

Edinburgh & Lothian Prostate Cancer Support Group

Minutes of the Annual General Meeting

Thursday 8 June 2017 at Maggie's Centre, WGH Edinburgh

The meeting was chaired by Ian Hay, who started the meeting by welcoming those present.

1. Apologies

Apologies were received from Larry Foster, Charlie Hogg, Derek Howie, Graham Marchbank, Roddy McLean, Bill Platts, and Mike Shaw.

2. Registration

There were 32 members present, including three new members.

3. Minutes of AGM on 16 June 2016

Ian Hogarth proposed acceptance of the minutes, and the motion was seconded by Bob Scott. Acceptance was approved by a show of hands, and the minutes duly signed. There were no matters arising.

4. Chairman's Report

Ian Hay (IH) reported that the ELPCSG has had a busy and successful year in which our policy of dedicated duties for committee members has again worked well. We have missed our past Chairman Mike Shaw, who has been living in Galloway while having a new house built in Morningside. Hopefully he will return to our fold in the not-too-distant future. In his absence we have all stepped into the breach, especially new committee member Iain More, who has been highly successful in attracting top speakers to our meetings, which have been very well attended with regular capacity audiences.

During the year we co-opted David Milner to the committee as Minute Secretary, while all other committee members have agreed to stand for re-election. As always, we ask any member interested in joining our committee to give his name to our Secretary Alasdair Ferguson.

Our walking group, ably organized by Iain Sime, has had another successful year and as always welcomes members to join the bi-monthly walks. We have recently redesigned our posters and leaflets and will welcome your assistance in promoting these in GP surgeries and in other appropriate outlets. We are also in progress of producing new toilet cards.

IH thanked all those who have donated to our organization over the past year, and also thanked all the committee members for their willing work during the year. He expressed our

special gratitude to AF for his administrative work and to Jim Woodhead (JW) for his financial work for the group.

a) Edinburgh meetings

IH reported that in September 2016 we had Professor Alan McNeill, a prominent supporter of our group, who updated us on progress with robotic surgery, and we also heard from Gaynor Brown about the new Macmillan Cancer Information and Support Service operating in some of Edinburgh's public libraries. Mr Prasad Bollina was the principal speaker in November 2016, when he gave a detailed account of the *ProtecT* research study. In addition Alan Gow of Macmillan Cancer Support explained the practice of mindfulness and the benefits therefrom for cancer patients, and gave information on available courses.

Our good friends from Prostate Scotland, Adam Gaines and Mae Bell, addressed our February 2017 meeting, and were supported by Emily Ross (University of Edinburgh) who spoke about the research project "*Cancer and Society in the 21st Century*". Andy Anderson, Centre Head at Maggie's Edinburgh, was the speaker at our April 2017 meeting, when in addition to talking about the work and aims of Maggie's centres worldwide, he told us about the planned extension to the Edinburgh Centre. At this meeting we also reverted to our tried and tested formula with two members, Bill Platts and David Milner, giving much appreciated accounts of their personal prostate cancer journeys.

Looking ahead, we have a major event planned for Murrayfield Stadium on 7th September 2017, which will form our September meeting. The theme will be "*Fit for Life – Fit for Treatment*" and full details of the programme and speakers will be published soon. The attendance will be limited so it is important to get your name down now or as soon as possible.

IH thanked our team of helpers at meetings who organize the registration process and the seating arrangements.

b) West Lothian meetings

IH read the following report from Charlie Hogg, in the absence of a representative from West Lothian:

"The West Lothian support group continues to flourish with on average 55 at each of our four meetings. This year we celebrated our tenth anniversary in March 2017 and held a special event at Livingston Stadium with over 130 guests. The day was seen as a great success with excellent speakers and a chance to enhance our community links with many of the invited guests, and a chance to thank all those who had donated funds over the year to our support

group. The total raised this year was £4165.

We have been very active this year with a publicity campaign about our “buddy” programme. We have distributed leaflets to all local golf clubs and health clubs plus local GP and dental surgeries. All this has been enhanced by the local newspaper articles from the publicity connected to our tenth anniversary.”

c) External activities

Rob Lester (RL) reported that ELPCSG has been represented at meetings of the SCAN Urology Group, SCAN Patient Representative Group and the Cross-Party Group on Cancer at the Scottish Parliament. Several of our members are active volunteers with **Prostate Scotland** and are involved in increasing the public awareness of prostate cancer as well as helping in the production of informative literature.

We welcomed the introduction of a robot-assisted prostatectomy service at the Western General Hospital, which was officially launched by Health Secretary Shona Robison in November 2016.

ELPCSG has continued to work with the **Scottish Medicines Consortium** in the process of approving new drug treatments for prostate cancer, and it was in December 2016 that Cabazitaxel was finally accepted for use as chemotherapy for men who have been treated with Docetaxel.

RL reported that there have been significant research developments in the past 12 months, with the *ProtecT* ten-year report being of particular interest to our members when it was published in September 2016. The main finding was that 10-year survival is the same for men whether they have had active monitoring, radiotherapy or surgery. Another important study was the *PROMIS* trial which was published in January 2017 and showed that there are distinct benefits in having an MRI scan prior to a biopsy during the process of investigation for suspected prostate cancer. The *STAMPEDE* study results were published in June 2017, showing that Abiraterone, in combination with hormone injection treatment, is very effective at delaying progression of advanced cancer and also in reducing the death rate.

Finally, we say farewell to Sandra Bagnall, who, after six years of service, retired in November 2016 from her post as Patient Involvement Manager for SCAN. We thank her for the encouragement and support that she has given to both the Edinburgh and West Lothian groups, and wish her well in her new post with Midlothian Council.

d) Buddying

Ian Hay reported that our much-admired buddying system has had another successful year. During the year have had five new buddies fully trained by Andy Anderson at Maggie’s, and four have quickly passed on their experiences to newly diagnosed men whose condition and treatments were similar to theirs. The fifth buddy has been through a more specialized experience and has not yet had a suitable opportunity of sharing his experiences with others.

Our new buddy service telephone number has become well established and after a quiet spell in the early part of the year, we have over recent months been able to help 15 new members, all of whom have become attendees of our meetings at Maggie's.

IH stressed the importance of using buddies with recent experience of treatments, as these are changing and improving all the time. With this in mind, he intends to run another training course during the first half of 2018.

e) Administration

Alasdair Ferguson reported on membership and administrative issues related to the group. ELPCSG currently has 238 members and another 90 individuals we keep in regular contact with, including medical professionals, colleagues in related charities, and others outwith Edinburgh and the Lothians. Our current membership total is 17 more than 2016, and we have gained 25 new members in Edinburgh, East and Midlothian in the last year. The committee meets six or seven times a year and the meetings are organized and minuted by David Milner. ELPCSG interacts with our members in a number of ways including: regular meetings at Maggie's throughout the year (thanks to the helpers who come early and prepare the venue); receiving and responding to e-mails from individuals seeking information, including requests for buddies; sending out e-mails about forthcoming members' meetings and current issues related to prostate cancer, to members in the Edinburgh & Lothian area; maintaining a website which includes in addition to lots of information about the group, links to other websites which provide information about prostate cancer and treatment, plus regular news updates (in the last year over half a million people have visited our website); and production of new leaflets and posters in 2017. Plans are afoot to make the website more accessible, and we are also on Twitter and Facebook.

f) ELPCSG Walking Group

Iain Sime reported as follows:

"The last year has seen our walking section continue to be popular, with walks in areas such as The Fife Coast, Galashiels, Peebles, The Forth Shore in Edinburgh, Colinton, and part of the John Muir Way in East Lothian. The core interest group fluctuates at about 20 people, with the need to continue marketing in order to maintain numbers, but more importantly to promote the clear link between good health and exercise."

5. Financial Report.

Jim Woodhead (JW), our Treasurer, prepared a written report of the Group's accounts for the year 1st April 2016 to 31st March 2017. Donations of £7,012.05 over the year were received, with expenses for both Groups totalling £6,902.01. Excess receipts and payments amounted to £283.03. The opening year bank balance was £13,296.92 and the closing year bank balance was £13,534.95, so the finances of the group remain healthy. Acceptance of the accounts was proposed by Ian Manderson and seconded by David Patterson.

The report was independently examined by Mr T M Mackin. Members approved the honorary re-appointment of Mr Mackin as independent examiner for the current year, subject to his agreement, which JW will seek. This was proposed by Bob Geddes and seconded by Jonathan Williams.

JW also took the meeting through the likely programme for our forthcoming 7th September meeting at Murrayfield, and encouraged members to sign up there and then if they wished to attend.

6. Election of Chairman.

Ian Hay has agreed to act as Chairman of the Group. This was proposed by Bob Scott and seconded by David Milner.

7. Election of Committee Members.

The current committee members were prepared to stand for re-election:

Ian Hay

Charlie Hogg

Rob Lester

Mike Shaw

Jim Woodhead

Roddy Maclean

Iain More

Alasdair Ferguson

Support for all these names was carried by a show of hands after having been proposed by Chris Garner and seconded by David Patterson.

The election of David Milner to join the committee was proposed by Yvonne McIntosh and seconded by Iain More, and approved by the members present.

8. Election of Trustees

The current trustees are:

Ian Hay

Charlie Hogg

Rob Lester

Mike Shaw

Jim Woodhead

Alasdair Ferguson.

Following a proposal by Joe Walker, seconded by Bob Geddes, the board of trustees was confirmed by a show of hands.

9. Any Other Competent Business.

There being no other business the meeting was concluded.

David Milner

Minute Secretary.