Annual General Meeting

Campaign Against Painful Hysteroscopy (CAPH)

28th July 2020 – 7.00 pm

On line Zoom meeting:

Meeting Code: 978 980 3416 Pass code: CAPH

CHAIR'S REPORT

This year's work came to a sudden halt when the COVID-19 pandemic took hold in the UK and made it inappropriate for CAPH to continue campaigning. This has also delayed this year's AGM which is the first since we became a community group with a constitution that states we will hold an Annual General Meeting to report back to members. I would like to remind everyone that being a member of the private "Action" Facebook page means that you are a voting member of our community group.

Unfortunately our numbers continue to grow, because women are still having horrific and unacceptable outpatient hysteroscopy experiences, and I know that sadly, many of you are still coping with the ongoing fallout from your dire procedures.

We have now welcomed 257 women to our closed group since it began in 2014. Our main role on the closed Facebook page is to offer each other support, and share experiences which will help each other, especially to women as they join us immediately after awful procedures. Because of our publicity and campaigning, it is noticeable that some women are now finding us before they have the procedure and we are able to give them information they need to help them make decisions that suit them. For example, RCOG/BSGE statements relating to their rights to refuse an OPH without anaesthetic, if that is their informed choice.

Another important role of CAPH is to campaign for change! The year to March was very busy with the launch of our painful hysteroscopy survey in October 2019. We continuously tweeted about it, shared it to other women's groups, in particular health groups such as those working with menopause, and fund-raised to buy advertising posts on Facebook. All of this, combined with some excellent media coverage (see report – Katharine Tylko, Jocelyn Lewis and Lorraine Shilcock have all broadcast this year), has led to 1506 responses.

The survey is very grim to read, but it's amazing we managed to make contact with so many women who have had painful experiences, without access to clinics or a publicity budget. If these had been available, undoubtedly the figure would have been much higher. Katharine Tylko and Gill Johnson are currently working on the data to get it into a suitable form for us to take further. The Committee is currently debating the best way to get full benefit from the tragic results especially in light of the Cumberlege Report, *"First do no harm"*. So much of what has been said in that report could also be said about hysteroscopy, and we will be ensuring we get the most benefit we can from this.

Katharine Tylko and Lorraine Shilcock met with Eddie Morris, RCOG President and Justin Clark, BSGE President earlier this year and were able to provide them with data from the survey and Eddie Morris appears to be very much on side to push for changes to OPH. However, Justin Clark of BSGE appeared to be less impressed, and so far, despite our request to him, has not shared the results from their own in-clinic research survey, also carried out last autumn at 30 hospitals.

Twitter has proved to be important for us this year. Several members have taken every opportunity to comment about women's painful experiences, which has led us to be blocked in a few places! Clearly gynaecologists/hysteroscopists/equipment manufacturers are averse to the truth. But Twitter has also led to contact being made with some supportive gynaecologists, GPs, anaesthetists and lawyers. Hopefully they will help us bring about change!

We have continued our connection with the Department of Health through the very supportive Lyn Brown MP who has spoken passionately several times in the House on our behalf and continues to work with us. Pamela Howe continues to be our parliamentary lead (see Secretary's Report). We have also attended meetings of the All Party Parliamentary Group for Women, which are currently suspended due to Covid19.

Several members tried to influence the renewal of NHS tariffs for OPH by officially commenting and objecting during the consultation period, giving reasons why rewarding hospitals for carrying out OPH procedures, as opposed to procedures under general anaesthetic, was causing bad outcomes for women. Unfortunately our input was dismissed. CAPH (under our pseudonym Hysteroscopy Action) was also included as a reviewer of the National Institute for Health and Care Excellence (NICE) paper on heavy menstrual bleeding (HMB).

Just prior to "lockdown" we began working with Patient Safety Learning. They describe themselves as "a charity and independent voice for improving patient safety." We are hoping that they will be good allies for us.

We continue to seek out media opportunities and would encourage members to write to their MPs about the abysmal treatment of women. A letter to GPs has also been added to files on the Facebook page as it was pointed out how ignorant they are about what happens after they refer women on for investigations.

I would like to finish by thanking you all for your amazing support of each other and all the other input you have made over the year to fly the CAPH flag! Please carry on promoting pain-free hysteroscopy wherever you can – join us on Twitter maybe! I am optimistic that great advances will be made in the next year as we build on the work we have started and with the added input from the Cumberlege report.

A good outcome in the next year would be to report CAPH is no longer needed! I live in hope! Ever onwards!

Elaine Falkner , Chair *Dated: 24 July 2020*

SECRETARY'S REPORT

a. Committee Meetings.
Since the 'official' formation of the group we have held 12 online Committee meetings, from 11th June 2019 to 16th July 2020.
Meetings were paused from 25th March 2020, due to the Covid19 pandemic lockdown and resumed on 16th July 2020.
Meetings have been well attended, brilliant Campaigning suggestions have been put forward and acted upon. There has been excellent teamwork by members.
Minutes of all meetings have been taken and forwarded to all Committee members.

b. Parliamentary Liaison.
I have sent updates on our Campaign progress to our wonderful MP Lyn Brown, who champions our cause, including for example, the articles which were published in the Health Service Journal and the Daily Mail and also the ongoing Survey results.
I have also liaised with Ben Bessey, Lyn's P.A.
Lyn is waiting for a date for her next debate regarding Outpatients Hysteroscopy, in the House of Commons, which has been delayed by the Covid19 lockdown.
We are also hoping to arrange a meeting with the Health Minister later this year, to raise our issues and concerns.

c. Best Practice Tariff.
I am registered with the Pricing Team and I receive updates on the Best Practice Tariff when they are published.
Regarding the 20/21 Best Practice Tariff - Committee members strongly put forward their views on the Outpatient Hysteroscopy Tariff, to be considered during the Tariff proposals, consultation procedure, disappointingly our views were disregarded.
The BPT has been suspended from 1st April 2020 until 31st July 2020 due to the Covid19 pandemic and a block contract arrangement is in place for all Providers and Commissioners.
Now that we are all returning to a new normal and our Campaign is strongly going forward again, I am hopeful that we will be successful in achieving 'Pain Free' Hysteroscopy/biopsy procedures for all women. We will not give up!

Take care ladies,
Best wishes to you all.

Pamela Howe
Secretary
Dated: 22/07/20

TREASURER'S REPORT – MAY 2019 TO JULY 2020

Income Received - £702.20
The bank account was opened 22/5/19 with £14.20 held over from previous donations.
£250 compensation was credited from HSBC as a result of errors made during the account opening process.
Throughout the period in question, £438 has been received from individual donations.

Expenses paid – Total £698.19
Printing costs £171.20
Facebook advertising for Survey £363.18
Travel expenses £113.81
Website £50

Current Situation
Current account credit balance stands at £4.01

Fundraising ideas discussed
'Donate now' button on website
Approaching Trusts/Foundations for funding

Jocelyn Lewis
Treasurer
Dated 19/7/20

PR/MEDIA REPORT

2 x Daily Mail articles
2 x BBC Woman's Hour coverage
Health Service Journal article
Patient Safety Learning Hub
MegsMenopuase article online
BBC Radio Shropshire coverage
VICE article online
Hysterical women online blog
Diane Danzebrink Instagram Live
Many newspapers, radio and TV shows have been approached, but as yet, no positive response.

Jocelyn Lewis
Dated: 19/7/20

RESEARCH MANAGER'S REPORT

Here are some highlights and on-going work from May 2019 – July 2020

May 2019 – With Elaine Falkner researched and wrote BSGE-e-poster-Hysteroscopy-2019.pdf *"A Freedom of Information Act (2000) survey and analysis of English NHS Trusts' adoption of the BSGE 2018 statement on Outpatient Hysteroscopy and the RCOG Patient Information Leaflet"* Attended the 2019 BSGE Annual Scientific Meeting. Heard lecture by Prof Attilio Spiezio di Sardo. Networked.

Later in the year I followed up the BSGE study with Freedom of Information Act requests to all English Trusts who refused to use the RCOG patient leaflet, which our campaign had helped write. In light of the Montgomery ruling on informed consent, I asked if they'd start using the leaflet. This request was prompted by a discussion with Lauren Montgomery QC.

I sent FOIA requests for hysteroscopy pain-control protocols to all the Scottish Health Boards, who are now beginning to do more hysteroscopy in outpatients.
Also used FOIA to access the Whipps Cross Virtual Reality trial as 'distraction technique for the acute pain of OPH'. Analysed this with Lorraine Shilcock and have confronted Barts NHS Trust about this trial.

June 2019 – with Lorraine Shilcock supplied background info and then gave an interview to the Radio 4 Woman's Hour programme.

Throughout the year worked with all members of the committee on designing, testing and running a detailed 'google' survey of painful hysteroscopies. Gill Johnson and I are currently preparing a report on 1,000+ stories of procedures all done before the covid pandemic.

Just before lockdown in 2020 – with Elaine Falkner met Helen Hughes, CEO of 'Patient Safety Learning' and intensive care outreach nurse Claire Cox. We explored how CAPH could work with these two experts in patient safety.

Early 2020 - with Lorraine Shilcock had a productive meeting at RCOG, with its president – Eddie Morris and BSGE president, Justin Clark. Gave them both copies of our survey.

March 2020 – Relayed info from the RCOG via the Women's Voices Involvement panel to CAPH re hysteroscopy care during Covid-19

June 2020 – WVIP webinar with President Eddie Morris on gynae care during Covid-19.
Lobbied for regional anaesthesia/sedation for OPH during Covid-19
Ordered copy and read preview of Connor & Clark's 'Diagnostic & Operative Hysteroscopy' and left critical review on Cambridge University Press website

Throughout the year, with Lorraine Shilcock I've collected www.careopinion.org.uk 'bad' hysteroscopy stories, (and some good ones!) and tweeted them to the hospitals' CEOs

Have been an active member of the RCOG's Women's Voices Involvement Panel. Have followed and been a link with the Eve Appeal, Jo's Trust, Prof Emma Crosbie, pain researcher Dr Richard Harrison et al.

Katharine Tylko
Research Manager
Dated: 27/7/20

COMMITTEE MEMBERS -JUNE 2019 TO JULY 2020

Chair	Elaine Falkner
Secretary	Pamela Howe
Treasurer	Jocelyn Lewis
Research Manager	Katharine Tylko
Fundraising Manager	Liz Vining
Patient Safety & Quality Control Manager	Lorraine Shilcock
Analyst & IT Manager	Gill Johnson (Gill was invited to join the committee during the year)
Voting Member	Denise Shafeie

Liz Vining is standing down as Fundraising Manager and leaving the committee, due to personal commitments. The position is therefore vacant.