

BSSVD AUTUMN 2018 NEWSLETTER

Update

The highlight of our year has undoubtedly been the award of the biggest research grant to date from the BSSVD to fund the Lichen Sclerosus Priority Setting Partnership. This has been a project lasting 18 months, ably led by Rosalind Simpson, to establish the top 10 research priorities for lichen sclerosus. This work, in partnership with patients, carers and clinicians, is now complete and the research questions will be published very soon. We are proud to have supported this work which has strong potential to springboard badly needed future research. Funding bodies do take notice of these priorities and indeed, there has already been a call for research proposals resulting from a dermatology-based Priority Setting Partnership (UK DCTN Themed Research Call 2018).

The academic highlight of the year was the splendid conference organised in Salisbury by Abi Kingston which was attended by 146 delegates. The educational highlight was the release of our Training Fellowship. Please make a note of the next one day meeting *to be held in Warwick on Friday 3rd May, 2019*

Finally, we have a number of new Council members listed at the back of the newsletter and are grateful to Marian Dixon our patient representative for her time to the Society. Please review the work programme for 2018 which gives a high level review of our work to date and to do for 2018. If you would like to get more involved with our work please let us know admin@bssvd.org

Have a great autumn
Sue Cooper (President)
Chris Bates (Secretary)
David Nunns (Chair)

New website launch (Lead Abigail Kingston)

Abi Kingston, our webmaster, has been working to produce a three-tier site for the general public, health professionals and members. The website will be ready very soon which will replace our existing site. We will have a member's area with private access to more information. We hope the member's area will include many resources including uploaded lectures, clinical photos as well as a discussion forum. Our thanks go to Abi for taking the lead on this and working with EMU our web designers.

Quality assurance group (Lead Eman Toeima)

This is a new group focusing on quality assurance in vulval disease. Our initial plans are to repeat the vulval service survey previously carried out by Julia Palmer. This will enable more data on the 'current reality' of existing services. It's an ambitious plan and such a survey would be important as we move to greater equity and quality within each service and measure them against the standards document we have already produced in 2013 (*Standards of care for women with a vulval condition* - see BSSVD website). We plan one survey per service rather than individual. Should we work to service accreditation of services? Please let us know your thoughts.

When we carry out this nationwide survey of services it will be important to accurately capture each service including the clinical lead, frequency of clinic and specialty. Please can you check your own service on the current website? If you have any knowledge of other services not on the database please let us know and we can write to the lead. We have 288 members and approximately 80 services on our database.

Education training group (Lead David Nunns)

We are in the process of harmonising the core curriculum for vulval disease in line with new GMC requirements. This workforce for all specialities is under the umbrella of the BAD Education Unit. Updates include, 1) Caroline Owen from the BSSVD has joined the Royal College of Physicians Speciality Certificate Examination (SCE) question writing group. Each year between 10 and 15 new questions in each subspecialty area have to be written for the Dermatology SCE exam. The plan is to ensure that the

Dermatology SCE reflects the importance of vulval disease and the new vulval curriculum. In time, it is hoped that we may be able to align SCE questions in vulval disease across the different specialities in the same way that we are harmonising the vulval curriculum. 2) The RCOG is reviewing its core curriculum and as a recognised specialist society the BSSVD have contributed to their draft. Although the changes to the whole curriculum appear to quite a generic and less prescriptive in content, vulval disease does have a mention. We do see this as an opportunity for us as a specialist society to push forward even more so with our standards. There is a challenge in how we enable and validate the Consultant's capacity to sign off trainees. Perhaps their education and training needs should be equally weighted as trainees? Please let us know your thoughts. We have pushed for inclusion that trainees '*recognise common vulval disorders, recognise when to refer on to allied specialists and the importance of the MDT, recognise the psychological impact of vulval disease*'. Also, we have requested that '*taking a vulval biopsy*' be included as a key outpatient, diagnostic gynaecological procedure.

Communication

We have produced some new promotional leaflets for our Society which includes our new logo. If you would like some copies for conferences or events to help promote our Society please contact us on admin@bssvd.org

Book discount

We have agreed a discount and free delivery on the textbook *Gynecologic Dermatology* by Sue Cooper/ Gurdula Kirtschig (9781909836013). Please encourage friends and colleagues to purchase! The discount is for 15% and includes free delivery until 31.12.18. The code is BSSVD18 and can be used on the company website – www.jpmedpub.com – enter the code and click 'Apply' at checkout, or by calling our distributor NBN International on +44 (0)1752 202301. The link to the exact page on their website is <http://www.jpmedpub.com/bookdetails.aspx?SearchTxt=kirt&OBookID=2191>

Trimovate update

Trimovate now belongs to Ennogen Healthcare and some patients have been experiencing difficulty in getting prescriptions filled. It is now available through Alliance Specials as an unlicensed special. It is anticipated that a licence will be available in about 4 to 5 months, but the current cost is £54.50 a tube. If there are any problems regarding prescribing then Ennogen say they are happy to receive phone calls. 01322 629220

Pathologists and GPs on Council

We are in need of pathologists and ideally GPs on Council. If you have any colleagues interested please encourage them to join the BSSVD and get in contact with us admin@bssvd.org

Reflection - Prescribing pain modifying drugs for vulval pain. Is there concern?

There have been some concerns made about the use of gabapentinoids and tricyclics for patients. This issue was raised by a member. I'm mindful that we often prescribe these drugs for vulval pain and many any of us will be prescribing drugs or suggesting these treatments to GPs. We would like you your opinion on whether we should agree a position statement this on this issue? Can we have your thoughts please?

Vulvodynia is a chronic pain condition commonly diagnosed by doctors working in women's health. The desired outcome of treatment is to reduce the level of pain and improve patient function. The British Society for the Study of Vulval Disease (BSSVD) has previously issued guidance on the management of vulvodynia (1). The guidance recognises the different individual needs of the patient and the frequent need for a multidisciplinary approach to management.

One such treatment strategy is the use of pain modifying drugs such as gabapentin, pregabalin and the tri-cyclic antidepressants (amitriptyline and gabapentin). These drugs may be an appropriate treatment option for some patients with unprovoked pain, despite limited and poor quality evidence to support their use.

There have been increasing clinical concerns about the prescription of these drugs. The tri-cyclic antidepressants have anticholinergic effects and a possible impact on cognitive function in the elderly (in particular with higher doses of drugs e.g. greater than 75mg amitriptyline). Anticholinergics have been linked to a future dementia risk (2). Gabapentin and pregabalin have issues with abuse and dependence; combinations of these drugs with opioids and benzodiazepines increases the risk of overdose.

We would encourage clinicians who prescribe or suggest these drugs to be mindful of the concerns relating to these concerns. We suggest best practice prescribing for vulvodynia patients;

- An adequate prescription history is taken (to include previous use of the drugs). Be familiar with other drugs that are anticholinergic and the concept of the anticholinergic burden and avoid these drugs in the frail elderly.
- Exercise caution if the patient is currently on drugs that may affect cognitive function (e.g. antidepressants).
- Prescribing them should be cautioned in patients with a history of drug or alcohol dependence.
- Give patients adequate information such as information produced from the British Pain Society (3) and discuss the potential side effects of treatments.
- Arrange adequate follow-up to review compliance and side-effects. This should be the prescriber, delegated health care professional or instruction to the GP. Patients should be reviewed regularly.
- Consideration of a stopping the drug. If the treatment has a lack of clinical benefit clear communication with the patient and instruction to the GP to stop the drug should be given.

Ref

- 1.Nunns D1, Mandal D, Byrne M, McLelland J, Rani R, Cullimore J, Bansal D, Brackenbury F, Kirtschig G, Wier M; British Society for the Study of Vulval Disease (BSSVD) Guideline Group. Guidelines for the management of vulvodynia Br J Dermatol. 2010 Jun;162(6):1180-5
- 2.Richardson K1, Fox C2, Maidment I3, Steel N2, Loke YK2, Arthur A, Myint PK4, Grossi CM1, Mattishent K2, Bennett K5, Campbell NL6, Boustani M7, Robinson L8, Brayne C9, Matthews FE10, Savva GM1. Anticholinergic drugs and risk of dementia: case-control study. BMJ. 2018 Apr 25;361:k1315. doi: 10.1136/bmj.k1315.
- 3.<https://www.britishpainsociety.org/british-pain-society-publications/patient-publications/>

Presidential Essay competition for 2018 was won jointly by Eleanor Crane and Jeremy Solly. The winning essays will be available on our website shortly.

Marian Dixon - BSSVD patient representative.

I was diagnosed with Lichen Sclerosus over 25 years ago but I believe I have had the condition for more than 35 years. I found it extremely difficult to get a diagnosis and relevant treatment and was originally told that I had vulvodynia and then vestibulitis. I was also told by one dermatologist that it was all in my mind. It was only after consulting a number of gynaecologists and dermatologists both on the NHS and privately that I eventually found a professor of dermatology who diagnosed LS. It was a very lonely time to have this condition as it was before the days of the internet and online forums and obtaining information about the condition and about specialists who had knowledge of LS was very limited. Fortunately, I did eventually come across the Vulval Pain Society which gave me hope that there was someone out there who would have some answers to my problem. I am happy to say that I am now under the care of an excellent and empathetic dermatologist.

I was appointed as a patient representative for the British Society for the Study of Vulval Disease (BSSVD) in Autumn 2014. I am one of two lay members who sit on the Council and try to provide input from a patient's perspective.

During 2018 I was one of the patient representatives on the Steering Committee of Lichen Sclerosus Priority Setting Partnership. I am very pleased that the results of the project are to be published very soon and am hopeful that it will generate interest and funding for research into this very neglected disease.

Current council membership and specialties information

BSSVD Council members May 2018

President	Sue Cooper	Dermatology, Oxford
Past President	Jennifer Yell	Dermatology, Manchester
Chair	David Nunns	Gynaecology, Nottingham
Secretary	Christine Bates	GUM, Liverpool
Asst Secretary	Eman Toeima	Gynaecology, London
Treasurer	Ursula Winters	Gynaecology, Manchester
Webmaster	Abigail Kingston	Gynaecology, Salisbury
Trainee rep	Rosalind Simpson	Dermatology, Nottingham
Patient rep	Marian Dixon	Patient representative
	Antony Hollingworth	Gynaecology, London
	Victoria Swale	Dermatology, London
	Jill Pritchard	GUM, London
	Caroline Owen	Dermatology, Lancashire
	Stephanie Ogden	Dermatology, Manchester
	Isabelle Hay	Dermatology, Glasgow
	Claire Bailey	Gynaecology, Birmingham
	Daisy Nirmal	Gynaecology, Norwich

Resources <http://vulvovaginaldisorders.com/>

This is an excellent resource which cover the spectrum of vulval disease from all disciplines. Registration is a short process.

Progress with 2018 work programme

Green completed/amber in progress

BSSVD	2018 plan		
1	Research	Complete priority setting partnership project	RS, DN, MD, SC, RM
2	Education	Explore vulval fellowship award for a trainee	SC
3	Service	Establish job description for physician associate/nurse specialist in vulval disease	DN /RM
4	Membership	Prepare new membership leaflet with an emphasis on something that will last	UW, SC, CB
5	Membership	Abolish need to have a sponsor by proposing amendment of statutes at the AGM	SC
6	Membership	Establish on line membership subscriptions	UW/AK
7	Website	Establish members only section of website	AK
8	Guidelines	Agreement to start work on LP with BAD and VIN with RCOG	RS, ET, UW
9	Audit	Audit of standards for vulval disease	ET/RM
10	Service	Establish Quality Assurance group and decide on members	ET
11	Website	New logo	UW/
12	Statutes	Update rules on council membership and officers to circulate to council and then propose at the next AGM	CB/SC
13	Annual meetings	Plan annual meetings for 2018 and 2019	AK, VS