Behçet’s Syndrome Society AGM and introduction of the Medical Advisory Panel

PRESENT: Members of the Behçet’s Syndrome Society

The meeting was opened by Jan Mather, chair of the BS. Jan handed over to Chris Phillips for information regarding health and safety.

Jan introduced herself and mentioned the AGM as part of the wider patients conference and gave a summary of the morning’s agenda, which included:

1. AGM Essentials
2. Interim financial report
3. Working Group updates
4. Director’s Update
5. Conference next year
6. Presentation from Dr Reuben Ayres

Jan asked the trustees to stand up and identify themselves to members and handed over to Richard West. Richard asked for the minutes of the last meeting to be agreed. The members agreed the minutes for the previous meeting.

Jan said that more trustees were needed.

Jan introduced Dr Colin Barnes. Colin recruited the medical advisory panel. Colin was presented with an award at the Patient’s Soiree on the previous evening.

Dr Barnes said he suggested that the panel be renamed the medical advisory panel, rather than the ‘medical panel’. The 15 members of the panel give anonymous advice, which could be regarded as an anonymous “2nd opinion’. Queries are usually routed to 2 members of the medical panel. Dr Barnes introduced the members of the medical panel by name; Dr Colin Barnes, Dr Clive Archer, Dr Adnan Al-Araj, Dr Reuben Ayres, Dr Paul Brogan, Dr Andrew de Burgh-Thomas, Professor Farida Fortune, Professor Dorian Haskard, Dr Desmond Kidd, Professor Sue Lightman, Professor Robert Moots, Professor Philip Murray, Dr Catherine Nelson-Piercy, Dr Jane Setterfiled and Dr Graham Wallace. He also gave a brief summary of their history and current areas of specialism.

Emails to the society with medical queries are sent to Dr Barnes who then directs it to the relevant specialist.

Chris asked Dr Barnes to present Jan with a present from the society.

1. AGM Essentials: Financial changes

Subscriptions: Will increase to £20 per year as agreed at the last AGM, forms will come out with the next newsletter.

Subscriptions 2011/12 : will remain at £20 per year

Grant Aid: the limit for any individual grant will remain at £750 for 2010/11

Jan introduced Alex Williams to present the accounts.
2. Interim financial report

Membership subscriptions and donations expected at similar levels as last year. Fundraising is doing very well. Alex expressed thanks to all doing fundraising. Grants are currently difficult to obtain, thus income from grants is lower than previously.

Largest cost is Chris Phillips' salary. Alex highlighted Chris' significant contribution to the society. Tender put out for newsletter and website costs. No plans to change website but hopes to decrease costs. £1000 contribution to GWAS study. Main point to stress is keep on with the fundraising!
Questions invited, none asked.

3. Working Group updates

National Commissioning

Jan introduced Kathryn Proudlock. Kathryn introduced National Commissioning with the objective: To submit a fully costed 5 year bid for National Commissioning. This was successfully achieved. Yesterday the data was submitted. Thanks to all those involved for their hard work Plans for next 12 months – we wait to see if we are successful.

What is National Commissioning? It is a government scheme, now running for 4 years, to set up services for a small number of people who require specialist care.

The aim is to create specialist centres to provide those with a rare condition with the best possible care. The BS could not directly apply, the society contacted trusts to support and were successful in gaining support.

It allows doctors and nurses to develop their skills and expertise by seeing as many patients as possible
- in diagnosis
- in treatment

What does our bid look like?

- 3 Behçet's Centres– Liverpool, Birmingham, London
- Centres treating adults and children
- Several specialists available (both in the clinic and fast track access if not in the clinic)
- Specialist nurse available with expertise in Behçet's
- Access to the nurse via telephone outside clinic hours
- Annual check-up for patients
- Prompt treatment of flares
- Treatment can be delivered locally if possible
- Access to a support worker

What will it mean for me?

Our aim is:

- provide a better, faster service for flare treatment
- reduce the need to see multiple specialists in multiple hospitals
allow you to be treated by experts who will be sharing their knowledge in a structured way
allow the development of a treatment protocol
access to increased support groups
still allow treatment locally
provide a greater group of patients for research
  
  For undiagnosed patients
  
a quicker route for definitive diagnosis

Patients can carry on with existing specialists if they do not want to attend a centre of excellence. It will also provide more patients for research.

**Question:** Will all the units be up and running by April? Yes, that is expected.

**Question:** How do you envisage a patient who attends multiple clinics – transferring their care to a single centre? This is not known at present but will be investigated if we’re notified we’re successful.

**Question:** Are the indications that the funding will be successful? The funding is ringfenced, though it looks like the process may change next year.

**Question:** Is this a one-off bid? The society can re-bid. After passing the first hurdle, the indications were positive that the BS is precisely the type of organisation wanted.

**Question:** Which London NHS Trust? Prof Fortune’s clinic.

**Question:** How do patients transfer? Included in the bid is information for patients, it will be distributed through the newsletter.

**Question:** If not based in England can you attend? (if you are in the UK). Scotland is ok, Wales needs pre-approval from PCT. Northern Ireland use existing services / process for consultations outside of NI.

Dr Barnes highlighted that the relevant physicians would much prefer to work together in centres rather than relying on existing protocol of separate clinics. Physicians know each other through the UK Behçet’s forum. Time to diagnosis is most frustrating at present.

**Youth**

Matt Shea covering for Jo Durant as she was unfortunately too ill to present. The Facebook group is going well. The aim is to provide advice, information and support to young sufferers and their carers. The group has succeeded to reach more young sufferers and carers. The group took over an existing Facebook group - now growing to be a popular place for people to share their stories online. There are now 250 members. The group will continue to provide support and advice, and to put people in touch. The group will be issuing a tender to set up our youth website – awarded a grant from the British Association of Dermatologists of £2500 to do this.
Website

Matt also presented on the website:

- The sub-committee was created to steer the website and create an informative environment for all Behcet's sufferers and carers alike
- We have achieved a huge amount since starting the site including an ever growing forum and large amount of medical information
- Over the next year we are looking to do a redevelopment of the site that will allow for a better forum system and a quicker way to get to specific information
- A tender has been issued for the website. These will be evaluated and a decision made during the Autumn.

Research

Unfortunately Kirsty could not get to the AGM, so Jan presented on the following:

Alpha Interferon Trial

- Treatments are now finished
- But patients will be followed up at set intervals
- Interim report expected in 2011

GWAS Study

- Genetic Markers
- Further research is needed

Quality Of Life Survey

- Postal Survey
- 447 participants
- 70% response rate

Results:

- Average 12 year delay for diagnosis
- Multiple Symptoms
- Underestimated the burden of Behçets – much greater than first expected
- Full results will be published in the newsletter
- Broad based research – hopes to focus on more specific
- Same QOL scores as MS patients – quite an alarming result
Benefits
Jan introduced Aaron McPeake.

- To provide members with access to the best advice on individual benefits claims, particularly DLA and IB
- Established a subscription to a national expert benefits advice agency www.benefitsandwork.co.uk
- To continue to investigate best delivery of advice for members particularly in light of benefit cuts by government & signpost information on our website
- Specialist attached to the helpline to provide benefits specific advice
- National Voices are focusing on this
- Richard has arranged with a London law company who offered to assist with appeals on a pro-bono basis (ie free to those in need)
- Helpline volunteers are aware of these issues and can offer advice to callers and direct them to information

Grant Aid
Richard highlighted the following:

- To review grant applications made to the Society
- Patients can apply for grants if in financial need
- 3 grants agreed
- Total of £1375.93 paid out.
- **Question:** Is the money from fundraising? Yes it is.
- Grants are often approved quickly in cases of need
- Limit of approx 5% of funds held by society on grant aid

Fundraising
Richard thanked all fundraisers and said the highlight of the year was Ben Nevis with thanks to John Mather for organizing this.

- Total funds raised via fundraising in 9 months since last AGM approx - £20,000
- This coming year – New fundraiser – Claire Mawdsley appointed.
- Considering clay pigeon shooting, a ball, a large raffle draw which will become an Annual event and the money will be used for a Specific purpose

4. Directors Update
Jan introduced Chris Phillips. Chris said he is involved in all aspects of the society.

- Medical advisory panel – Chris acts as 'go-between' to assure anonymity
- British Association of Dermatologists
- Attempted to recruit celebrity support – not successful thus far
- The NHS leadership day
- National Voices
• Fundraising and PR – high on the agenda – heartfelt thanks to members.
• Support groups

Umbrella groups:
• Prescription charges coalition is moving on, pressure being applied to provide free prescriptions for those with long term and complex conditions.
• Specialist Health Care Alliance
• Genetic Alliance UK
• Rare Disease UK

Approx 2000 hits per month on website – from all over the world.