

## **BSS 2014 Conference and AGM**

The 2014 BSS Conference and Annual General Meeting took place at Carnatic House, North Mossley Hill Road, Liverpool, on 18 October.

### **AGM essentials**

Alan Booth opened proceedings, and Judi Scott then presented the minutes of the previous AGM, which were accepted by the members present. She confirmed that the annual subscription will stay at £20 for 2014/15 and the Grant Aid limit will remain £750.

### ***Treasurer's update***

Alan Lane reported that as of 1 September 2014, the Society had 989 members. These included 715 full members, 4 junior members and 46 associate members (mostly medical professionals). The total also includes possibly lapsed members who will have to be deleted from the database to comply with data protection legislation if their subscriptions are not received. More than 125 members now pay their subscriptions by direct debit, and over 250 Gift Aid their subscriptions. The number of members in receipt of state benefits was 458, up from 362 last year; many of these make donations when they can, which are gratefully received.

The Society continues to rely almost completely on subscriptions and donations from members, for whose support the Trustees are enormously grateful. Although the subscription income was reduced from last year (£12,402 in 2014), the amount received in donations has more than doubled (to £47,671) and that from fundraising activities has more than trebled (to £8247). Receipts from sales of goods have also almost doubled (to £2653). The Society's running costs have been slightly less than those of the previous year, when there was a major upgrade to the website. Postage costs have been stable, despite increases in charges, as many members have kindly chosen to receive newsletters by email.

The general fund received income of £73,405, including £12,974 from the Behçet's Patients Centres (BPC). Its expenditure was £52,198, with £9092 being on behalf of the BPC, making an accumulated reserve of £54,850. The research fund had a total income of £14,677 and had no expenditure, thereby increasing the accumulated reserve to £20,322. It is planned to make a further substantial research grant in the next few months. The past year has thus been a very successful one for the Society.

### ***Director's update***

Chris Phillips reported that the number of visits to the website in September was 3449, but 59% of these visitors move on after viewing the home page. The average time on the site is 2 minutes, and the average number of pages viewed is two. The website is still in need of some development. The helpline continues to be well used, with 84 calls received in the past 12 months. Of these, 50% were first-time callers and 35% were members. Forty-nine email enquiries from patients were referred to the Medical Advisory Panel members in the past year.

Fundraising has been even more varied and successful this year, with events from skydiving to bicycle riding, including the ride from London to Paris which was very successful and has raised more than £6000.

### ***Young people's weekend***

Amanda Moseley (the Vice-Chair) gave details of the weekend event for young Behçet's disease patients that has been planned. This will take place on 24–26 April 2015 at White Lakes Activity Centre near Tamworth. It will be open to any patients aged 10–20 years and will include indoor activities run by the Teapot Trust and outdoor activities run by staff from the centre. Other professionals will be available for enquiries and information.

### ***Update on Centres of Excellence***

John Mather, Interim BPC Operations Manager, introduced the two Support Coordinators, Jackie Pooler from Liverpool and Jean Christians from London. There is a vacancy for the post in Birmingham. Between them, the centres run 14 clinics a months and see 125 patients a month (52 in London, 33 in Birmingham, 40 in Liverpool). Of these, 80% are repeat patients and 20% are new. An average of six home visits are made every month, and 25 support/benefits letters are written. All patients are asked to complete a feedback form after visiting a centre. The Quality of Life Survey 2014 is being produced for BSS members and patients attending the clinics to complete. This is intended to assess the impact of Behçet's disease on people's lives.

The two Support Coordinators then spoke about their roles, explaining that their title had been changed from Support Worker because some patients and staff found this title confusing. Their role is to liaise and coordinate with outside agencies. They signpost patients in the direction of help, refer them to services and agencies, create and help new support groups, act as a resource for information, and seek out experts in the field to solve specific problems.

### *Chair's report*

Alan Booth acknowledged all Jan Mather's work in her years as Chair, saying that she was a hard act to follow. He said that the Society is a small charity, but it achieves great things. Several personnel changes occurred in his first few months as Chair, but new people have stepped in and the Society now has a substantial Board of Trustees with representation from Northern Ireland, Scotland and Wales as well as England. New events such as the young people's weekend have been established, and this will hopefully become an annual event. The Society's finances are looking healthy. The Society aims to help all people in the UK who are living with Behçet's disease.

### **Medical presentations**

Prof Robert Moots, Clinical Lead at the Liverpool Behçet's Centre gave a presentation entitled 'Behçet's syndrome: a new approach'. He emphasised that Behçet's disease (BD) is difficult to diagnose, especially in Western Europe where it is very rare. The national patient survey showed that many current patients had to wait for as long as 12 years for a diagnosis. The BPCs were set up in 2012 and represent a unique collaboration between the NHS and the BSS. They run multidisciplinary one-stop clinics offering patient-centred care and funding for expensive biologic drugs. These drugs (such as infliximab, adalimumab and interferon) are known to be effective in BD, but are not a cure. Questions remain about which one is best for which patient and how long they should be given for.

Dr Anu Jacob from the Liverpool Behçet's Centre discussed how Behçet's disease can affect the nervous system in a presentation on headaches and other neurological features of Behçet's disease. Headaches are a common feature of Behçet's disease, reported by up to 70% of patients. The most common form is migraine. Leading a regular lifestyle can help in their management.

Dr Wendy Farrar from the Liverpool Behçet's Centre then presented on skin problems and Behçet's disease. There are more than 2000 named diseases in dermatology, so identifying and treating the BD-specific skin problems is a challenge. Among the cutaneous manifestations of BD, papulopustular lesions are the most common; they occur in about 75% of patients. Diagnosing these lesions requires differentiation from other conditions such as acne vulgaris, rosacea and folliculitis. Treatment may include emollients, topical antibacterial agents and oral medications such as antibiotics and colchicine. Other cutaneous manifestations of BD include erythema nodosum-like lesions, which are fairly common, and the much rarer pyoderma gangrenosum.

Dr Leo Makris, Retinal Fellow to Mr Ahmed Kamal at the Liverpool Behçet's Centre, spoke about eye involvement in Behçet's disease. He emphasised that eye involvement is serious but treatable and needs to be managed by a specialist. Initial involvement may be just in one eye. Retinal inflammation affects both veins and arteries. Treatment can be via a local or a systemic approach. To prevent long-term damage, disease activity needs to be suppressed as much as possible.

Next, Mr John Kirwin from Liverpool Women's Hospital spoke about gynaecological problems in Behçet's disease. Vaginal manifestations of BD include Fordyce spots (tiny elevations visible on skin surface of labia minora) and angiokeratomas. The latter are tiny single or multiple lesions that usually develop in the labia majora between the ages of 20 and 40 years; they may be papular, globular or warty in appearance and are usually asymptomatic. BD appears to have mostly little or no detrimental effect on pregnancy. However, some drugs (thalidomide, mycophenolate, methotrexate, chlorambucil and cyclophosphamide) are unsafe; women should discontinue these for 3 months before trying to conceive. Uro-genital ulcers are very painful and can cause problems during labour.

The final presentation was by Dr Graham Wallace, Senior Lecturer in Immunity and Infection at the University of Birmingham, who talked about science and research in Behçet's disease. One problem is that there is no diagnostic test for the condition. Some good news is that funding has been received from Qatar for research into Behçet's disease.

The day finished with the medical speakers answering questions from the audience.

**Judi Scott, Hon. Secretary**

**Clare Griffith, Editor**