

Behçet's UK 2025 Conference and AGM

The 2025 edition of the Behçet's UK Conference and Annual General Meeting took place on Saturday 18 October 2025 at the Pentahotel Reading and online. A total of 160 people registered to attend, of whom 74 registered to attend in person and 86 to attend online.

Welcome

Tony Thornburn, Chair of Behçet's UK, welcomed everyone to the 2025 Conference and AGM. He reported that more than half of people who registered were patients, and almost two-thirds of those living in the UK had attended one of the centres of excellence. Baroness Margaret Ritchie of Downpatrick, Patron of Behçet's UK, thanked Tony for his year-round efforts, Prof Fortune and her London team for sponsoring the conference, and Gemma Darlow for organising the event, as well as all the clinicians, staff, family carers and friends who support people with Behçet's. She mentioned that the living guideline for Behçet's has just had its first annual review and helps to raise awareness among general clinicians. Finally, she encouraged patients to share their data in the planned Behçet's patient registry and to join the Our Future Health study.

Behçet's UK AGM

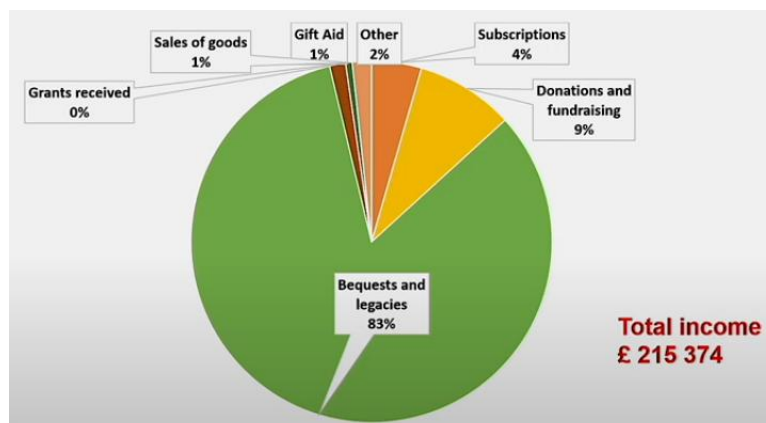
Tony Thornburn thanked Baroness Ritchie for her support and opened the AGM by encouraging members to read the Annual Report, which is available on the Behçet's UK website. He thanked the officers, trustees and administrators for their work. Looking back on the past year, Tony highlighted the closer cooperation between the three centres of excellence, the maintenance of wider visibility of Behçet's through social media etc, a webinar on management of Behçet's in Scotland, the excellent fundraising by members, and the great success of the Friends and Family Day. He noted that the Constituent Relationship Management (CRM) system had been initiated and was already starting to make a difference.

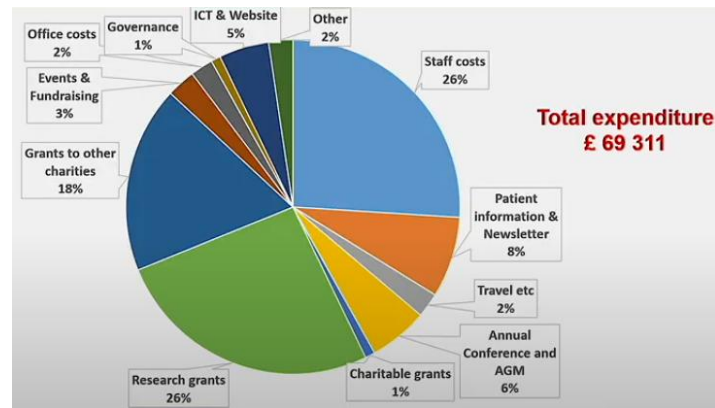
Looking forward, Tony announced that the Behçet's patient registry is about to start and has been endorsed by Sarah Watson, the NHS England Highly Specialised Services Senior Commissioning Manager. The initiative is being led by Dr Deva Situnayake at the Birmingham Centre, in collaboration with the other two centres.

Tony then recommended patients and their families to sign up for Our Future Health, of which Behçet's UK will be an affiliate member. He finished by saying that there had been no qualifying nominations for the 2025 Behçet's UK Membership Award and reminding members that nominations for the 2026 award will close on 30 April 2026.

Alan Lane, Honorary Treasurer, reported that Behçet's UK now has 1285 standard members, of whom 1155 are patients. Benefits of standard membership include a welcome pack, quarterly newsletters, access to the helpline, participation in local and online support groups, invitations to family days, and the ability to participate in workshops and initiatives such as Breathe Creative. The annual membership subscription increased to £30 for 2025/26, but there will be no further increase for 2026/27.

The charity's total income for 2024/25 was £215,374, a big increase from the previous year, with 83% coming from bequests and legacies. This was due to one person leaving the balance of her estate (£183,000) to the society. An important 9% of the income came from donations and fundraising, with subscriptions contributing 4% and Gift Aid 1%. The expenditure for the year was £69,311, with staff costs and research grants accounting for 26% each, information and newsletters for 8%, and the Conference and AGM for 6%. In addition, a grant of £25,000 was made to Behçet's Patients Centres to help with their continued running when NHS funding changed from monthly in advance to quarterly in arrears. The general fund now stands at £64,000, with £161,000 in the research fund (£100,000 of which has been allocated to the patient registry over the next 5 years) and £49,000 set aside for a specialist nurse in Scotland.





Rachael Humphreys, Behçet's UK Trustee, highlighted some of the amazing fundraising efforts over the past year, from a Halloween Spooktacular to multiple marathons and a trek to Everest Base Camp. Behçet's UK is very grateful to all the imaginative fundraisers and supporters, including those who chose to forgo birthday presents in exchange for donations through Facebook and Instagram. All these efforts have a huge impact. Ways to help include joining the society, making a donation, organising a fundraising event, buying merchandise, shopping through shopping partners, participating in payroll giving or match funding through an employer, and leaving a legacy.



Rachael then announced that the recipient of the Judith Buckle Award 2025 was Alan Lane. Alan became Honorary Treasurer in 2011 and is the longest serving trustee. He started mapping where Behçet's UK members lived, which was invaluable in the establishment of the centres of excellence, and he then helped to

set up the charitable company to run the centres and became its Financial Director. Rachael highlighted Alan's steady approach; his diplomatic and solutions focused approach to problem solving probably stems from his previous experience as a teacher and head teacher. His presentation of accounts at the annual AGM is always clear and easy to understand, and always sprinkled with humour.

Alan said that he was very grateful for the award and for Rachael's words. He started as a mathematics teacher 54 years ago and finished as a head teacher 35 years later. He described his time as Behçet's UK Honorary Treasurer as 15 wonderful years, during which he had learned a lot about Behçet's, met many amazing members and made great friends among his fellow trustees.

Finally, **Rachael** spoke about a new project involving children and young people with Behçet's, which builds on the Breathe Creative project with adults 3 years ago. This art-based project, which has received funding from the British Association of Dermatologists, involves six weekly Zoom meetings on Saturday mornings. It offers the opportunity to explore what it is to be a child or young person with Behçet's and to create art-based projects (animation, video, drawing, writing), with sessions focusing on the child's perspective, experience and ideas, and offering help to guide and create their project. A project for parents of children with Behçet's will follow in 2026; any parents who are interested in joining this should email info@behcets.co.uk.

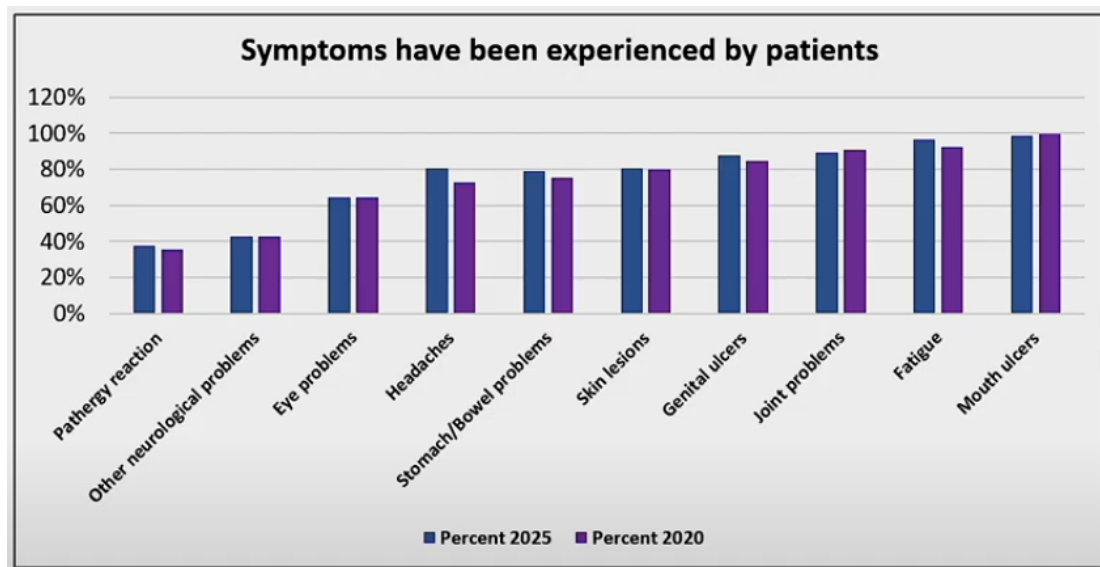
Introduction and conference overview

Prof Farida Fortune, Clinical Director at the London Behçet's Centre of Excellence, introduced the programme for the rest of the day. She reminded the audience that in the late 1970s at least 40% of people with Behçet's lost their sight, and in 2010 the average time to diagnosis was over 14 years. This time is now down to 2–4 years, or just a few months once a patient is being seen in a centre of excellence. So the centres have made a big difference, and a database covering all three centres will be important for future research. Prof Fortune noted that the core team at the London Centre has not changed since it was established.

Behçet's Quality of life survey

Prof Fortune then presented the first cut of the results of the fourth quality of life survey conducted since the centres opened. Of the 251 patients who responded, 81% were women, most were aged 45–64 years and 88% were born in the UK. It would be good to have more young male patients responding, especially as they are the ones with the most severe ocular disease. The number of patients with a confirmed diagnosis has increased to 96% (from 89% in 2009). The preliminary diagnosis and referral was made by a rheumatologist for almost 70% of patients. The most commonly reported triggers of symptoms are stress, fatigue and seasonal changes.

Mouth ulcers and fatigue are the most commonly reported symptoms, followed by joint problems, genital ulcers, skin problems and stomach/bowel problems. The latter are often caused by pain medications containing codeine. The number of patients with headaches has increased since 2020; some have migraine, although this is not a specific symptom of Behçet's. This pattern is typical for a cohort mainly composed of women.



The average quality of life score decreased between 2009 and 2020 but has now risen again; there is still room for improvement. The main symptom affecting quality of life is now fatigue, along with arthropathy, mouth ulcers, stomach/bowel problems and headaches. Fatigue is better understood since the COVID-19 pandemic, but more research is needed. Quality of life is better in people who work, even if it is part time, or volunteer. Better oral hygiene is also associated with better quality of life, while smoking, cannabis use and being on benefits are associated with worse quality of life. Prof Fortune concluded by saying that managing Behçet's is not just about medication; emotional support and community are also important, and focusing on all aspects of wellbeing will improve quality of life.

Behçet's – a patient's journey

Hannah, a Behçet's patient titled her presentation "Cushing's, clots, and cuss words: being a Behçet's patient". She described how being a 'sickly child' had led to school absences and the involvement of social services. She had her tonsils removed at the age of 8, which didn't solve her mouth and throat problems, and her appendix at 14

due to persistent abdominal pain. She had a pathergy response to both operations, with her body overreacting to the physical trauma, leading to internal scarring. Multiple visits to the doctor led to people, even her own family, believing that she was anxious or an attention-seeking ‘drama queen’. Only her Nan did not think it was all in her head, which helped to keep her going. As a teenager, Hannah was a perfectionist and tried to fix herself by being very active.

When Hannah was at university studying to be a dentist, she got sicker and was diagnosed with colitis. An infected genital ulcer led to her being sent to a sexually transmitted diseases clinic, although one doctor suspected Behçet’s. A biopsy of the ulcer showed a vascular problem, and she was referred to the Birmingham Behçet’s Centre. She had multiple problems by that time and was quickly diagnosed with Behçet’s. Azathioprine was effective but caused pancreatitis, while long-term prednisolone treatment resulted in symptoms of Cushing’s disease. In 2014, Hannah hit rock bottom and dropped out of university. She went to her first Behçet’s Syndrome Society AGM that year, where she met a patient who gave her Dr Kidd’s details. He dealt with her neurological problems and referred her to Prof Fortune, who started her on infliximab. This was a game-changer for Hannah, and it was at this point that she met her future husband and realised that she was worth loving had something to offer to a partnership.

Hannah returned to university, to study English at Cambridge, but this time she lived at home and sought out disability support. During COVID, she started getting blood clots that could only be treated with warfarin and also developed adrenal insufficiency as a result of the years of steroid treatment. After her degree, Hannah did a masters in medical history at York, receiving a scholarship that she used to get a Motability car and an electric wheelchair to enable her to attend classes. Although further clots and adrenal crises meant that she had to move back home and study online, she achieved a distinction. Hannah became pregnant in 2023, under strict medical supervision; her Behçet’s went into remission during the pregnancy, but she fractured her back as a result of osteoporosis due to the steroids. This necessitated staying in hospital until the birth and a lot of help afterwards. The baby boy was immunocompromised for 6 months but is now perfectly healthy. Hannah has had plenty of health problems since then, but she is now doing a PhD on the day-to-day life of disabled people.

Psychology and Behçet's

Dr Steve Higgins, Clinical Psychologist at the London Behçet's Centre of Excellence, said that the role of the clinical psychologist is to support ordinary people who are living with Behçet's. He uses a biopsychosocial approach, as a patient's concerns are rarely just psychological but may be related to physical, social and environmental factors. Early experiences shape how people cope with living with adversity and how they make sense of the medical journey of symptoms, ill health and seeking help. Medical trauma can result from the delay between symptoms and diagnosis, major medical events, repeated minor healthcare events or repeated difficult consultations. In the case of Behçet's, diagnosis leads to treatment and often feelings of relief, but not to a cure. This can result in shattered dreams and loss of hope.

The five stages of grief are denial, anger, bargaining, depression and acceptance, but Dr Higgins suggested that for people diagnosed with an autoimmune disease such as Behçet's the final stage is various degrees of acceptability rather than acceptance. Patients have to adjust to living with their symptoms and the effects on their work, relationships and social life. They learn how to mask themselves and how they are feeling, but this takes energy and can lead to isolation. They have a changed sense of who they are, which, along with the effects of Behçet's on the body, affects relationships and intimacy.

Autoimmune flaring has a direct impact on a person's psychology and behaviour, which is a normal response mechanism to infection or disease. The effects include malaise, fatigue, lethargy, excessive sleeping, increased sensitivity to pain, loss of appetite, reduction in self-care, loss of enjoyment and lack of concentration. Psychological aspects include flat mood, negative thoughts and mild cognitive impairment. Even patients whose Behçet's is well controlled might still have chronic fatigue, brain fog and low mood associated with low level peripheral symptoms.

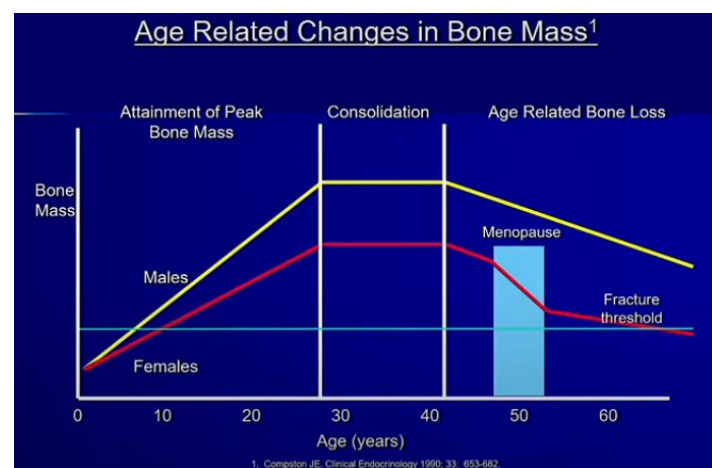
There are many ways a psychologist can help with these problems, such as mindfulness-based cognitive therapy to cope with stress or compassion-focused therapy for trauma. Values-based living concentrates on the acceptability of the aspects of life that you cannot change and building the commitment to continue living in accordance with your values. While many psychological therapies emphasise individualism, an approach that aims to reshape relationships with others focuses on

collectivism, emphasising rootedness, belonging and reciprocity to give rise to purpose and meaning in life through looking outwards. With limited time and energy available, it is important to concentrate on the people who are most important and supportive to you.

Behçet's and bone health

Prof Ali Jawad, Consultant Rheumatologist at the London Behçet's Centre of Excellence, explained that looking after your bones is important to improving overall health. Bones are composed of collagen, which provides a framework for the bone and ensures flexibility, and calcium to make bones strong and hard. Spongy (cancellous or trabecular) bone makes up about 20% of the skeleton, providing support in places such as the skull and the pelvis where it is not under great mechanical stress. It is metabolically active and can be affected by infections and cancer. Compact (or cortical) bone is denser and stronger and is present in the limbs.

The human skeleton is replaced approximately every 10 years in adulthood. Every 6 months, about 5% of the bone is broken down (resorbed) and then replaced. Bone cells known as osteoclasts take about 2 weeks to break down bone, whereas osteoblasts take over 5 months to make new bone. Osteocytes are long-lived cells inside bone that direct the osteoblasts and osteoclasts. Peak bone mass occurs between 25 and 35 years of age; after that the rate of bone loss exceeds the rate of replacement. Women have a lower bone mass than men and also lose it more quickly with age. During and after the menopause, osteoclasts resorb more bone than the osteoblasts can replace. This affects both spongy and compact bone, with bone becoming more porous and susceptible to fractures.

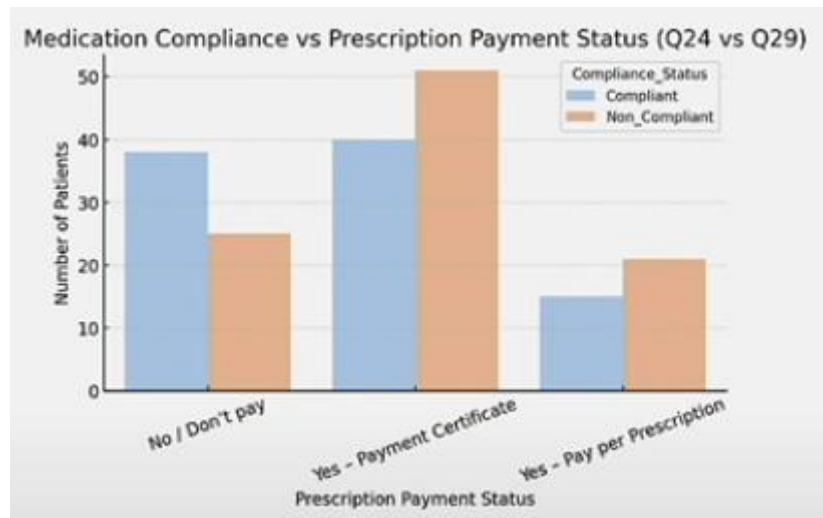


Prof Jawad said that the seven golden rules for preventing osteoporosis are a healthy nutrient-rich diet, adequate calcium intake (minimum 700 mg/day, preferably from food such as dairy products and dark green vegetable), adequate vitamin D (minimum 400 IU daily, preferably from food such as oily fish or from supplements in winter), regular weight-bearing and muscle-building exercise, not smoking, restricting alcohol intake, and a falls assessment for anyone with fragility. Some treatments can suppress the menstrual cycle, which leads to reduced oestrogen and hence decreased bone mass. Women aged 18–50 years with low bone mass should try to keep their body weight above 50 kg to protect their bones. In men, the three main causes of osteoporosis are senility, chronic obstructive pulmonary disease (COPD) and body weight under 70 kg.

Medication adherence and compliance

Dr Sarah Sacoor, Speciality Doctor in Behçet's at the London Centre of Excellence, presented some findings from questionnaires completed by patients over the past few years. Compliance with medication is important to manage the symptoms of Behçet's and to prevent severe complications such as loss of vision, blood clots and neurological disease. In addition, some medications, such as steroids, should not be stopped abruptly. The questionnaire was completed by 214 patients, of whom 58% were female and more than half were in full-time employment.

One of the main findings was the importance of social support in maintaining compliance. For example, patients living with a partner or family were more likely to adhere to their medication than those living alone or with a friend or flatmate. However, behavioural patterns are more important than socioeconomic factors; patients who do not take medications at consistent times are significantly more likely to be non-compliant. Some reasons for not complying differ according to the type of medication. For example, non-adherence to azathioprine may be due to access or availability problems, while adalimumab may be missed due to scheduling delays and prednisolone due to low perceived importance. Healthcare professionals can offer strategies to help patients who are having problems with adhering to their medication.



Adjusting, not stopping: enjoying life with Behçet's

Jean Christians, Support Coordinator at the London Behçet's Centre of Excellence, explained that her role was to promote living well with Behçet's and encourage patients to continue their work or education and to participate in activities that matter to them. Behçet's can be very isolating, and recreation and leisure activities are important in supporting wellbeing, whether that's continuing with a previous activity or taking up a new one.

Clare Gibson, a Behçet's patient and former army combat medic and fitness instructor, said that she was diagnosed in 2012 after being misdiagnosed with Crohn's disease 4 years earlier. It was her general practitioner who did the investigating and put the pieces of the puzzle together. Finding Behçet's UK and reading the medical factsheets was a game-changer for Clare, who was referred to the London Centre in 2014. Clare struggled to come to terms with the effects of Behçet's on her mobility, but using a wheelchair gave her back her independence. Military charities such as Help for Heroes and the Royal British Legion have been an invaluable source of support in enabling her to participate in sports.

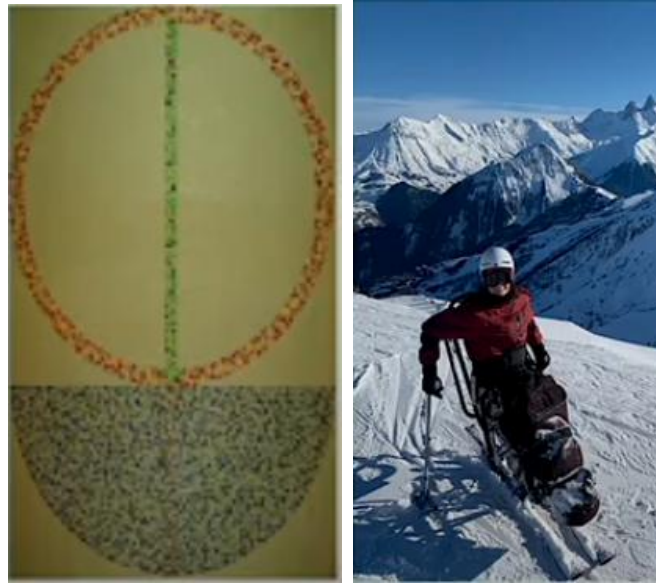
The first sport Clare tried was archery, followed by handcycling. During COVID, she used a hand bike on a turbotrainer in her garden shed and then discovered Zwift, which meant she could ride virtually with other people. She now plays wheelchair basketball, which is the UK's biggest Paralympics sport. Jean helped her to source funding for a basketball wheelchair, with the support of Behçet's UK. In 2022, Clare attended training camps for the Invictus Games and she was selected to represent the

UK in Dusseldorf in 2023, where she won three gold medals in wheelchair racing and two silvers in handcycling. Clare emphasised that there are many adaptive and inclusive sports available for those who are interested.



Jean then described some of the physical and creative activities enjoyed by patients at the London Centre. Jonathan used to be a master wood carver and decided to take up watercolour painting when the tools became too heavy for him. Alex is another talented artist who exhibits his work internationally. Daisy has participated in many more sporting activities since her Behçet's diagnosis, including sit-skiing. Jean said that resources to get people started are available on the Behçet's Patient Support website (<https://behcetpatients.org.uk>) and reminded everyone that, as Jonathan says, "there is always something you can do".





Behçet's research update

Dr Graham Wallace, Senior Lecturer at the University of Birmingham, mentioned a paper by Hasan Yazici which asked the question of whether Behçet's can be cured. The paper suggested that linking Behçet's with other disorders might not be helpful; it is necessary to study the condition itself ('splitting' rather than 'lumping'). What is needed are well designed studies to determine how long to treat Behçet's and with which therapies. It is important to consider the effect of the patient's sex on the disease course, which means conducting large enough studies with the correct proportion of male and female patients to enable meaningful subgroup analyses. Regarding the possibility of a cure, the answer is not yet yes, but there are some pointers to how this might be achieved.

Another aspect of clinical trials in Behçet's is what to use as the read-out. A recent review looked at the neutrophil-to-lymphocyte ratio (NLR) as a predictor of disease activity in Behçet's. NLR is emerging as a potential marker for systemic inflammation. The strengths of NLR include ease of use, low cost and correlation with disease activity for mucocutaneous and articular involvement. However, it lacks specificity and has limited utility with other disease manifestations.

Dr Wallace then explained that the immune system is usually tolerant to the person's own body. This is mostly achieved by central tolerance in which most autoreactive T cells are eliminated in the thymus. With peripheral tolerance, T effector cells are activated but controlled by T regulatory cells (Tregs). Tregs have all three chains of

the interleukin-2 (IL-2) receptor, including the high affinity chain CD25. Treating patients with low-dose IL-2 preferentially stimulates regulatory cells, down-regulating the immune response. Behçet's may be triggered by a defect in immune tolerance involving decreased Tregs. A study in 2021 showed that low-dose IL-2 restored the decreased Tregs seen in Behçet's without changing the effector cells, leading to improvement in symptoms. A 2024 study in patients with various autoimmune diseases showed that IL-2 treatment increased Tregs in all 13 diseases, with a good response seen in those with Behçet's.

Finally, Dr Wallace showed some recent data from a study using roflumilast (a PDE4 inhibitor used to treat COPD) for oral ulcers in patients with Behçet's or recurrent aphthous stomatitis. Roflumilast reduced the number, duration and pain of ulcers; similarly to apremilast, it has potential to be a useful drug for treating oral ulceration in Behçet's.

Medical Panel Q&A

The day finished with a question and answer session with a Medical Panel comprising the day's speakers. The panel were asked whether different versions of a product could have different effects. Prof Fortune replied that it is usually the excipients, rather than the active ingredient, in a product that cause bad reactions. There is a difference now that the UK is outside the EU; sourcing cheaper products for a smaller market can mean increased reactions to the cheaper excipients. Regarding biosimilars, some of these may also have different excipients even though the biologic drug is the same. For example, the first adalimumab biosimilars caused allergic reactions but the later ones are much better. In most cases, a biosimilar has the same efficacy for a lower cost, but the drug and antibody levels should be monitored and the treatment switched back to the original one if these are abnormal. The centres have been told to switch patients to biosimilars, but they are being very careful and collecting data.

Asked whether vagus nerve stimulation was worth exploring in Behçet's, the panel did not think it was, suggesting that it might even be quite dangerous in some situations. In response to a question about the reproductive effects of cyclophosphamide, the panel said that it was used in severe Behçet's before biologic drugs became available. It may be used in certain circumstances such as severe vascular problems, as it is very fast acting and can be useful if biologics are not

immediately available. However, it must be given under supervision and can affect sperm production.

Responding to a question about vaping, Prof Fortune said that some of the additives such as colourants and flavourings can cause allergies and inhalation of tiny particles can damage the lungs and induce inflammation.

Clare Griffith, Editor