to increase steadily, now standing at 1236. In addition to the standard members, there are 30 junior members, 77 associates, 21 donors and 79 lapsed members. Almost all (1184) members are patients, with 121 carers, 52 supporters, 52 medical staff and 20 overseas members. Most members are aged 40-60 years, and most (1172) live

in England. For the 12th year in a row, the membership subscription remains at £20 per year in 2022/23. A typical grant award is capped at £500, but up to £1000 can be awarded in exceptional circumstances.

The charity's total income for 2021/22 was £55,560. Just over a half came from subscriptions and donations, with another third from fundraising activities and nearly 10% from Gift Aid. Total expenditure was £62,743, 42% of which was accounted for by staff costs. Although this represents an operating deficit, the balance remains high at £155,250 as a result of a large legacy; the ideal balance would be between 6 and 12 months' normal income (~£40-80,000). However, some large items of expenditure are planned, including a patient registry and a specialist nurse for Scotland, so continued fundraising efforts are essential. Finally, the research fund currently has a small balance of £7855.

Neil Williams, Behçet's UK Trustee, reported that the amazing fundraising efforts this year brought in £17,500 for the charity. Several events relating to the 40th anniversary of Behçet's UK are planned for 2023 (see page 6). Other ways to help the charity's finances include buying merchandise and Christmas cards, shopping through Amazon Smile and other shopping partners, donating through sales on eBay, playing the weather lottery, fundraising on Facebook and considering leaving Behçet's UK a legacy. Neil asked people with ideas for fundraising to reach out to him and consider joining the newly formed Fundraising Committee.

Rachael Humphreys, Behçet's UK Trustee, announced that the recipient of the Judith Buckle Award 2022 was Richard West. Richard was diagnosed with Behçet's by Prof Dorian Haskard in the 1990s and, like many others, spoke to Georgina Seaman at what was then the Behçet's Syndrome Society and realised that he was not alone. Wanting to do the same for other patients, he became a Trustee in 2001 and went on to be Secretary and Vice Chair of the Society. He has made a major contribution to improving care for people with Behçet's, raising the profile of the condition across Europe as a patient representative at EURORDIS and acting as a patient representative on the EULAR Guidelines



Brian Robinson accepting the first Behçet's UK Members' Award on behalf of his wife, Annette Robinson (below)



Committee. Richard thanked everybody involved in selecting him for the award, saying that he has always enjoyed talking to people about Behçet's. He emphasised the importance of the inclusion of support coordinators and psychologists at the Centres of Excellence, pointing out that this is not available to people with other rare diseases.

Tony then announced a new initiative to recognise the contribution of individuals who have been instrumental in supporting anyone in the Behçet's UK community, improving their quality of life, independence and dignity. The first Behçet's UK Members' Award was awarded posthumously to Annette Robinson, who ran support groups in London and East Anglia as well as a private Facebook site where more than 400 people could share personal information. The award was accepted by Annette's husband Brian, who said that she was very fond of all her friends in the Behçet's community and that it had meant a lot to her to be able to talk to people with the same condition that she had.

To finish the AGM, Rachael spoke about the Breathe Creative project, in which Behçet's UK members were invited to register for a creative project to explore their lived experience of Behçet's through the arts, with the end goal being an animated film. Behçet's UK worked with Breathe Creative, an organisation that supports health and wellbeing through the arts. The 13 participants explored and reflected on their diagnosis, care, treatment and experiences in a safe space through creative writing, art, poetry and music. They then worked on the

script. The end result (<https://behçetsuk.org/breathe-creative>) reflects the lived experience of Behçet's.

COVID-19 vaccination

Prof Farida Fortune, Clinical Director of the London Behçet's Centre of Excellence, began her presentation by reminding everyone that COVID-19 has not gone away. COVID-19 symptoms are now much milder than they were in 2020 and are very like those of a cold or flu. The most common symptoms in people with Behçet's in 2022 are cough, fever, fatigue, joint pain, flu-like symptoms and shortness of breath. COVID-19 symptoms do not appear to differ between the various phenotypes of Behçet's. Patients from the Mediterranean and Middle East are more likely to have had COVID-19 than others, but the rate of infection in Behçet's patients overall is lower than in the general population and long COVID has been rare. Shielding was beneficial for people with Behçet's.

Response to COVID-19 vaccination was similar in male and female patients and among those with and without Behçet's disease activity. The response was better in younger patients and in those who received the Pfizer rather than the AstraZeneca vaccine. Response was lower in patients with neuro-Behçet's and in those taking versus not taking medication. Prof Fortune reiterated that the potential dangers of COVID-19 outweigh the risks of vaccination.

Dealing with pain in Behçet's

Prof Ali Jawad, Consultant Rheumatologist at the London Centre, explained that there are many causes of pain in patients with Behçet's, including ulcers, skin lesions, headache or migraine, arthritis and arthralgia (joint pain), and there may also be unexplained pain that is difficult to treat.

Joint pain without swelling is called arthralgia and is very common in many diseases, including COVID-19 and flu. It occurs in half of Behçet's patients

and is related to active disease manifestations elsewhere in the body, usually easing when they do. It responds to colchicine or anti-inflammatory tablets such as ibuprofen. Joint pain with swelling is due to arthritis and usually has an acute onset and resolves in a few days or weeks. It can be treated by removing the fluid from the joint and injecting steroid. Joint pain is not very often the main problem in Behçet's, and joint damage is very rare. Joint pain unrelated to Behçet's may be caused by problems such as hypermobile joints or scoliosis in patients under 40 and by menopause, early osteoarthritis, degeneration of the spine or lack of exercise in older patients.

Up to 40% of Behçet's patients have widespread body pain or fibromyalgia that is unrelated to disease activity and does not respond to analgesics or steroids. It is associated with fatigue, poor sleep, headache, irritable bowel and bladder, painful periods and exercise intolerance. Tests are normal. Management involves staying as active as possible, eating a balanced diet and getting enough vitamin D, and practising good sleep hygiene; Tai chi has been shown to be helpful.

Understanding neurological complications in Behçet's

Dr Desmond Kidd, Consultant Neurologist at the London Centre, explained that neurological complications of Behçet's include inflammation within the brain, the veins and the arteries, as well as



Richard West receives the Judith Buckle Award 2022

headaches and cognitive/psychological symptoms. Neurological involvement has been reported as occurring in 3-20% of people with Behçet's, usually in the first few years. Meningoencephalitis (inflammation of the brain and the surrounding membranes) most often involves the brainstem but can also involve the hemisphere, spinal cord or cranial nerves (including the optic nerves). Inflammation within veins can lead to venous sinus thrombosis, cortical vein thrombosis, intracranial hypertension, headache, visual changes and, rarely, stroke-like events. Inflammation within arteries is very rare but can cause headache, stroke-like events, aneurysm formation or brain haemorrhage.

Headache is common in people with Behçet's; the prevalence is >80%, with 98% being vascular-type headaches. Debilitating symptoms are common, and treatment is often inadequate. Migraine preventatives, anticonvulsants and triptans are used in the treatment of Behçet's headaches, but codeine should not be used. Dr Kidd finished by mentioning that psycho-neuro-Behçet's symptoms include cognitive dysfunction, fatigue, anxiety and depression, and (very rarely) psychotic symptoms.

Eye problems in Behçet's

Mr Marwan Ghabra, Consultant Ophthalmologist at the London Centre, said that ocular involvement is one of the principal manifestations of Behçet's. It occurs in

around 50% of patients overall, with rates as high as 70% among young male patients. Eye disease usually develops within 3 years of oral ulcers first appearing and is the initial symptom in around 20% of patients. In early disease, the only complaint may be a slight impairment of vision associated with a few floaters, but some patients complain of redness, pain, sensitivity to light and tearing.

Hypopyon (the presence of pus cells in the anterior chamber of the eye) is seen in a third of cases of anterior uveitis in Behçet's. Anterior uveitis may resolve spontaneously

or can progress to glaucoma. Acute anterior uveitis alone usually has a good outcome. Posterior uveitis is a more serious condition and can involve vitritis, retinal infiltrates, recurrent ischaemic retinal vein occlusions, macular oedema/ischaemia, and neovascularisation/vitreous haemorrhage whereby new vessels form which are abnormal and can bleed and leak.

Anterior uveitis may not need treatment, and if it does then topical treatment is usually sufficient. Posterior uveitis on the other hand almost always needs systemic treatment; 80-90% of eyes will be blind within 4 years if left untreated. Treatment should be prompt and closely monitored. First-line treatment of uveitis at the Centres of Excellence is effective in 80% of patients, although 50% later relapse.

Psychology and Behçet's

Dr Steve Higgins, Clinical Psychologist at the London Centre, spoke about the psychological aspects of living with Behçet's. It is important to determine whether a patient's presentation is a result of their physical state or their social and environmental context. It is rare that someone presents with a purely psychological concern. Diagnostic delay can lead to medical trauma; diagnosis leads to help and treatment, but not a cure, so patients need to adjust to living with a long-term condition.

One has to adjust to living with the symptoms, as well as with the effect on family life, work and socialising.

Some people 'mask' themselves and do not let other people see how much they are affected. Having a chronic condition changes your sense of who you are; it is important to make sense of your experiences and realise that the problem is not who you are but your circumstances. In the case of an autoimmune disease such as Behçet's, some of the psychological, behavioural and functional changes are caused by the immune system's inflammatory response. Flares can lead to increased pain sensitivity and fatigue, low mood and mild cognitive impairment such as memory problems.

In terms of ways of helping, family and personal relationships are very important, and wider communities and support networks can also be of great benefit. Psychological therapy mainly involves self-help strategies such as mindfulness-based cognitive therapy to help cope with stress, acceptance and commitment therapy to help build a meaningful life and compassion-focused therapy for developing a better relationship with oneself and others.

Is this Behçet's?

Dr Bindi Gokani, Specialist Staff Doctor at the London Centre, explained that history and symptoms, physical examination and investigations are used to determine whether a person has Behçet's. Sometimes the process is easy and the answer is clear, but often it is very complex. Many areas of the body are affected by Behçet's, but the symptoms are common to others as well. Blood tests can give information about nutritional deficiencies, infections and other conditions, as well as much other information. Common deficiencies include iron, vitamin B12, folate and vitamin D, which can cause symptoms similar to those seen in Behçet's.

Dr Gokani described several cases seen in the London Behçet's clinic, including three women in their 60s or 70s who were found to have iron deficiency anaemia, lichen planus and pemphigous. In each case, symptoms improved with appropriate treatment. In a younger woman, a thorough history and examination provided clues to the diagnosis of erythema multiforme, which was successfully treated. An 8-year-old girl who presented with oral and genital

ulcers, skin lesions, leg pain and fever, was found on genetic testing to have Majeed syndrome, a rare disease characterised by recurrent episodes of fever and inflammation in the bones and skin.

Dr Gokani concluded that Behçet's can be difficult to diagnose, as there are many conditions with similar symptoms. Establishing a diagnosis requires a team approach and careful attention to the history, examination and any test results.

Behçet's Patients Support

John Mather, BPS Operations Manager, said that the team wanted to reach out to patients and listen to their issues and concerns. In the morning, he asked the patients attending (in-person or online) who have visited or had contact with one of the Centres of Excellence to contact him during the day and let him know what went well, what did not go well and how things could be improved.

Key themes included:

- Clinic logistics (can be difficult to find)
- Shared waiting areas (reception staff not always aware of Behçet's)
- Clinic administration (post-clinic support/information, notification of new/cancelled appointments)
- Supportiveness of staff (medical, psychological and non-clinical all very good)
- Communication (checking in with patients waiting to be seen)
- Waiting times (to see consultant, have blood taken, collect prescription)
- Medical information sharing (impact of Behçet's on other medical procedures)
- Out of clinic support (how to contact clinic, where to go for support)
- Processes (information flow, prescriptions, follow-up appointments)

John said that the team would first look for any 'quick wins' and then develop medium- and long-term goals to improve patients' journey through the clinic.

Medication and compliance

Dr Sarah Sacoer, Specialist Doctor in Behçet's at the London Centre,

offered some practical tips on taking medication. It is important to take medication as instructed because it manages symptoms and prevents severe complications of Behçet's such as vision loss, blood clots and neurological disease. Patients take their medication because it was prescribed by their doctor, they understand the need for it and are aware that stopping it will result in their symptoms worsening, and they are worried about severe disease. They may stop their medication because they have side effects, forget to take it or run out of it. They may feel better and think they don't need it anymore, or they may be worried about immune suppression or COVID-19. Other reasons include having an infection, not being sure how long to take the medication for and being pregnant. Dr Sacoer emphasised the importance of collecting blood test results and seeking medical advice before stopping taking steroids.

Medical Panel Q & A

The day finished with a question and answer session with a Medical Panel comprising the staff of the London Behçet's Centre. The panel answered questions from the audience in the room and submitted online.

Clare Griffith, Editor

A longer version of this report is available at <https://behcetsuk.org/2022-conference> where you will also find the links to watch again.

Feedback

Feedback was received from 30 people who attended the Conference and AGM either in person or online, 24 (80%) of them Behçet's patients.

Almost half (43%) had found out about the conference from the newsletter.

Almost all respondents agreed or strongly agreed that the conference was relevant to them (93%), was informative (97%) and met their needs (88%); a higher proportion of in-person than online respondents agreed or strongly agreed.

All would attend the conference again (41% in person, 43% in person if local, 38% online only).

Update from the Chair

I hope that you have all read the Annual Report, in which I summarise what your Trustees have been doing, on your behalf, this past year. A lot is going on to underpin the foundations of what the Society needs to do in the best interests of its membership. Since the report was promulgated, we have held a highly successful hybrid Conference and AGM. While some did not attend (whether online or face to face), 193 people registered (125 being members or accompanying members), with 19 from abroad demonstrating that we reach more people in this combined way, which will likely become the norm in years to come.

We offer many thanks to Professor Fortune and her London team, who were our 'Sponsoring Centre' this year - and Clare Griffith has kindly summarised the day. It was particularly good to see eight research posters from Queen Mary, University of London, which were also displayed at ICB2022 in Athens and usefully segue to an update on research-related matters.

BAD/BSR Clinical Guideline

Much research into Behçet's is going on, which shows the commitment that many people are making, internationally, to help our community (underpinned it has to be emphasised, particularly at this time, by the dedicated clinicians in our country, with whom you interact routinely). My only criticism is that no strategic 'research road map' links all these initiatives together - a topic I first broached in the summer 2018 newsletter. One initiative that will assist here is the clinical guideline being prepared jointly by the British Association of Dermatologists (BAD) and British Society for Rheumatology (BSR), for UK-specific treatment of Behçet's, with input from 20 or so Behçet's 'experts' across the country (whose time, incidentally, is offered voluntarily). The guideline will list research recommendations, adding a degree of coherence to the aforementioned need. Moreover, all members of BAD and BSR will readily have access to the guideline on their respective member web portal, significantly increasing awareness of Behçet's across the UK. Behçet's is 'merely' one of over 7000 rare diseases!

In time, this guideline should logically lead to the development of a NICE quality standard "... which can be used to help define and measure quality in health, public health and social care" [NICE website], and then audited against to ensure equity for all UK Behçet's patients, whether being treated in a Centre of Excellence (CoE) or not. This process will benefit considerably from all the clinical evidence garnered by the three multidisciplinary centres in Liverpool, Birmingham and London since 2013/14, which neatly moves me to the vital research that Dr Priyanka Chandratre is leading.

Behçet's Epidemiology study

The Behçet's Epidemiology study started in July 2021, match-funded by Behçet's UK and South West Birmingham Hospitals NHS Trust charitable funds. One of my reasons for recommending to Trustees that we should support this initiative was to facilitate aggregation and sharing of all the data collected at the three CoEs since 2013 (such a rich and validated resource for a rare disease), which should not be under-utilised, not to mention best use of taxpayers' money, and can be used to optimal effect to support research - a true 'gold standard'.

The study objectives are to establish the incidence and prevalence of Behçet's in England and analyse the prevalence, incidence, clinical characteristics and mortality for patients at the three CoEs compared with those not on their books. Secondary objectives include addressing risk factors for Behçet's (demographic and clinical) and diagnostic delay (timeline of clinical features before diagnosis is made). Finally, a cluster analysis of the clinical phenotypes (the set of observable characteristics of an individual resulting from the interaction of genes with the environment) to distinguish between Behçet's in 'endemic' and 'non-endemic' areas. This could subsequently be used to facilitate research, pharmaceutical company interest, genome testing and so on. Once the UK has 'got its act together', data can be selectively and appropriately shared with the international community (in anonymised form).

The study is using data obtained from

the Clinical Practice Research Datalink (CPRD) and CPRD-linked Hospital Episode Statistics (HES), using the international ICD-10 code to register Behçet's patients. The algorithms used to identify cases of Behçet's could with appropriate consent be used to populate the first Patient Registry for Behçet's in the UK - starting, probably, in England, and perhaps linked in some way with the National Disease Registration Service (NDRS); however, it might need to be independently managed by the Society, as done by the Cystic Fibrosis Trust (<https://www.cysticfibrosis.org.uk/the-work-we-do/uk-cf-registry>) which has been independently collecting data to populate its registry using three 'trusted third party' individuals, with ethics approval from NHS England. The Rory Morrison Registry (WMUK) is another exemplar. There are many specific condition-targeted disease registers, usually sponsored by clinical teams treating conditions mainly for research purposes. We need to learn from the experience of others in setting up these registers.

An underpinning process is to establish the validity of HES datasets coded with the ICD-10 code for Behçet's, by using the Birmingham CoE data as a reference. SNOMED-CT and ICD-10 coding is widely used in the NHS across all care settings; however, the accuracy of coding is always an issue, so the validation exercise will give an indication of the extent of inaccurate coding. SNOMED-CT is usually used to code diagnoses and ICD-10 to code treatments. A substantial amount of the process is automated, which reduces errors.

I add detail here because it is important to understand the challenge that Dr Chandratre (who has marvellously secured additional funds to continue the work while abroad) and others in the team face thanks to the disparate and incoherent manner in which data is captured across the NHS. For example, the CPRD GOLD database contains longitudinal health records from UK primary care practices,



Tony Thornburn

routinely collected using Vision® general practice patient management software. CPRD Aurum contains routinely collected data from practices using EMIS Web® electronic patient record system software. SNOMED-CT is an international coding ontology (see above) used by healthcare organisations. These are the two main systems used in general practice.

Then there is the Optimum Patient Care Research Database, which holds anonymous data from over 1000 general practices in the UK and over 18 million patient records. A licence payment is needed for access to this data, but it is a rich source and valuable to obtain from GP practices. In each GP practice, electronic health record software is used, but differently, to record their patients' signs, symptoms, diagnoses, test results and medications - using two software tools EMIS (60%) and TPP (40%). Hospitals use electronic patient record systems, the main providers of which are Cerner and Epic. These systems are widely installed.

The formation of Integrated Care Boards and their associated summary care records systems (ICS) hopes to bring together data from various care providers in a geographic region. The OneLondon project is an example of this - a collaborative project between all five London ICSs designed to showcase the value of novel, large-scale, population-level health projects. Interestingly, Mendelian, who presented at our 2019 Conference, may have the opportunity to apply their MendelScan rare disease case-finding technology to the entire London population, all 9 million patients. In the past few months, Mendelian have scanned nearly 270,000 patient records in England-based GP practices with MendelScan. In every deployment they have included the Behçet's case-finding algorithm, identifying 37 patients who were, according to their electronic records, already diagnosed. Mendelian identified a further 38 patients who could be clinically reviewed for the condition. To date, they have received feedback on 21 of these patients and nearly 20% (four) have been moved forward on a path towards diagnosis.

Returning to Dr Chandratre's results, 4452 cases of Behçet's including 515 CoE patients were identified in HES between 2011 and 2019, and 559 Behçet's cases were confirmed between 2012 and

2020 in the CoE database - so that's an additional 44 patients. However, HES data only identified 1157 patients attending the CoEs from the total of 4452 (see comment about coding above). The prevalence and incidence thus seem to have increased. Most (65.5%) Behçet's cases were female, and 84.9% were white; prevalence peaked at ages 40-49 years. Male patients with Behçet's were more likely to have ocular, vascular and cardiac characteristics. Non-white/Asian ethnicity was associated with higher prevalence of genital ulceration and ocular, neurological and vascular signs of Behçet's. Three-year all-cause mortality was higher in the non-CoE cohort than in CoE attenders. However, there were no differences in mortality associated with ethnicity in the study. Infliximab reduced risk of mortality..

In summary

There is an advantage in developing a disease-specific register for Behçet's to gain a longitudinal view of the incidence and progression of the disease and its impact on people's lives. This will provide an invaluable resource to encourage research and development of new treatments by providing access to a single source of data as opposed to accessing multiple sources. The apparent increasing prevalence of Behçet's might result from misclassification, improved recognition, migration effects or improved survival. Interestingly, during the COVID-19 shielding exercise in Wales, David Tucker at CARIS identified some 450 patients with apparent Behçet's, highlighting another example of an

increase in prevalence of the condition.

The study confirms differences in phenotype and mortality between people diagnosed with Behçet's in England versus endemic regions. Future work will examine primary care datasets (CPRD and linked HES data) to evaluate the national prevalence, incidence, phenotype clusters and risk factors for Behçet's, and will ultimately facilitate the creation of a National Behçet's Register. Unfortunately, as HES data linked to CPRD is not identifiable, one is unable to validate the diagnostic accuracy of the codes by cross-examining medical records at the CoEs. That's why this all needs to be captured in an appropriate Patient Registry and data shared comprehensively.

The NDRS has legal permission to collect named, individually identifiable patient data to protect the health of the population. Previously this permission was granted to Public Health England (PHE) under section 251 of the Data Protection Act, and now under section 254 of the Health and Social Care Act 2012, to publish anonymous statistical data under section 260 of the 2012 Act and to share data under section 261 of the 2012 Act. This can be facilitated via the National Congenital Anomaly and Rare Disease Registration Service, but it has restricted capacity in my view to achieve what is ultimately required. Neither does it cater for the needs of those in the devolved nations.

The need is to comprehensively corral, in one stream, longitudinal data across primary and secondary care, accompanied

by real-world (patient entered) data, captured in context (with environmental factors). This is key to really understanding rare diseases and to treating patients in an optimal, timely manner and being able to subsequently audit their care pathway, thus enabling true 'gold standard' underpinning research. Data is currently collected mainly on an 'intervention-based' basis, which makes it difficult to link data together into a longitudinal record. Holding us up is getting to the bottom of how this would take place, on what platform, who is inputting data, how, when and where, and who is needed to manage the whole thing - from which costs and a project plan can be articulated and a joint vision formed with a governing body to oversee it. When this is done, the Trustees can make an informed decision and commit resources to the project.

I will reiterate what I said back in the spring 2021 newsletter. One overriding message comes through from all I have researched. If this initiative is to work and make a significant difference to your lives, it is vital that member engagement/involvement is as near to 100% as possible so that we capture as much data as possible; by having a significant majority of patients, we will have a data source that is authoritative and makes it easier for research to be conducted. NICE protocols demand 75%.

Data for cancer is probably one of the largest disease registers. In the US, the first hospital registry for cancer was established at Yale-New Haven Hospital in 1926, and the first central or state registry was established in Connecticut in 1935. In the UK, it has become a national initiative embodied in the National Cancer Registration and Analysis Service (NCRAS), part of PHE. It is the population-based cancer registry for England, collecting, quality assuring and analysing data on all people living in England diagnosed with malignant and pre-malignant neoplasms, with national coverage since 1971. It is custodian of the national cancer registration dataset for England. The primary role of NCRAS is to provide near real-time, cost-effective, comprehensive data collection and quality assurance over the entire cancer care pathway. To achieve this, it receives data from across the NHS. This represents a true collegiate effort. We have some catching-up to do!

Tony Thornburn, Chair

Working with Behçet's

Thinking of returning to the workplace or changing your career? In this article, part of which is based on what patients at the Liverpool Centre have told me, I'm going to look at the support that people with disabilities can access when both looking for and in work.

According to the NHS website, almost half of working-age people with disabilities in the UK are employed and it's recognised that working has health benefits. Many patients with Behçet's work in full-time, part-time and self-employed roles and report anecdotally the benefits of being in work, not just financial but psychological and social too. Going back to work does not mean giving up all your benefits. Some benefits may carry on, and others may be available once you're working. The good news is that if you are in receipt of any PIP award, you can work full or part time and not lose any of your entitlement.

The changing workplace

Post-pandemic the 'workplace' has taken on a whole new meaning; remote and flexible working arrangements may assist in improving the working lives of people with disabilities. Some search engines for jobs/careers allow you to select home based jobs/careers from their menu, and several patients have told me how this new way of working is helping them to stay in paid employment and develop their careers. However, not everyone can work remotely. Many jobs/careers require face-to-face contact when delivering services such as in the retail, care and hospitality sectors. So it's absolutely vital that you know your rights in the world of work.

But where to start? It may seem daunting, especially if you've not worked for some time and may have lost your confidence in job application and interview skills. However, there's lots of help available, not just in finding you 'a' job but in making sure that it's the 'right' job for you. For some people that may mean starting with voluntary work so they can ease into the world of work and get a feel for what they want as a job/

career. Voluntary work can often lead to paid work too. A good place to start when thinking of returning to work is to talk to your Behçet's Centre's Support Coordinator, who can signpost you to the appropriate help.

Know your rights

Whatever your disability, you have a right to equality, fairness, respect and understanding at your workplace. Employees and jobseekers with disabilities are legally protected against discrimination under law by the Equality Act 2010; if you live in Northern Ireland, it's the Disability Discrimination Act 1995. You're legally entitled to fair treatment when it comes to recruitment, promotion and pay. It also means that employers must make their workplaces accessible.

Help with looking for work

Your local Jobcentre Plus is a government-funded employment agency that can be found in most towns and cities. Its aim is to help people of working age to find employment in the UK. Jobcentre Plus can arrange an interview with a work coach. This person is specially trained in supporting people who may have been out of the workforce for a short or long time and are now looking for work. They can also refer you to a specialist work psychologist, if appropriate, or carry out an 'employment assessment', asking you about your skills and experience and what kind of roles you're interested in.



When you're looking for work, look in adverts and on application forms for the 'disability confident' symbol. This symbol means that the employer is committed to employing disabled people and that you'll be guaranteed an interview if you meet the basic conditions for the job. You can search on the internet for a list of employers/companies who have signed up to the disability confident scheme.

40 years caring for all those affected by Behçet's, and it doesn't stop here!



Fundraisers for 2023

Visit our website at <https://behcetsuk.org/40years>, where you can read more about the three 40th anniversary fundraisers for 2023 as announced in our autumn newsletter and at our annual conference:

- **Bake for Behçet's:** host a bake sale, a baking competition, a coffee morning or an afternoon tea in aid of Behçet's UK. Take part throughout 2023 on a date to suit you
- **40 in 40:** Run, walk or push 40 miles or 40 kilometres in 40 days starting in June 2023. You choose and set your own pace.
- **Life Begins at 40:** Tick something off your bucket list in aid of Behçet's UK. Take part throughout 2023.

Registration is now open for all three fundraisers, and we hope there is something to tempt you to take part! If you would prefer to speak to one of the team to find out more about taking part, please call the admin team on 0345 130 7328.

40-year history

Read more about Behçet's UK from Judith Buckle's founding years to establishing the Behçet's Centres of Excellence, the present day and what the future holds on our website and in our quarterly newsletters throughout 2023.

Financial support and government programmes

Your work coach at the Jobcentre Plus can tell you about programmes and grants (for which you may be eligible) to help you back into work. These include:

Access to Work, which can help you to get or stay in work if you have a physical or mental health condition or disability. The support you get will depend on your needs. Through Access to Work, you can apply for a grant to help pay for practical support with your work such as taxi fares to work or a support worker if you cannot use public transport, as well as money to pay for communication support at job interviews.

Your workplace can include your home if you work from there some or all of the time. It does not matter how much you earn. If you get an Access to Work grant, it will not affect any other benefits you get and you will not have to pay it back.

Intensive Personalised Employment Support, which is one-to-one support

and training to help you into work if you have a disability. You are eligible if you have a disability that affects the work you can do, you are unemployed, you are between school leaving age and state pension age, and you are a UK resident living in England or Wales. For Scotland and Northern Ireland, visit the respective government websites which you'll find in the red box below.

You'll get a dedicated support worker to help you to identify what work you're able to do, match your skills to a job/career, access training to help you find work, build a personal support network and manage work around your specific disability. They will also support you during your first 6 months of work; this may be extended by an additional 6 months.

Charitable sector

Some charities also support people with a disability to get into, and stay in, the workplace. The Shaw Trust and Leonard Cheshire charities both provide dedicated employment support for

disabled jobseekers. You can find out more about the Shaw Trust and Leonard Cheshire by following the links at the end of the article.

Employment law

It's important that you know your rights. It is against the law for employers to discriminate against you because of a disability. The Equality Act 2010 in England, Wales and Scotland, and the Disability Act 1995 in Northern Ireland protect you and cover areas including:

- Application forms
- Interview arrangements
- Aptitude or proficiency tests
- Job offers
- Terms of employment, including pay
- Promotion, transfer and training opportunities
- Dismissal or redundancy
- Discipline and grievances

Recruitment: The general position is that it is unlawful for an employer to ask any job applicant about their health or disability unless and until the applicant has been offered a job. However, there are some specific circumstances when questions about health and disability can be asked. You can read more about this by visiting the links for the Equality Act 2010 and the Disability Act 1995 in the box on the left.

Reasonable adjustments in the workplace: An employer has to make 'reasonable adjustments' to avoid you being put at a disadvantage compared with non-disabled people in the workplace. This might entail adjusting your working hours or providing you with a special piece of equipment to help you do the job.

For further information on this topic, visit the Behçet's UK website page on Employment, where you can view two important booklets, one for employees and the other for employers, which cover the subject in greater detail. Also please do approach your Behçet's Centre Support Coordinator who will be happy to help.

Jackie Pooler
Behçet's Support Coordinator,
Liverpool Centre

Behçet's Patients Support update

Good news

- Advocated re cost of living with NHS colleagues to try and increase understanding on impact on patients' attendance, compliance and mental health.
- Advocated for a patient to try and aid more successful clinic visits.
- Making sure that patients, especially those who travel long distance, know how to claim transport costs.
- Redirected patient to their local council for a successful Blue Badge application as she did not qualify for one under the usual rules; Support Coordinator supplied a support letter to evidence the need for a blue badge.
- Helped patient with application to Behçet's UK for a grant to provide financial assistance with replacement of an essential piece of domestic equipment.
- Directing young patients before appointments to our Behçet's Children's clinic journey video so they can be better prepared for the clinic day.

Trends

- Continuing to support patients:
 - In education to ensure schools make reasonable adjustments for exams and assessments

- In PIP/DLA applications, reviews and appeals
- In employment, including job application and interview advice and signposting.
- Cost-of-living crisis is really affecting patients.
- Support Coordinators are seeing a hardening up of DWP responses to first PIP applications.
- Several patients are losing awards on reassessment.
- More patients are applying for PIP for the first time, possibly because of the cost-of-living crisis.
- Redirecting patients, when appropriate, to local services for help with housing, support needs and welfare rights.
- Helping patients who are in work to negotiate with managers about applying reasonable adjustments under the terms of the Equality Act.

Team working

- Wrote and updated a cost-of-living crisis guide for Behçet's patients which has been added to the website, shared in clinic and sent to patients via text and email.
- Working with Clinical Psychologist on several mutual patients whose social needs are impacting mental health.

Patient feedback

- *Support Coordinator is always in touch just before the clinic to see if we need anything. Her support is very valued.*
- *Support Coordinator has been extremely helpful and kind for everything I have needed.*
- *Did not require support but always offered help with anything if needed later.*
- *I got information about the Behçet's Centre and was given information about Behçet's UK membership. I was also helped with advice on travel and transport.*
- *Support Coordinator gave invaluable advice regarding benefits. She really is a star!*
- *General chat and support. Support Coordinator was great.*
- *I have received information and guidance for Behçet's and benefits advice.*
- *Extremely helpful. Support Coordinator did a letter for me confirming how Behçet's can affect your life.*
- *I managed to get benefits sorted on initial application which is unusual. Support Coordinator was the first person to support me through accepting my disability and was great at listening.*

Continued overleaf

Useful links

- **NHS England Work and Disability**
<https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/work-and-disability/>
- **Help with moving from benefits to work**
www.gov.uk/moving-from-benefits-to-work/support-when-you-start-working
- **Equality Act 2010**
<https://www.gov.uk/guidance/equality-act-2010-guidance>
- **Protection against disability discrimination (NI)**
<https://www.nidirect.gov.uk/articles/protection-against-disability-discrimination>
- **Disability Discrimination Act 1995**
<https://www.legislation.gov.uk/ukpga/1995/50/contents>
- **Jobcentre Plus**
www.jobcentreguide.co.uk/jobcentre-plus-guide/4/what-is-the-jobcentre-plus
- **Access to Work**
<https://www.gov.uk/access-to-work>
- **Behçet's and Employment** - <https://behcetsuk.org/behcets-and-employment/>
- **NI Direct** - <https://www.nidirect.gov.uk/>
- **The Scottish Government** - <https://www.gov.scot/>
- **Shaw Trust** - <https://www.shawtrust.org.uk>
- **Leonard Cheshire** - <https://www.leonardcheshire.org/>

Contact details for Behçet's Centres

London

Clinic address: Behçet's Centre of Excellence, Clinic 6, 1st floor South Tower, Luckes Entrance, Stepney Way, The Royal London Hospital, Whitechapel Road, London E1 1BB

Postal address: Royal London Hospital/Dental Clinic Office, Turner Street, London E1 1BB

Lead clinician: Prof Farida Fortune

Clinical nurse specialist: Elizabeth Ssendi, 020 3594 6085

Receptionist and admin
Bridie Sweeney, 020 3594 6111

Email address:
Bhnt.londonbehcetscentre@nhs.net

Usual clinic times: Thursdays and Fridays

Who to contact for urgent advice:
Elizabeth Ssendi

Support coordinator: Jean Christians
07804 880655*
Jean@behcetspatients.org.uk

Birmingham

Address: Behçet's Centre of Excellence, Sandwell and WestBirmingham Hospitals Trust, Birmingham Midland Eye Centre, Dudley Road, Birmingham B18 7QH

Lead clinician: Dr Deva Situnayake

Lead nurse: Debbie Mitton

Telephone number: 0121 5074243

Email address: behcetsbham@nhs.net

Usual clinic times: Thursdays 13.30 to 17.00, Fridays 8.45 to 13.00

Who to contact for urgent advice:
Debbie Mitton

Support coordinator: Rebecca Hyder
07467 945269*
rebecca@behcetspatients.org.uk

Liverpool

Address: Behçet's Centre of Excellence, Clinic F (near the main entrance), University Hospital, Aintree, Lower Lane, Liverpool L9 7AL

Lead clinician: Prof Robert Moots

Lead nurse: Sarah Hardy

Telephone number: 0151 529 2091

Helpline number: 0151 529 8123

Email address: BEHCETS@aintree.nhs.uk

Usual clinic times: Currently Tuesdays 9.00 to 12.00

Who to contact for urgent advice:
Sarah Hardy

Support coordinator: Jackie Pooler
07775 645714*
Jacqueline@behcetspatients.org.uk

**Please note that the*

support coordinators are part time and may not respond the same day

Continued from page 9

- Made a difference as it is a diagnosis that people are not aware of, so the letter Support Coordinator carefully prepared explaining the symptoms and how they affect one's life was amazing.
- Support Coordinator always introduces new patients to us all and makes everyone feel at ease.
- I was nervous about having to travel so far to the centre but was put at ease straight away. The coordinator plus all the staff were very friendly and were only eager to help and answer any questions I had. Would highly recommend the Behçet's centre.
- It was always lovely to chat with Support Coordinator at Behçet's Centre appointment. She was always welcoming, knowledgeable and interested in patient.
- Support Coordinator support is very valuable and must continue. The clinicians are 'firefighting' like most NHS departments. With patient numbers increasing there are no extra staff so her calm support is welcome.



Dental self-care

As we all know, trying to access dental care since COVID has been a major problem in many areas of the UK. I hadn't managed to see my dentist for nearly 2 years, and my teeth were badly in need of a check-up and scale and polish. I was informed that it would be months before I could be seen, as the resident dentist had left the

practice and it was taking a long time to recruit another one.

In desperation, I phoned around and managed to be seen by another dentist the following week. After my check-up I was then seen by the hygienist, Shirley. To my surprise she told me that she had never heard of Behçet's but she had researched several papers before

my appointment and was very aware of the importance of good oral hygiene to prevent mouth ulcers and to cut down the risk of inflammation and infection. She told me that she would be really careful when examining and cleaning my teeth in case she set off any ulceration. She was very gentle and descaled my teeth without using water or chemicals.

The data on the amount of bleeding and plaque on my teeth was fed into the computer, and I was shown a diagram on the screen of the location of the bleeding and plaque on the individual teeth. Shirley was able to show me where I was not reaching specific teeth when I was brushing. She explained that in a normal healthy mouth there should be no more than 10% of plaque and bleeding on the teeth. I was astounded to learn that my score was 36% for plaque and 25% for bleeding. She recommended that, as I had Behçet's, my score should be as near zero as possible to keep my mouth free of inflammation.

I was then shown the specific teeth that needed most attention when brushing and how to hold the brush for optimum results. It was recommended that I invest in a good quality electric toothbrush and floss every day if possible.

I was given another appointment within 2 weeks to check how I was progressing. My teeth were checked again and the results mapped on the computer. The results were illuminating. My plaque score was now 12.5% and the bleeding score was 6.2%. Clearly my new brushing and flossing technique was helping, but still had a way to go to get the plaque down below 10%.

I am grateful to Shirley for taking time to research Behçet's so that she could tailor the treatment to improve my dental health and avoid further inflammation, which is so important for Behçet's patients. She can now also confidently support any other Behçet's patients she comes across. The role of the dentist and hygienist cannot be overestimated in diagnosing and treating conditions such as Behçet's that affect the mouth.

Since sticking to this regime, I have had fewer ulcers and less inflammation in the floor of my mouth. I know I will never be free of Behçet's, but self-help such as this will add to the arsenal of ammunition available to attack the symptoms of Behçet's.

Catherine O'Hara

The cost of living

Talk of the 'cost of living crisis' is everywhere, and for many of us it has become a daily challenge

As a Support Coordinator at the Birmingham Centre of Excellence, I know that many of our patients are particularly concerned. Almost half of all adults are finding it hard to pay all their bills, and this rises to over half of disabled adults. With food and energy prices at record highs, people on a low income are disproportionately affected as they spend a larger proportion of their monthly budget on food and energy, and even people who were previously financially comfortable are now feeling the pinch.

At the Behçet's centres, we understand that these are very tough times and that it's difficult to know where to find the support you might need. So, with this in mind, I drew together a list of links and useful places to find help. The Support Coordinators are making this list available to patients and we are updating

it regularly. Everyone (patient at a centre or not) can access the latest copy on the dedicated Cost of Living page on our Behçet's Patient Support website at <https://behcetspatients.org.uk/cost-of-living>.

We were lucky to have a warm autumn to help us out, but as we move into winter time, the weather is getting colder. Local charity shops can be a great way to increase your selection of warm jumpers (I've managed to get some really good ones that way this year). If your house is really cold and you need somewhere to warm up, then a 'Warm Spaces' scheme has been established to offer 'warm banks' in places such as local libraries and churches and a host of other venues. Some of these will also offer a free meal as well as a space to get warm, so it is definitely worth checking out what is on offer in your local area. Many of these spaces will also have sources of extra help and advice on hand. You can find your local warm

banks at <https://warmspaces.org/>.

Finally, it is very important to be aware of, and look after, your mental health at a time like this. The NHS also has a helpful website with links to further targeted support (<https://www.nhs.uk/every-mind-matters/>). There is a Clinical Psychologist attached to each of the three Centres of Excellence who can help with Behçet's related mental health issues and signposting to other services. If you feel that you need more urgent help then you should always reach out to your GP in the first instance

If you have any tips or links that you think I should add to my Cost of Living list, please do email me at rebecca@behcetspatients.org.uk.

The best way we can get through this is together. Wishing you all the best possible festive period with hope for a more positive national outlook in 2023.

Rebecca Hyder
Support Coordinator,
Birmingham Centre of Excellence

About us

Behçet's UK (formerly Behçet's Syndrome Society) was founded in 1983 by Judith Buckle and is a Registered Charity No. 326679.

The main aims and objectives of the Society are:

- provision of information
- promotion of research
- relief of distress/poverty

The Society is a member of National Voices (formerly known as the Long Term Conditions Alliance or LTCA), Genetic Alliance UK, EURORDIS (European patients' organisation for rare diseases), the Behçet's Forum and the International Society for Behçet's Disease (ISBD).

Contact us

- Post: Behçet's UK, 124 City Road, London EC1V 2NX
- E-Mail: info@behcetsuk.org
- Website: <https://behcetsuk.org>
- Admin team & general enquiries tel: 0345 130 7328
For all general enquiries including information on membership, events, fundraising, grants etc

Helpline: 0345 130 7329

The helpline is available between 09:00 and 21:00 7 days a week. Answerphones may be used at certain times so leave a message and we will return your call.

Our helpline is run by volunteers who can provide general support and guidance about the condition. They are unable to give direct medical advice and do not deal with emergencies.

Follow us      @BehcetsUK

Patron Baroness Ritchie of Downpatrick

Trustees

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		Trustee	Neil Williams

Newsletter

Editor: Clare Griffith

Design and print: INQ Design Ltd

Member support

Support groups

These are the contact details for the various local support groups that have been, or are in the process of being, set up. Please get in touch if you are interested in becoming involved, or contact the admin team for more details.

Area	Email contact
England (online)	Clare via info@behcetsuk.org
Liverpool area	yvonne.liverpoolbehcets@gmail.com
Northern Ireland	fionnuala.mckinley@behcetsuk.org
Parents of Children with Behçet's	Amanda via info@behcetsuk.org
South Wales & Wales online	rachael.humphreys@behcetsuk.org
Scotland	catherineohara@behcetsuk.org
Thames Valley	thamesvalley.support@behcetsuk.org

Befriending service

We run a befriending service to match up members who would like to stay in touch with each other by phone or email. If you are interested in registering or would like to know more, contact our admin team on 0345 130 7328 or info@behcetsuk.org

Facebook support groups

We have a number of groups which offer peer-to-peer support for Behçet's UK members who are on Facebook. Request access on our Facebook page @ BehcetsUK.

Can you help?

Would you like to support others with Behçet's? Would you like to help to organise a support group near you, or do you have spare time when you could help with our Helpline? Please contact info@behcetsuk.org for more information.



Amy's skydive

On Sunday 16 October, Amy Gonis completed a skydive to raise funds for Behçet's UK in support of her mum who has the condition. Amy smashed her £850 target and raised a magnificent total of £950 for Behçet's UK. She emailed us to say: "The skydive couldn't have gone better! I had reached the target two days prior to the skydive and it just kept going

up. I was happy to do something meaningful for my mum and raise money for a charity that doesn't get spoken about a lot. The experience was truly amazing and I will definitely be doing it again in the future."

Many congratulations to Amy, and thank you to everyone who donated.



Great North Run

Cat Ray and her partner Chris took part in this year's Great North Run together on 11 September, with Chris pushing Cat in her wheelchair around the course. Cat emailed us to say: "Taking part in the Great North Run together is something we will never forget. The atmosphere was incredible and there wasn't a moment when there wasn't someone cheering us on from the sidelines or patting Chris on the back as people ran by us. So many people came up to us asking about our Behçet's UK t-shirts. It was amazing to be able to chat and educate people on such a rare disease."

"We completed the half marathon in 2 hours 39 minutes, and we were over the moon with the £805 we raised for Behçet's UK. Chris is now looking at our next fundraising challenge - possibly a marathon!"

"We got so much support on social media too after we posted our 'finisher' photo, we even got a like and comment on Instagram from TV presenter and former Invictus Games medallist J J Chalmers!"

Many thanks and congratulations to Cat and Chris for their amazing achievement, and thank you to all who donated.

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January 2023