

**The Behçet's Syndrome Society – caring for those with a rare, complex, and lifelong disease**

The 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), Rare Disease UK, EURORDIS (European patients' organisation for rare diseases), the Behçet's Forum and the International Society for Behçet's Disease (ISBD).

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### HELPLINE

**0345 130 7329**

### TRUSTEES

Chair	Tony Thornburn
Vice chair	Richard West
Hon. Treasurer	Alan Lane
Hon. Secretary	Judi Scott
	Mark Friston
	Rachael Humphreys
	Hazel McLachlan
	Amanda Moseley

#### FROM THE CHAIR

## Introducing our new chair: Tony Thornburn

I am privileged to introduce myself as your new Chair, elected to the post by your Committee in August. I take over with immense pride and equal humility. My transition from Trustee to Chair has been a tad swift, and I hope to live up to expectations and "help to make a difference". For this to be realised, I will need all your support. When I say all, I mean just that – the eight constituent parts that I have thus far identified as comprising the "Behçet's community": patients, family/friends and acquaintances, helpline(s) and local support groups, the Medical Advisory Panel, the Behçet's Forum, Behçet's Patient Centres, Centres of Excellence, and finally the Officers and Trustees of the Board. The essential link between these entities is the passage of information, and one of the first tasks I have set myself is to identify how this can be improved upon, particularly routine interaction with patients.



*"This is a "team effort" if ever there was one. I have been enormously impressed to witness all that has been achieved by the Society since 2006, when I first became a member."*

### Guiding principles

I follow a line of dedicated individuals who have preceded me since Judith Buckle set up our charity. Considerable

advances have been made since those early days thanks to the endeavours of many people, and this will be a theme of one of my guiding principles. This

## BSS 2017 Annual Conference & AGM - Manchester

The BSS Annual Conference is taking place on Saturday 14 October at the Pendulum Hotel/Manchester Conference Centre in central Manchester. The Annual Conference is free to attend, but you will need to book your tickets in advance.

See our website or call our administrator for more information.

is a “team effort” if ever there was one. I have been enormously impressed to witness all that has been achieved by the Society since 2006, when I first became a member. These things do not just happen; they reflect the hard work and commitment of many people, each as important as the other, whatever their role. I have been back-reading all the newsletters since that time, and it really is testimony to what can be achieved when everyone works together – an organisation set up in 1983 “for the people, by the people”; and the fundamental aims and objectives of our charity have not changed since that time.

I am conscious in this regard that I am the first Chair of the Society not to have Behçet’s disease, but I believe

I have empathy with those who do. It is another of my aims to ensure that the right information gets out to the farthest flung reaches of Great Britain and Northern Ireland, not only to improve the time to diagnosis in the first instance but also, importantly, to aid the experience of patients. The odd wrong word given to a patient, not through malice but often out of a lack of awareness of the complexities of Behçet’s disease, can be utterly devastating. Thus we all have a duty to help overcome this lack of awareness. My daughter was eventually diagnosed with Behçet’s disease, practically by accident, in 2006 and undoubtedly has experienced what I suspect most of you have. Now I am Chair, we can’t really avoid a conversation (neither

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of us, previously, wanting to worry the other)!

### First priorities

So I seek to achieve additional clarity of purpose and coherence with everyone involved so that we move forward together in harmony. It goes without saying that Behçet’s disease is a complex systemic issue involving many viewpoints, stakeholders and players (if you will pardon those “managerial” phrases just for the moment), competing in an environment of limited resources and an individual’s time; but at its heart are the patients, the Society’s purpose in being of course. As identified by the Committee, an immediate task will be to update our website; it was launched in 2007, and IT has moved on considerably since then. This will also assist our industrious Website Editor, Clare Griffith, who has served us outstandingly and tirelessly all these years, on top of her role as Newsletter Editor. We should aim for it to be the world’s first “portal of choice” for information on Behçet’s disease – so there’s a challenge for us all to assist in this regard. Anything that you feel is out of date or confusing, please let us know, as I aim to encourage more interactivity with our IT platform.

Another priority I have set myself is to take steps to encourage the widest possible patient membership across GB and NI, as I believe it will help to raise visibility for the disease when we are fighting our corner for funding and, importantly, assist with capturing information for research. In this regard, the Behçet’s Patient Centres (BPC) and related Centres of Excellence (Birmingham, Liverpool and London) are an essential element (on top of their prime purpose, to optimise

## Annual General Meeting and Conference Programme 2017

The BSS Annual Conference is taking place on Saturday 14 October at the Pendulum Hotel/Manchester Conference Centre in central Manchester. It is free to attend, but you will need to book your tickets in advance. See our website or call our administrator for more information.

The programme for the day is as follows:

- |                      |  |
|----------------------|--|
| <b>10:00 - 10:30</b> | Registration<br>Tea and coffee   |
| <b>10:30 - 11:30</b> | Welcome and report from the Chair – Tony Thornburn<br>Financial report – Alan Lane<br>News from the Society – Judy Scott and Julie Collier<br>Introduction to the Judith Buckle Award – Richard West<br>Introduction to the conference – Rachael Humphreys |
| <b>11:30 - 12:00</b> | Patient experience – Mark Friston  |
| <b>12:00 - 12:30</b> | Behçet’s Patient Centre update – John Mather   |
| <b>12:30 - 13:30</b> | Lunch  |
| <b>13:30 - 14:00</b> | Update on the clinical trial of infliximab vs interferon alpha – Prof Robert Moots   |
| <b>14:00 - 14:30</b> | Microbiomes and Behçet’s disease – Dr Graham Wallace   |
| <b>14:30 - 14:50</b> | Tea and cake break   |
| <b>14:50 - 15:20</b> | Behçet’s disease in children in the UK: results from the British Paediatric Surveillance Unit study – Dr Clare Pain  |
| <b>15:20 - 15:50</b> | Psychology in Behçet’s disease – Dr Roisin Cunningham  |
| <b>15:50 - 16:20</b> | Medical Panel Q&A  |
| <b>16:20 - 16:30</b> | Close  |

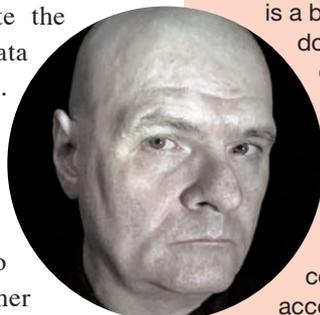
## A busy journey

patients' treatment and promote a better patient experience). I am only too conscious that patients wish to get on with their lives and, whenever possible, push this debilitating disease to the back of their minds, but I would respectfully ask (for those of you that don't already) if you can please try to keep a diary of what is going on as this will, collectively, really help us to combat this frustrating disease.

To emphasise my point about membership and the Centres of Excellence, I recently attended the Cambridge Rare Disease Showcase, where I met a patient who was not a member but had been well supported, clinically, to get to where the individual is now – unsurprisingly with Addenbrooke's to hand, where, as they claim, "research is central to Cambridge University Hospital's identity, and home to one of the richest pools of clinical and scientific knowledge and expertise not only in the country but in the world". An appointment with Professor Rob Moots

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at the Liverpool Centre of Excellence has now been arranged to see what other options might be available. To my mind, all patients where possible should visit these centres now that they have been established, which will not only assist patients with specific treatment but also facilitate the capture of much-needed data to support further research. It was mentioned that there were a few other Behçet's patients in and around Cambridge, so I asked if they could be encouraged to join our Society, and whether they might wish to set up a local support group.



So, to conclude, I trust I can successfully lead the Behçet's Syndrome Society into its next stage of development, which I know is going to be a busy journey for me. I welcome communication from any of you at any time, and on any matter (though not medical advice!) to support me in this endeavour – chair@behcetsdisease.org.uk.

I am very much looking forward to the AGM and Conference in Manchester on Saturday 14 October, where I shall be able to meet many more of you. I strongly encourage as many members as possible to attend. It's your AGM and Conference, but please let us know if you are attending so we can organise sufficient seating.

**Tony Thornburn, Chair**

## Behçet's Syndrome Society officers and trustees

We are pleased to announce some changes to the Society's Officers and Trustees. The Board is now as follows:

- ☛ **Chair:** Tony Thornburn
- ☛ **Vice Chair:** Richard West
- ☛ **Honorary Treasurer:** Alan Lane
- ☛ **Honorary Secretary:** Judi Scott
- ☛ **Trustees:** Hazel McLachlan  
Amanda Moseley  
Rachael Humphreys  
Mark Friston

Hazel has stepped down from being Vice Chair, and we thank her for everything she did when she stepped up to act as Chair. She did a brilliant job.

New trustee Mark Friston (below left) is a barrister and former doctor. He was first diagnosed in 1994; he underwent a successful bone marrow transplant in 2016 under the supervision of Prof Moots (Liverpool Centre of Excellence). He is committed to ensuring equal access to high-quality medical care for all patients in the UK.

## Have you renewed?

Our new membership year started on 1 September. If you have not already paid for 2017/18 and are not exempt, your subscription is now due. Once again, there is no increase this year.

Renewal forms were enclosed with the summer newsletter, and we are grateful to all those members who have returned them with payments or direct debit instructions. If you already pay by direct debit and have not changed your contact details, there was no need to do anything. If you have informed us that you are in receipt of UK state benefits, you will have free membership. Otherwise, do please renew your subscription by the end of October as, if we have not received a payment or heard from you for over a year, we may have to take you off our mailing list.

You can pay by card or set up a direct debit on our website, or you can send a cheque to Behçet's Syndrome Society, Kemp House, 152-160 City Road, London EC1V 2NX. If you are not sure, or would like us to check the details on our database, please do not hesitate to send us a note or to email me at treasurer@behcetsdisease.org.uk.

Thank you to all who have renewed their membership recently, and a special thanks to everyone who kindly made additional donations. We are very grateful for all of your generous support.

**Alan Lane, Hon. Treasurer**