

BSSVD Newsletter – Spring 2019

Happy New Year!

This newsletter is to keep you up to date with the various projects being undertaken this year, further more detailed information can be found by following links on the BSSVD website.

[BSSVD Website](#)

BSSVD National Audit of Vulval Services

This survey launched a couple of weeks ago and aims to:

- 1) define current UK practice against the BSSVD Standards of care for women with vulval conditions
- 2) support and develop vulval services that are already in place
- 3) support appraisal and job planning
- 4) place vulval services in the spotlight as demands on services increase against a background of financial constraints

If you are the lead of a service do please take the time to complete the survey which closes on 1st February.

[National Audit of Vulval Services](#)

Flashcards

This valuable educational resource has been reviewed and updated. Originally intended for trainees it has also been found useful by senior hospital colleagues and GPs. It is sited within the members area of the website. They are available for download.

[Flashcards](#)

VIN guidelines [RCOG-BSSVD]

Dr Eman Toeima, our Quality Assurance lead writes:

I am delighted to let you know that the RCOG has approved the application which I have submitted with the proposal for developing the VIN guidelines. This will be a joint guideline (RCOG - BSSVD) and will be co -badged.

Research Grants

The BSSVD supports research into vulval disease and gives small grants when funds allow. Applicants must be members of the BSSVD at the time of application and for the lifetime of any grant awarded. Applications should be received by the BSSVD secretary by March 31st 2019.

NEW 2019 BSSVD Vulval Trainee Award**

The BSSVD invites applications for the 2019 BSSVD Vulval Trainee Award, the aim of which is to facilitate an individualised programme of vulval training. One award will be funded in open competition to UK trainees (including post CCT fellows). Applications are welcomed from dermatology, genitourinary, sexual health, dermatopathology and gynaecology trainees. Each



award will be funded up to a maximum value of £2500: a suggested programme might be 10 visits to centres where vulval experience can be gained, in addition to attendance at a relevant meeting or conference. The training may be in one or several centres so the training may involve several supervisors at different sites. All applicants must be BSSVD trainee members. Applicants will normally be within the last two years of their expected completion of training.

BSSVD now have a formal admin team who are here to help you with all matters of administration for the BSSVD.

Website access

Sharp eyed readers will have noticed a new look to the [BSSVD site](#). There are now 3 levels of access to the site:

1. General public – This is open to any patients who would like general information
2. Practitioner – Available for professionals who would like access to vulval information, to enrol for BSSVD membership and register for meetings.
3. Members – You will have full access to the site including newsletters, meeting presentations and videos, a private BSSVD members forum and notification of new or special offers.

Username and passwords are required for Practitioners and Members, both can be set up when you first click on to the appropriate box on the home page.

Existing BSSVD members will be contacted shortly by our admin team with a personalised username and password to access the site. You can easily change the password at any time.

Website content

We are inviting members to submit content for the website, for example:

- Research papers that may be of interest to our members
- Details on meetings throughout the year that may be of interest to our members
- Register your clinic on our website - complete the form below.

Please send any content to admin@bssvd.org.

[BSSVD Website](#)

Annual Scientific Meeting

The BSSVD Annual Scientific Conference is on 3rd May 2019 at The Slate Building, Warwick University, Coventry, follow the link below to register or for more information.

[Annual Scientific Meeting 2019](#)

Is your clinic listed?

Please follow the link below to see if your clinic is listed then either amend or add your details so that we can ensure a comprehensive list across the country.

[Clinic Registration](#)

hELP Study – Systemic therapy for erosive Lichen Planus – Research lessons

During 2014-2016, members of the BSSVD were involved the development and delivery of a study on vulval erosive Lichen Planus, the 'hELP' trial. The study opened as a pilot randomised controlled trial to compare systemic treatments for moderate to severe disease. It aimed to recruit 40 patients from 12 UK sites over 14 months. Eligible participants were randomised to a 6-month course of either hydroxychloroquine, methotrexate, or mycophenolate mofetil or a 4-week reducing regimen of prednisolone; all received super-potent topical corticosteroids. Unfortunately, the study closed without reaching the recruitment target of 40 patients, but valuable lessons were learned. The problems with recruiting to this study included;

- Patients with mild disease were not eligible for study
- Re-education about use of topical treatment led to improvement in some patients meaning they no longer needed systemic treatment
- Patients were reluctant to take oral medication, so did not consent to enter the study
- Variation in quality of medical photography (images were required to assess treatment response)
- Patient embarrassment to have photographs taken

This study was a challenge in the first instance due to the rare nature of the disease, but there are no regrets in embarking on a study of this type. A pilot RCT is an excellent first step to assess study feasibility and identify potential problems before launching a full randomised controlled trial.

Results have been now been published open access:

['Help for Future Research: Lessons Learned in Trial Design, Recruitment, and Delivery From the "hELP" Study' in the Journal of Lower Genital Tract disease \(October 2018 Volume 22 - Issue 4\)](#)

Lichen Sclerosis Priority Setting Partnership: Results published

We are delighted to announce that results of the Lichen Sclerosis Priority Setting Partnership have now been published Open Access in the British Journal of Dermatology:

[Future research priorities for lichen sclerosis - results of a James Lind Alliance Priority Setting Partnership.](#)

Simpson RC, Cooper SM, Kirtschig G, Larsen S, Lawton S, McPhee M, Murphy R, Nunns D, Rees S, Tarpey M, Thomas KS; Lichen Sclerosis Priority Setting Partnership Steering Group.
Br J Dermatol. 2018 Nov 25. doi: 10.1111/bjd.17447. [Epub ahead of print]

The final detailed report is also available on the Lichen Sclerosis Priority Setting Partnership website:

<https://www.nottingham.ac.uk/research/groups/cebd/projects/5rareandother/lis-ppsp/index.aspx>

Factsheet 10 facts on Lichen Sclerosus in women

We have produced this summary factsheet for members of the public now that the Lichen Sclerosus PSP has been completed. It is available as a download on the website.

1. It is a genital skin disease and can also affect men and children.
2. It is estimated to affect up to 3% of the adult female population.
3. The commonest symptoms are itching, pain, tearing/cracking of the skin and painful sex.
4. The cause of Lichen Sclerosus is not fully understood.
5. Without treatment the skin can look white, bruised, scarred and shrunken.
6. The condition should be diagnosed by a doctor such as a GP or hospital specialist, for example a dermatologist or gynaecologist. We would avoid self-diagnosis and treatment.
7. Effective treatment is with the regular application of strong steroid ointments (to suppress the skin inflammation), emollients (to keep the skin hydrated and act as a barrier) and good skincare (to avoid irritation by, for example, feminine hygiene products, wet wipes, talcum powder etc.). Approximately 8 out of 10 patients have an excellent response to this approach.
8. The long-term use of topical steroids on an intermittent basis can maintain symptom control in most women without causing any side effects.
9. There is a small cancer risk but this risk is low, affecting approximately 3% of women who have had Lichen Sclerosus over many years.
10. The condition can be misdiagnosed. Patients with the symptoms outlined above should have a medical history taken and an examination by a qualified health professional who is able to make a diagnosis. A small skin sample (biopsy) may need to be taken and examined under a microscope to confirm the diagnosis.

Happy to help

Feel free to contact us at admin@bssvd.org for any further information or comments.