ANNUAL GENERAL MEETING
Campaign Against Painful Hysteroscopy (CAPH)
27th September 2022: 7.00 pm

On line Zoom meeting:

CAPH COMMITTEE MEMBERS' REPORTS

Chair's report from Elaine Falkner

This is our third AGM since CAPH Action group 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 member of this community group.

Committee

Current members are:
Chair: Elaine Falkner.
Secretary, Parliamentary Lead and BPT monitor: Pamela Howe (re-instated)
Treasurer and Communications Manager: Jocelyn Lewis.
Research Manager: Katharine Tylko.
Patient Safety: Lorraine Shilcock.
I.T. Manager and Analyst: Gill Johnson.
Member: Philippa Hammond
Member: Grace Lloyd (joined October 2021)
Member: May Hooper (joined August 2022)
Jessica O'Neill stood down during the year.

Fundraising Manager: Position vacant.
PR/Advertising Manager: Position vacant

Membership

Unfortunately membership has continued to rise. We have now welcomed 397 to our closed group since it began in 2014, an increase of 61 since our last AGM, and many more have commented and been supported on the public CAPH page.

Social Media

- CAPH is followed by 1,500 people on Facebook, has 2,421 followers on Twitter, and 182 followers on Instagram.
- We have spent £400 on advertising on Facebook around the country in the last year, promoting the survey which inevitably brings people to our CAPH page and some then join this Action Group.
- Several of our members are regularly tweeting, which is helping to raise awareness.
- Some of our members are also on the RCOG Women's Voices Involvement Panel where we also raise awareness of gynaecology shortcomings – "The RCOG Women's Voices Involvement Panel is an online group of over 700 members of the public who want to use their experience of women's health services to

influence the work of the College and the wider women's health sector." (It now seems to be open for new members, so others in this group can apply if they wish. https://www.rcog.org.uk/for-the-public/rcog-engagement-listening-to-patients/womens-voices-involvement-panel-wvip/

Activities

Our committee has had quite a tough year personally, with bereavement, ill-health and family illness being to the fore for several members. Also many have had COVID during the year or family members with COVID that has caused ongoing issues. Despite, these challenges we have continued to push our agenda forward wherever possible, with mixed results.

SURVEY:

Our Pain Survey continues to run, and has now been completed by 2,908 women. Several localised facebook ads promoting the survey have been run through the year. Sadly, these always bring new people who have had horrendous experiences. We have continued to use these accounts and stats to draw attention to the awful hysteroscopy situation wherever appropriate.

RCOG:

Over the years we have built a good relationship with the President of the RCOG, Eddie Morris, who will cease to be President in December to be replaced by Dr Ranee Thakar who is a consultant at Croydon Hospital. Eddie assisted in arranging a meeting for us with NHS England members, the deputy president of the RCoA, Will Harrop-Griffiths, and BSGE president (now past) Justin Clark. We learnt from this meeting on 4th February, that NHSE isn't responsible for anything relating to hysteroscopy protocol and they recommended we approach each commissioning group separately! Lack of anaesthetists was acknowledged and Eddie said he would contact Maria Caulfield, Health Minister about this. As mentioned under "Parliamentary", our meeting with Maria Caulfield (instigated through Lyn Brown, MP finally) was due to take place on 21st September but was cancelled due to the government reshuffle. We will attempt to reschedule with the new minister. (See also Maria Caulfield's response to Liz Twist under "Parliamentary" relating to the 4th February meeting.)

BSGE

Our relationship with BSGE deteriorated this year due to what appears to be their determination to cut us out of hysteroscopy discussions/conferences. Katharine Tylko applied to present at their annual conference, and this was declined. She submitted the BSGE video presentation abstract: Strengthening Patient & Public Involvement in Hysteroscopy Research. They clearly don't want our input or that from a patient group. BSGE has also have a change of President with Andrew Kent from Royal Surrey NHS Foundation Trust, replacing Prof Justin Clark, Birmingham Women and Children's Hospital.

"**GETTING IT RIGHT FIRST TIME" (GIRFT)**

In March we submitted a "Getting It Right First Time" (GIRFT) review contributed to by several members. However we have seen a report in which there is no mention of choice for women, any kind of triaging, percentage of failed procedures and the need for GA facilities,

and no mention of pain at all. Anyone not familiar with the procedure reading this would assume it is a harmless procedure for all women. It is very concerning that NHSENGLAND are responsible for GIRFT, and equally concerning, if not more so, West Midlands GIRFT are proposing 100% of hysteroscopy be carried out in outpatients. Another presentation suggests 90%. We have raised all these concerns with Eddie Morris (RCOG). On a better note, Katharine, Lorraine and Pamela met with Dr Chester from Worcester Acute Health Trust. Dr Chester said they are committed to the highest quality of care and to "Getting it Right First Time" and the need to listen. He hoped that working with us would improve patient experience and empower women to make the right choices for them regarding hysteroscopy.

NEW GREENTOP GUIDELINES

We submitted comments some time ago but have yet to see the final item for review. These are now very overdue. We think they are being held up by BSGE.

PARLIAMENTARY

Lyn Brown MP

We are very grateful to Lyn who remains a very strong advocate for CAPH. Pamela Howe has kept Lyn and her office up to date with campaign activities throughout the year. She has spoken about hysteroscopy in the House twice this year, bringing the number of times she has raised the issue to ten. Firstly she brought a debate to the House on 31st January, attended by Maria Caulfield, then Health Minister. She spoke passionately relating awful experiences women have suffered and made clear points about lack of data collection. https://twitter.com/lynbrownmp/status/1488582551287570432. In response to the request by the Minister during that debate, we supplied a detailed update on the current state of the campaign, survey and ongoing new horrendous cases. A copy was sent to Eddie Morris, President RCOG.

The second occasion Lyn Brown spoke on behalf of CAPH this year was on 6th July when she paired with Emma Hardy's debate in Westminster Hall regarding gynaecology waiting lists. She raised that women are succumbing to painful outpatient procedures because they are threatened with a long wait for GA which is unacceptable, again illustrating her points with accounts from women.

Pamela and Elaine worked together on a detailed letter sent to Maria Caulfield on 11th July on behalf of CAPH, requesting a meeting with the Minister, to also include Lyn Brown and the RCOG. This was successful but unfortunately the meeting was cancelled due to the government reshuffle. We will now be approaching the new Health Minister for a meeting.

Liz Twist MP also tabled a question to ask the Secretary for State and Health and Social Care, what discussions his officials have had with NHS England about "the meeting held on 4th February 2022 with the Campaign Against Painful Hysteroscopy; and if he will make a statement."

Maria Caulfield responded on 17 March 2022: "NHS England and NHS Improvement's National Speciality Adviser for Gynaecology met with representatives of the Campaign Against Painful Hysteroscopy, the Royal College of Obstetricians and Gynaecologists, and

The Royal College of Anaesthetists. Officials have been advised that all attendees agreed that hysteroscopy is an effective way of assessing and treating abnormalities in the cavity of the uterus and it is essential women feel able and safe to have the procedure.
The Royal College of Obstetricians and Gynaecologists are consulting on a good practice paper 'Pain relief and informed decision-making for outpatient hysteroscopy and procedures'. This paper makes clear that all doctors or nurses carrying out hysteroscopies must make sure women are listened to before, during and after their procedure."
She is referring to the paper we were asked to comment on.

ANALYSIS OF REPORTS

CAPH carefully reviews and researches published reports and litigation on health matters to see what lessons can be learned which may be relevant to our campaign.
Much of our focus is on the issue of informed consent, as many of our members relate horrific experiences during medical procedures for which they have not given informed consent- either in writing or verbally- or have withdrawn consent mid-procedure but been ignored.
Recently, we have reviewed the Ockenden report into maternity services and, in particular, have spent considerable time on the Kennedy reports on the 'rogue' surgeon Ian Paterson, who was sentenced to 20 years in prison for unlawfully wounding patients (mainly women).
The Kennedy report investigates the way in which concerns about his surgical practice in both the public and private sectors were mis-handled for more than 14 years.
During this period, Ian Paterson subjected many women to repeated and unnecessary breast surgery, as they had been put in fear of having cancer.
Other women were coerced into 'agreeing' to unauthorised surgery for breast cancer which endangered and, in some cases ended, their lives.
Paterson bullied both other surgeons and consultants as well as more junior colleagues; whilst whistle-blowers who came forward found themselves being investigated.
The report makes it clear that, for years, health trusts and private sector hospitals completely failed to recognise what should have been the central issue in their investigations, which was the lack of informed consent, including:

- even where consent forms had been signed, these were legally invalid as incorrect information had been given to induce patients to agree to surgery;
- patients cannot agree to surgery where unrecognised procedures are used;
- patient records were entirely missing, incorrect or inadequate.

We glean a great deal of useful, relevant information from published reports- not just about governance processes and failures, but also about the culture and systemic failures in health trusts and private hospitals which (for example) led to Paterson being allowed to continue what has been described as 'butchery'.

<u>Other work in brief:</u>

- We met with Matt Westmore from Health Research Authority, to discuss whether we could challenge any of the research relating to hysteroscopy. It appears that none meets the criteria for an investigation.

- We provided feedback for the Women's Health Strategy, with emphasis on legalities and informed consent.
- Katharine, Lorraine and Pamela met with Dr Chester from Worcester Acute Health Trust. Dr Chester said they are committed to the highest quality of care and to "Getting it Right First Time" and the need to listen. He hoped that working with us would improve patient experience and empower women to make the right choices for them regarding hysteroscopy.
- We worked with FTWW relating to improving the health of women and girls in Wales.
- We talked with Redzi Bernard, an audio producer working on gender bias in medicine.
- We were contacted by Eve Appeal regarding publication of a research paper on womb cancer. Prof Widschwendter, (UCL) research into an early detection cervical/vaginal swab test to check biomarkers for risk/presence of womb cancer should greatly reduce the need for invasive procedures, such as hysteroscopy. We were asked to provide a quote for their press release which led to an article mentioning CAPH in i News.
- In March we were invited to review the RCOG Good Practice Paper (new): *Pain relief and informed decision-making for outpatient hysteroscopy and procedures.* Several members contributed to this, and a very long and detailed response was made.
- We have made several attempts to have access to the data used for the BSGE Patient Satisfaction Survey benchmarking research paper, but this has been withheld.

THANK YOU:
Finally, thanks go to all our members who have tenaciously endeavoured to keep the campaign moving forward, and supported and encouraged each other along the way. I wish this campaign wasn't necessary, but I'm proud to be a member of it.

Elaine Falkner, Chair

<u>Research Manager's report from Katharine Tylko</u>

It's been a tough year on many counts, one being the rejection of our annual presentation to the British Society for Gynaecological Endoscopy.
For seven years we were welcomed at the BSGE Annual Scientific Meeting where we presented research on severe pain in outpatient hysteroscopy and debated with gynaecologists and industry reps. Recently BSGE chiefs haven't shared our serious concern about the serious harm of painful outpatient hysteroscopy, just as they downplayed the serious harms of vaginal mesh.

Fortunately, there is much information in the public domain and nothing to stop our campaign from being successful. Here are some of our research threads:

CARE OPINION

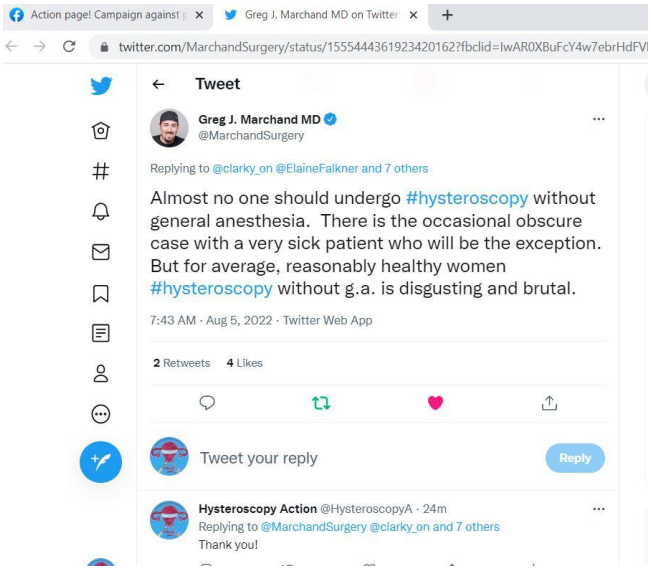
This independent organisation has actively supported us. The number of stories of severely painful hysteroscopies reported to www.careopinion.org.uk is decreasing but many hospitals ignore or delay responding to the bad stories. Since posts are anonymous and in the public domain we're able to tweet them and sometimes provoke improvements from the bad clinics.

TWITTER

Without social media CAPH would not have got off the ground. That's how we 'survivors' all met.

We daily monitor Twitter for instances of painful hysteroscopy and for health care professionals prepared to speak out about the need for genuine pain-relief. This year, USA celebrity gynaecologist

Dr Greg Marchand gave us gold-dust, "Almost no-one should undergo hysteroscopy without general anaesthesia."



We're beginning to hear via Twitter from nurses and – recently – several NHS gynaecologists who support informed choice of anaesthesia for hysteroscopy. We are gathering a library of their quotes as valuable evidence to be included in Department of Health policy.

'SCOPE'

We regularly monitor this BSGE periodical for hysteroscopy reports. The RCOG President is interviewed at length in the most recent issue. Disappointingly he doesn't make a single mention of hysteroscopy. The same issue advertises the next meeting of the 'Ambulatory Care Network' – a euphemism for Outpatient Hysteroscopy. No patient and public involvement is planned for the meeting but there is an evening meal and the opportunity to 'glam up'.

MEDICAL PRESS

CAPH committee members regularly receive both old and medical publications about hysteroscopy pain. Thanks to statisticians within our group we're able to assess the likely quality of this information. We've made it clear to the BSGE that some of their research

contains statistically ill-founded conclusions. For example, BSGE members' own 'Benchmarking' audit of 5,000+ OPH performed in 77 clinics includes only a SINGLE patient's survey returned from several hospitals. We found this extraordinary info in an annex. We asked the lead author for an explanation but received nothing plausible.

We've fine tooth-combed through a British Association of Day Surgery report to discover that their recommendation that 90% diagnostic hysteroscopies should be done in outpatients has found its way via Getting It Right First Time into the Women's Health Strategy. This is totally at odds with the BSGE/RCOG assertion that women have the right to choose mode of anaesthesia for hysteroscopy.

FREEDOM OF INFORMATION ACT, 2000
The BSGE omitted to declare the percentage of patients who suffered severe pain (of 7/10 or more) during their benchmarking audit. We used the FOIA to ask the host hospital - Birmingham Women's & Children's - for this crucial data. They have twice employed an extraordinary exemption to withhold this information from the public. Apparently they need not disclose the information if they intend to perform further research!! Meanwhile, successful FOIA requests to individual hospitals in the audit suggest that approx.. 1 in 3 women are suffering severe pain during outpatient hysteroscopy.

We use the website Whatdotheyknow.com to process and store hundreds of FOIA responses to requests to NHS hospitals nationwide for their pain-control protocols. When members of our Action/Support group ask for details of what to expect at their local hospital we're able to use these hospital letters as a basis for accessing good or better pain control.

PATIENT & PUBLIC INVOLVEMENT
We've provided PPI for two women gynaecologists in different Trusts who are trialling genetic biomarker non-invasive tests that will make much hysteroscopy redundant. We've spoken to and – thanks to May Hooper – given an interview for a medical podcast on the gender pain gap. We're currently trying to build teams of CAPH members who are prepared to work with the following Trusts: Worcestershire; Kettering and – I hope – Luton & Dunstable.

FORGOTTEN
Apologies for loads I've forgotten. None of this research would happen without a determined bunch of caring people who support one another through thick and thin.

IT Manager and Analyst report from Gill Johnson

- Oct -Nov 2021 Worked with Grace and Katharine on survey analysis
- Nov 2021 Pointers for non-Facebook member in sending her complaint
- Jan 2022 Precis-ed study into "acceptability" for Katharine
  Wrote to my MP asking her to support Lyn Brown's debate
  Contacted WVIP to support review of consent guidance
  Advice for a gentleman complaining on behalf of his late wife

- Feb 2022 Commented on RCOG "Good Practice Paper"
- Mar 2022 Commented on "GIRFT" patient consent form
- May 2022 Own complaint: Reply to Ombudsman
- June 2022 Shared summary of my "complaint bullets" to Action Page
  Extracted and formatted 2022 entries for journalist Martyn Halle, then same for Pat Hagan, Daily Mail.
- July 2022 Extract of Kidderminster & Worcs hospitals, working with Katharine and Lesley.
- Various Posted Care Opinion stories to CAPH page, requesting support.
  Responded to Menopause Support Group posts re OPH pain.
  Financial authorisations.

Treasurer's Report from Jocelyn Lewis

CAPH Finances September 2021 – 11 September 2022
At the end of 2021, HSBC introduced a monthly account fee of £5, so an alternative account provider was found.
In March 2022, a replacement account was finally opened with Lloyds Bank and the balance transferred.
The Lloyds bank details are now:
Sort code: 30 90 09
Account No: 61449160
Two signatures required for all transactions

Opening balance (1/9/21) £232.98 credit

Outgoings
- Facebook adverts £312.61
- Bank Charges £20
- GDPR Information Commission Fee £40

Total £372.61
(All receipts are filed in date order, with details and copies of emails attached confirming payments from a second signatory)

Income
- 18 x Donations totalling £555

Total £555

Current Balance (20/9/21) £415.37 credit
(NB: Since this report was produced, a further £100 has been committed to ads currently running).

Prepared by Jocelyn Lewis - Treasurer - 11th September 2022