



Council Meeting Minutes

Meeting Name:	Council Meeting
Date of Meeting:	21 st September 2023
Location:	Virtual - Teams
Chair:	Caroline Owen / Rosalind Simpson

Attendance	Apologies
Caroline Owen Ruth Murphy Stephanie Ogden Lisa Kirby Katie Robinson Tara Robinson Rosalind Simpson Archie Krishna Vanitha Sivalingam Ursula Winters Zoe Blakemore	David Nunns Jennifer Smith Sarah Schoeman Matilda Fox

Discussion	
Meetings	Action
<p>BSSVD One-Day 2024 Meeting</p> <ul style="list-style-type: none"> • Caroline spoke about meeting with the BAD Vulval Workstream to discuss the BSSVD meeting in 2024. • Katie and Caroline have put together a programme for a basic training course. • It will be run with BAD and maybe BASHH. • Katie spoke about a similar day they had run 3 years ago, focusing on ST3 – ST5 trainees and covering their core curriculum on Vulval Disease which received very good feedback. • The BSSVD course for 2024 is based on this previous course. • Sarah has also planned something so Caroline spoke about combining the two and maybe having the morning for everybody and then 2 separate afternoons; 1 more suited to gynaecology and 1 more suited to GUM. • Caroline highlighted that the decision for today is to choose from the following: <ul style="list-style-type: none"> - Training Day - Training Day + BSSVD 1 Day Scientific Meeting - If there is going to be just a Training Day, will there be 1 for GUM and 1 with the agenda already planned (Gynaecology & Dermatology focussed) 	



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- Vanitha commented that the benefit of having a BSSVD meeting would allow more of a research element to be provided. This meeting is usually the only scheduled activity for vulval research in the UK and the one opportunity for people to showcase their research and audits. Can it be added to the basic course programme?
- Caroline was worried it might be difficult to do this, especially from a timing point of view.
- There has been confusion over what the focus of the meeting should be.
- Roz spoke about previous feedback and that people weren't happy with basic levels of information. She highlighted this must be stressed in the marketing, so people are aware as the target audience would differ.
- Steph reiterated what Roz said and appreciates the meeting for CPD points and networking with colleagues. If the meeting would be every 2 years, this element of networking and knowledge updates would be lost.
- Ruth spoke about her experiences and said the sharing of diagnostic difficulties and why people don't get better is fundamental to what we do. She believes there has never been a better time to share our collective experience.
- Ruth is quite keen to see the concept of the vulva throughout generations explored a bit more, whether this be in the basic course or in the annual meeting.
- Ruth also spoke about doing further exploration on some of the key areas of understanding such as menopause, secondary vulvodynia.
- Caroline said there are a lot of people seeing patients with vulval disease without really knowing what to do so the basics course Katie has put together will appeal to a lot of people, from primary care and even gynaecologists who do not have a special interest in vulval disease.
- Caroline also spoke about the difficulty with time/costs of travelling to face-to-face meetings and questioned whether there should be a training meeting or a training meeting & scientific meeting.
- Roz and Vanitha asked what people thought about doing a basic course for the morning and then a more advanced session for the afternoon. Caroline was worried it wouldn't be possible to cover the whole curriculum this way.
- It was decided that recording the meeting would be too costly and difficult due to confidentiality with medical images.
- Ruth suggested the BSSVD reach out to the Royal College of General Practitioners as that is where the real lack of understanding is, especially in primary care. It would give necessary publicity to the BSSVD as being the people explaining the basics of vulval disease.
- Roz spoke about GP training hubs and putting together a stock talk for an hour to do several talks throughout the year as an alternative option.
- Ruth highlighted it is possible to evolve and mix with other societies.
- Archie asked what the barriers are to holding two separate meetings. She asked about inviting specialists to have more specific agendas. Archie also spoke about the British Society of Colposcopists meeting's agenda and if this was something the BSSVD could do.
- Roz answered that the main barriers are time, resource, and people power. The BSSVD also don't have the same infrastructure that other societies have, as it is a much smaller society.



- Zoe highlighted it is possible to have a virtual meeting with breakout rooms so the agenda can be broken down into different specialities if required.
- Ursula said agendas have been varied in the past and that you can't please everyone. She highlighted that many of the areas Ruth had mentioned – multispeciality input, GUM input, Crohns have been covered in previous scientific meetings – There will always be basic elements for some that aren't for others as the BSSVD is a multi-specialist society.
- Roz said the key thing is ensuring the meeting is pitched at the right level to start with and publicised accordingly.
- Ruth suggested asking people who register what cases they find difficult so when it's time for the meeting, the cases are there in advance and the challenging cases can be shared and solved in a group think way. It can be made a mandatory element on registration.
- Katie echoed what Caroline said and stressed there is a huge gap and real need for a basics course. VIN is not particularly well managed, there's no uniformity or national guidelines. She also suggested running regular evening meetings to cover basics throughout the year.
- Tara said from a patient's perspective, it is exciting to focus on supporting development of primary care as in support groups that comes up the most with people being sent away.
- Roz put everything to a final vote:
 - **One Day Basic Vulval Disease Course – This was the unanimous vote**
 - One Day Advanced Scientific Meeting
 - One Day Basic/Advanced Meeting
 - Face-to-Face Mixed

BSSVD 2025 Meeting

- Vanitha and Zoe confirmed we have had 2 expressions of interest to host.
- We have had an expression of interest from Arrowse Park and Liverpool (a joint bid) and Southampton Hospital.
- Vanitha suggested we contact both to provide a more detailed agenda to allow for an unbiased and fair allocation.
- Those who don't get the 2025 meeting, will be offered the 2026 meeting.
- Roz said we need to confirm a date for this to be decided.
- Caroline said the Southampton bid seems more solid and more promising. Vanitha highlighted that she has since worked with the Arrowse Park team to develop an agenda which has not yet been submitted to the Committee.
- EMU to ask both expressions of interests to provide more detailed agendas they plan for the meeting so the Council can decide.
- Ruth suggested asking people to bring/highlight difficult cases to the meeting.
- Roz highlighted there was an 'ask the experts' session at the Nottingham meeting and that Katie has a 'clinical cases quiz' session planned for 2024 too.
- Archie suggested doing other models and national MDTs and perhaps extend invites to vulval leads across all hospitals to have a bigger pool of expertise; then hold online meetings in the form of a national MDT which could maybe be tagged on to the end of a BSSVD meeting. Ruth agreed this is a good idea.

EMU



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- Roz highlighted this is an excellent idea, but it isn't as easy as it sounds – It's not impossible but its an idea that could be worked upon over time to see how feasible and achievable it is.
- Caroline said how good it is that 2 people have put themselves forward for the meeting. She said that the 1-day meeting doesn't have to be virtual, each year can be face-to-face if preferred.

Glasgow & Nottingham Meetings

- Zoe confirmed the profits have been paid to the BSSVD from both meetings.
- The profit from the Nottingham meeting came to £8,208.37. Congratulations were offered to Roz, David and Lisa for this.
- Roz would like the profit from the Nottingham meeting to go towards causes that need funding.
- Lisa said it would be nice for the funding to go towards something that isn't research, such as patient information resources.
- Vanitha said it could be a 'public engagement award'.

Patient Information Project

- Caroline spoke about the project and how it's come out of Sophie Rees study on living with Lichen Sclerosus.
- One of the things that came out of the study is that patients don't have good quality, reliable information and they get conflicting messages from some resources. Patients turn to self-help groups, but these don't always give the best evidence in terms of treatment advice.
- Sophie wanted to create a package of care for patients with Lichen Sclerosus and this is something Caroline wanted to work on with the BAD vulval workstream as they align quite well.
- Caroline had a meeting with the team who created Roz's husbands' information package for patients with Bowel cancer and showed the video to the group.
- The company who created the video is called Turbine Creative.
- Caroline confirmed to put a similar video together would cost between £10,000 and £25,000 depending on the amount of video content required.
- Caroline mentioned how useful it could be for patients, especially if it's advertised well on all websites.
- Caroline also said she met with Jeremy Barratt, who is research lead for Wellbeing of Women, to see if they would have any funding they'd be happy to support with. He said they would be keen for patient involvement and that they could potentially donate £5,000 - £10,000 but he asked what other groups are keen to support it.
- If we get funding from WoW and BSSVD, we could potentially get funding from other places too.
- Everyone on the call supported this project.
- Roz asked if it will just be LS specific or whether other vulval diseases can be brought in. Caroline confirmed it will just be LS for now to see if it works and then if so, other areas can be bolted on.



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- Roz suggested it might be worth contacting other providers to get competitor quotes. However, she said the Turbine Group are good and responsive. The project they did the Colorectal video for was very well received and did win awards.
- Caroline asked for confirmation on how much the BSSVD is willing to donate so she can go back to Jeremy.
- Steph suggested to wait for the quotes to come in first.
- Caroline said it would be good to get an initial sum from the BSSVD today so she can get the ball rolling.
- Ursula confirmed there is currently £67,000 in the account which is the total without committed funds.
- Roz asked per year, what goes out of the BSSVD account. There is the research grant (£10,000) and the fellowships (couple of thousand). Ursula said it's good to have some reserves in case of meetings going over budget but we could easily afford to donate £10,000 - £15,000.
- Roz asked about the donations made and whether there was a stipulation on how it was spent. Sylvia King donated £4,000, she is a vulval cancer survivor.
- Roz suggested using the total of donations towards this project. Ursula agreed.
- Katie asked about how success of the project can be measured. Roz said the PENA awards was one area, then there's patient feedback, metrics from online (hits/forwards/tweets etc.).
- Roz said it is good to have a plan on how to measure tangible outcomes beforehand.
- Ursula confirmed the BSSVD are happy to support the project with £15,000.
- Caroline will keep the Council in the loop with updates.

BAD Workstream

- Caroline met with the BAD workstream yesterday and they are tidying everything up with new constitutions and aims.
- Caroline read the aims which are similar to the BSSVD.
- The education stream is embracing research which is good thing.
- Caroline highlighted an education package was talked about and supported.
- Caroline has received a reply from the RCOG which was very supportive and had a meeting with Rosie Walworth, the Policy Unit Head. She said they put their position statement together very quickly and they wanted to ensure there was proper clinical engagement. She agreed vulval disease should be included and put Caroline in touch with the head of women's health at the Department of Health and Social Care, Lauren Ging.
- Caroline had a meeting with Lauren and Sue Mann (Public Health Background and interest in women's health) who is writing the commissioning documents for women's health hubs. Before the meeting Caroline shared the standards documents which they both really liked. Caroline said they discussed using vulval standards document to link services together and make sure that all appropriate services are commissioned to get vulval disease more on the map.
- Caroline highlighted this is something that still needs pushing forward.
- Caroline mentioned that the BAD workstream are keen to develop educational materials for vulval disease which they want to put behind a BAD paywall, so she is hesitant.



<ul style="list-style-type: none"> • Caroline suggested focussing on the e-learning for health vulval modules and ensure they are updated and then signpost people to these – This was agreed as being important. • Roz said that everyone should look at their local women’s health hubs and highlight vulval disease, so it isn’t forgotten. 	
<p>Social Media</p>	
<ul style="list-style-type: none"> • Zoe read out Matilda’s notes on Twitter – To be attached to the minutes. • Everyone was happy to have their photos and biographies tweeted except for Tara. • Roz suggested everyone’s bios need looking at and updating, then sending to Matilda. EMU to please send out the current bios to committee members so they can edit. • Council to reply to Zoe with 1 line about themselves. • Roz asked if people have any useful texts/information to share with Matilda. • Vanitha shared a QR code document regarding the vulval self-examination video for approval – Everyone approved. • Matilda to signpost people to the video on Twitter. • Zoe to send Vanitha a transparent logo for the poster. 	<p>EMU</p> <p>COUNCIL EMU</p> <p>COUNCIL</p> <p>MATILDA EMU</p>
<p>Research Update</p>	
<ul style="list-style-type: none"> • The Wellbeing of Women and the BSSVD awards closed at the beginning of August. • Roz confirmed there were 2 applications to the entry-level scholarship – 1 was not eligible as she already had an MD (post-graduate qualification) and 1 that is going through the peer review process with Caroline and Steph. • There haven’t been any applications for the post-doctoral research fellowship. • Roz said that advertising of these needs to be better. • WoW remain engaged and hopefully willing to support again next year. • Vanitha asked whether it shouldn’t be confined as a post-doctoral award. Roz explained this is because it is tagged on to WoW scheme so they align with their particular application processes. • Lisa spoke about another grant with the BSF and they have agreed in principal. It hasn’t been approved yet but Lisa believes it will be. There is usually a £10,000 pot for their small grant awards. Lisa thinks it’s a good idea to have it as part of the small grants process but asked for the Council’s thoughts. They usually award 10/12 small grants at the same time which might attract different cohorts of people. Roz put it to a vote and no one agreed it should be separate. • Zoe asked if we can get the research award closing dates sooner so they can be in the BSSVD newsletter in plenty of time. • Vanitha said trying to hit the trainee population is important too by highlighting this through Health Education England. • Vanitha asked if the money not allocated for this year rolls over and Roz confirmed. 	



<ul style="list-style-type: none"> • Roz spoke about the existing awards. There is one with Vanitha and one for Aurora Almadori which both have had non-cost extensions. • Neither has had any additional funding after original amount. • Lisa’s award is being wrapped up too and is just in the write up stage. • Vanitha brought up the Public Engagement Resource Award mentioned earlier in the meeting and asked if there will be money for this in the future. Roz said with agreement from the Council, it could be a rolling award with a certain amount each year but it needs to be thought about how it would run/applied for. • Vanitha mentioned she got money from Wellcome who have small pots of money. Roz asked if Vanitha could send through the documents from Wellcome. • Roz asked that the scope of the engagement would need looking at too. 	VANITHA
Awards	
<ul style="list-style-type: none"> • There are the 2 Fellowships – The Travelling and Training Fellowships which are for £2,000 per year • There have been no applications for either – Council agreed to extend to end of November. • The President’s Essay has also had no applications and Council agreed to extend this to the end of November as well. • Zoe to change these on the website. • Zoe to ask Matilda to tweet about these. 	EMU EMU
Any Other Business	
<ul style="list-style-type: none"> • Steph spoke about meeting Dr Louise Newson and said she is keen to collaborate with the society. She has a large following and influence which would be great to join up with. Steph asked for people’s thoughts on this. Caroline has already done a podcast with her. She said her business model is mainly virtual clinics, so the society needs to be careful as she doesn’t have a great evidence base. There are a lot of people in the gynaecological community who are concerned with how she works particularly with non-evidence based dosage of oestrogen. Caroline suggested she tries to do a teaching session for her practitioners to better explain vulval conditions. BSSVD needs to be cautious about how they are seen to endorse her. Ursula and Archie agreed. 	

Next Meeting	
To be decided – January/February 2024	