The first Belfast Behçet's Conference

It is exciting to be able to report on the first ever Behçet's Conference to be held outside the mainland in Belfast. The Conference was a natural progression from the Mapping Study carried out by the informal Support Group under the guidance of Prof Heping Xu of Queen's University Belfast (QUB). After some discussion between Fionnuala McKinley (Trustee), Prof Heping, Dr A J McKnight (QUB), Dr Graham Wallace (Birmingham University) and Ann Gough (Support Group member), plans were made in March to hold a Conference at a hotel in Belfast. A grant was applied for to fund the expenditure, and a final date of 8 October was set.

A large number of the Belfast Group were ill over the months leading up to the Conference, and the informal nature of the group, in which no-one holds an official office, meant that it fell to Fionnuala and myself (Ann) to organise the speakers from the Birmingham and Liverpool Centres of Excellence, as well as the experts from QUB who had supported the Group. The Support Group set up a shop to sell BSS merchandise, with Edith King in charge, and provided each delegate with information packs on Behçet's disease (BD). Fionnuala had got permission for doctors to get Continuing Professional Development Certificates to encourage them to attend.

We were delighted that 77 doctors, patients, families and friends registered on the Eventbrite site, of whom 57 attended the event. Unfortunately, at the last minute, the Chief Medical Officer of Northern Ireland, Dr Michael McBride, who had offered to open the meeting, was called away, but Hon Margaret Richie MP competently took his place, highlighting the need for a joined up service for people with BD and the need to improve the understanding of the condition. She offered to support the Group in whatever way she could and to bring the needs of the Society to Westminister.

Fionnuala, Prof Moots, Ann, Dr Graham Wallace and MP Margaret Richie

Morning presentations

Fionnuala McKinley described how the Group had evolved and why a Conference became necessary given the number of patients identified in the Mapping Study. She also talked of the diverse ways patients are looked after and how delighted she was to have so many of the professionals from the Centres of Excellence here in Belfast to share their knowledge and answer questions. She welcomed Prof Robert Moots and thanked him for his ongoing support of the Belfast Group.

Prof Moots gave a lively and informative talk on the origins of BD and the way the condition presents itself, and how he had been instrumental in setting up a Centre of Excellence in Liverpool. He also talked about the way the team he leads gives a ‘one-stop shop’ approach to patients who otherwise tend to see a range of five or six consultants in a number of hospitals outside the Centres. He explained the latest thinking on the drugs being used to help patients and how specialists have learnt how to put patients on a pathway to see what drugs are successful. He took a series of questions from the audience on different aspects of the condition and how to ensure that they got the best support from the consultants who treat them. He also told the group of the latest trials that the Centres are about to initiate.

After a short break, I talked about my ‘Patient’s journey’, illustrated with photographs of my life, explaining how I was diagnosed as early as 1975, but unfortunately the consultant moved to California and thereafter no-one who I consulted was as informed about BD. I talked about the ‘cures’ tried out on me, from Gentian Violet, which led my babysitter to wash out my mouth, to non-stop cortisone and cobalt crystals used to burn the ulcers. I explained how with

so many things going wrong, I felt like a hypochondriac. I talked about the challenges of the disease and said that medical professionals need training on the condition and that this is my hope for the future.

Next came an interesting presentation by Jacqueline Pooler on her role as Support Co-ordinator in Liverpool and of the others in Birmingham and London. She explained how the patient is at the centre with the support of the multidisciplinary team, and they are there to help establish a care programme tailored to each patient. She talked of the range of specialisms in Liverpool – ophthalmologist, dermatologist, rheumatologist, gynaecologist, psychologist and clinical nurse. Her role is to build up trust with patients and to identify any non-medical areas of concern. She does that by phone, text or email, so that patients are fully supported. Jacqueline often liaises with schools, colleges, universities and employers, and she gave an example of helping a staff nurse with her work in getting reasonable adjustments made under the Equality Act of 2010. She also attends tribunals with patients and helps them to complete the paperwork beforehand. She is continually checking what patients need and supporting them in finding help, whether from the Society, support groups or other authorities. The role is unique as a collaboration between the charity sector and the NHS.

Debbie Mitton, Lead Nurse and Centre Manager of the Birmingham Centre, took to the floor to talk about her work. She said that the centre works according to the 'Wagner Chronic Care Model', which aims for a well informed and activated patient being supported by a supportive, integrated community, which through productive interaction gives good functional and clinical outcomes. Whether it is a patient, a relative, a multidisciplinary team or a GP, even other trusts or other countries (such as Wales), Debbie is the first point of contact. She talked about education as being the key to BD and how she informs patients, relatives and practice nurses, even giving GP sessions and providing training for units and trusts. She explained how she leads clinics, monitors the immunosuppressive drugs, co-ordinates the use of biological drugs, keeps the all-important budget at the Centre and works closely with Birmingham City Hospital. Finally, she talked of the 6-week patient referral system whereby a patient is either diagnosed or discharged with supporting recommendations. Debbie told the Conference about the Patient Knows Best programme, in which the patient holds and controls an integrated digital record that can be shared by the numerous specialists that they meet in the course of their treatment. This led to questions from the floor, and Debbie answered a range of other questions on her work.

Dr Sarah Douglas, Ann, Jacqueline Pooler, Debbie Mitton and Fionnuala

Afternoon presentations

After lunch, during which delegates and speakers mingled and chatted and everyone spoke of the fact that they had welcomed such an event (many had never met anyone else with BD and several had travelled from the south of Ireland, making a 5-hour journey to be there), Dr Sarah Douglas, Senior Clinical Psychologist, was the first speaker of the afternoon. Despite what is known as the 'dead zone' for a speaker, she engaged the audience with an exercise in mindfulness and her interesting talk on her work. She gave examples of how she 'hovers' at the clinics, as she feels that being visible is part of connecting to the clinic and the ways patients are either referred by the team or self-referred. She needs to assess each person and formulate the intervention, whether that is with only the patient or with a partner or a family member or carer. She said that it is sometimes necessary to provide ongoing therapy or to work with other agencies through the Support Co-ordinator. When she discussed planning for future, she mentioned using Skype. She then described the levels of anxiety and depression in BD patients and how various therapies can be used, including cognitive-behavioural therapy, acceptance and commitment therapy, narrative processing, coping strategies and fatigue management. She summarised the work by telling the audience of the key points of a stepped model, collaborative interventions, the high rates of psychological distress and the complex biological, psychological and social processes of BD patients. There followed a question and answer session with the delegates.

Dr Graham Wallace, an Immunologist, gave the next interesting talk explaining, with the use of maps, how there were many silk roads and showing the distribution of the disease throughout the countries through which the roads ran. He gave the background to genetic research of all the various markers in BD, and gave some gems of information and questions

such as why the HLA-B*51 molecule found on chromosome 6, which is a risk factor for BD, is associated with Neanderthals. He overlaid the map of early homo sapiens migration from Siberia to Beringia with the trade routes. He carefully explained how cytokines are linked to the immune response in BD. Next, he extrapolated the activities of IL-1B, which reduces fever and pain sensitivity in the brain, induces bone absorption and cartilage breakdown, induces production of immune cells leading to a release of inflammatory molecules, and in the endothelial cells leads to production and release of acute phase proteins to the liver. Researchers are now creating a range of drugs to match the genes identified.

The final two speakers were Prof Heping Xu and Dr A J McKnight, both of QUB, who had worked with the informal NI Support Group. Dr Xu, Professor of Ocular Immunology at the Centre for Experimental Medicine, outlined how the Group asked him to head up the Mapping Survey carried out with the backing of the BSS and the Chief Medical Officer. He explained how it was executed with 350 letters being dispatched to GPs' surgeries throughout Northern Ireland, a task that fell to Fionnuala McKinley, Nicky Wheatley and myself, and how after 6 weeks the team collected the data returned. Of 127 returns, 80 people with BD were identified in all of Northern Ireland (30 in County Antrim, 22 in County Down, 8 in County Derry/Londonderry, 9 in County Tyrone and only 1 in Fermanagh). He concluded that if Northern Ireland had a population of 1,850,000, the incidence of BD would be 12.7 per 100,000 population. This compares with 19.6 per 100,000 in Turkey, 7.1 per 100,000 in France and 7 per 13,500 in Japan. Prof Xu saw this as significant and worth following up with genetic research in the future.

Dr McKnight, Senior Lecturer in Genetics and Director of the Postgraduate Educational Programme at the Centre for Public Health at QUB, spoke on how the Mapping Study illustrated the higher than expected prevalence of BD in the population, with clusters in Down and Antrim. This could be followed by research into the genetics of patients and their families, to discover why one person had BD and another member of the family did not. She explained that patients in NI were in a rare position with the NI Electronic Care Record, and that she was interested in the details of families who would be willing to participate in such a study should funding through grants make it possible. Such a project would involve deep phenotyping and strategies to improve recognition of BD, building collaborative partnerships, data collection, enhanced training and improved screening.

Speakers on the day, Prof Heping Xu, Dr A J McKnight and Dr Graham Wallace

The Conference closed with a question and answer session with some of the speakers and brief summaries by myself and Fionnuala about the event. Both of us had spent hours informing consultants, GPs and clinical teams within all the hospitals in Northern Ireland, putting up posters in public buildings, as well as using Facebook to send out the message about the day. It was a successful day and it will be interesting to note what might develop in Northern Ireland from now on.

Ann Gough, Member of NIBD Support Group