

Edinburgh & Lothian Prostate Cancer Support Group

Minutes of the Annual General Meeting Thursday 13 June 2019 at the Maggie's Centre, Edinburgh

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

1. Apologies

Apologies were received from Alex Downie, Alan Dickinson, Ian Dickson, Charlie Hogg, Rob Lester, and Lawrence Taylor.

2. Registration

There were 35 members present, including three new members: Douglas Hollinsworth, James Nisbet, and Robert Smith.

3. Minutes of AGM on 7 June 2018

Iain Annand proposed acceptance of the minutes, and the motion was seconded by David Patterson. There were no matters arising.

4. Chairman's Report

Ian Hay (IH) reported as follows:

2019 has again been a good year for the group with continued success in supporting our members and in promoting our activities to their advantage.

Committee

Our committee members have served the group well over the year and I have been very grateful for their dedicated support in managing and expanding this wonderful group of men of which we are all fortunate to be a part. Alasdair Ferguson is not standing for re-election this year. When Alasdair took over the role of Secretary five years ago, he was responsible for membership, minutes and our website. He has transformed our website and will continue to manage it on our behalf. He also masterminded the necessary changes to our regulations in order that we conform with the new GDPR regulations. David Milner is now our minutes secretary and we have a nominee to the committee who will take over membership duties. Alasdair's contribution to the group has been substantial and hugely appreciated.

I must also acknowledge the work done by other supportive members, including Eddie, Bob and Stuart on meeting evenings. Their assistance is invaluable. Thanks also to Bob for his provision of home baking treats and for taking over the provision of teas and coffees at our meetings. We are also indebted to Maureen Woodhead who served teas and coffees at our meetings for many years. Maureen was a great asset to our meetings and her helpfulness, charm and kindness will be missed by all of us.

Our walking group so expertly organized by Iain Sime for many years has continued to grow under new arrangements whereby different members take turns in organizing and leading the

walks with David Milner acting as overall co-ordinator. Iain is still an active participant and constantly on hand to help leaders. Members will be warmly welcomed to join these walks, which are well planned, not taxing and very sociable.

Our finances remain healthy in the very capable hands of Jim, as you will find out when he makes his report. We have benefitted from a number of donations, for which we are very thankful.

Meeting programme

Our bi-monthly meetings continue to be very well supported, with Maggies at times filled to capacity. In September our speaker was Stuart McKay, Professor of Medical Chemistry at Strathclyde Institute of Pharmacy. Professor McKay spoke about cancer drug discovery, and explained why it is so difficult to discover new drugs and develop new medicines.

At our November meeting, our main speaker was Richard Martin. Professor of Clinical Epidemiology at the University of Bristol. He was supported by Dr Emma Turner, Senior Research Assistant at the University of Bristol. They spoke on a range of subjects, but particularly covered the CAP Trial, in which they were both involved. This trial involved PSA testing involving 410,000 UK men, to evaluate whether the test could be developed into a screening programme for prostate cancer.

Jane Herbstritt, Scottish campaigns assistant for *Global Justice Now*, was our speaker in February. She explained to us *Global Justice Now's* recent report on the pharmaceutical industry, entitled 'Pills and Profits: how drug companies make a killing out of public research'. The report highlighted the level of UK public money used to develop new drugs – with two out of five of the NHS's most expensive drugs being discovered due to the investment of substantial public money.

Our April meeting was very different, but enjoyable, when our speaker was Donald Smith, former director of the Scottish Story Telling Centre. Donald told us about his many involvements in story-telling, and linked this to the many books he has written. He also entertained us with a number of folk tales and oral stories which he had gleaned from many sources over the years.

At our AGM we look forward to having Professor Alan McNeil, Consultant Urological Surgeon, who will update us on recent developments in diagnostic technology.

Thanks are also due to our members who have supported the main speakers by relating their own personal experiences of living with prostate cancer. Iain More has again excelled in finding interesting speakers, and already has an almost full programme arranged for our Winter season from September through to April 2020.

Buddy Report

Buddy requests have remained constant over the year and the feedback from all who have used this service has been very positive. We are grateful to Andy Anderson, Centre Head at Maggies, for continuing to train our new buddies. Five members recently attended a training course at Maggies and three more will do so soon. Grateful thanks are due to all our current buddies, who are a great credit to our group's mission of 'patients supporting patients'.

West Lothian meetings

In the absence of a representative from West Lothian, Ian Hay read the following report from Charlie Hogg:

“The West Lothian Group continues to flourish with on average 60-65 at each meeting. We recently added a new feature with a ‘Ladies Group’ meeting at the end of the formal part of the meeting for a discussion between some of our female members and the partners of our new members. This is to help them understand about treatments and topics around the diagnosis that their partner in many cases may fail to discuss with them.

Our future meetings starting from 1 August will be held at our new meeting venue in Crofthead Community Centre in Livingston. It was sad to leave the Ability Centre after 10 years but a re-structuring plan to add new Council services to the building meant we did not have suitable facilities for our meetings.

We have continued to expand our Buddy publicity programme throughout all the medical centres in West Lothian and this includes the leaflet being shown on the new screen information displays in many of the Health Centres.

In the last financial year we have received £1415.00 in donations.”

External activities

Ian Hay read the following report from Rob Lester, who was unable to attend:

Prostate Scotland: Our close link with Prostate Scotland has been maintained and I have attended regular meetings of the group to review the charity’s extensive range of information booklets on prostate cancer. We have updated several publications including ‘Early Prostate Cancer Explained’ and ‘Guide to minimum access surgery to remove the prostate’ and are currently revising ‘Active surveillance as a management for early prostate cancer’ which should be ready for publication soon.

Institute for Cancer Research (ICR): A new development this year was when we were contacted by The Institute of Cancer Research in London and asked for a volunteer to represent patients with prostate cancer. The ICR has recognised that it is taking too long for innovative new cancer treatments to reach the patients that need them and that ‘radical action is needed to bring down the price of modern cancer drugs, allowing as many patients as possible to benefit from advances in cancer treatment while not overburdening the NHS’. Many in our group participated in the Drug Access Survey organised by ICR which showed a high percentage of people had real concerns about the cost and availability of new cancer treatments. There were 1,064 responses to the Drug Access Survey and included 125 men with prostate cancer, most of whom were from ELPCSG.

d) Membership Secretary’s report

Alasdair Ferguson reported on membership and administration of the group over 2018/19 as follows:

“In 2016/17 we had to deal with our website crashing, and in 2017/18 new and quite complex GDPR rules meant we had to completely change the way we communicate with contacting our members. So I am very glad to tell you that 2018/19 has been a much calmer year.

Our membership currently stands at 179 (excluding West Lothian) and this figure is fairly constant as new members join and others move on. Three new members are attending the AGM tonight so that brings our numbers to 182.

As you know this self-help group is all about supporting men with prostate cancer, their families and carers. Things happen fast nowadays with lots of information coming out about new treatments, new diagnosis tools and information about exercise, diet and healthy living. We aim to inform our members of new ways of diagnosing prostate cancer and new treatments, and of course we are always particularly interested in what is happening in Scotland and particularly here in Edinburgh and the Lothians. We do this at meetings, in regular e-mails to members, and through our website, which continues to be popular with around a dozen new visitors every day. Sometimes this website-visitor figure leaps up to a hundred when there is something topical in the news, for example a well-known personality going public about prostate cancer.

I am and will continue to be the webmaster for the ELPCSG site and I will continue to update the website 2 or 3 times a week, with local news, reports on our activities such as the walking group, donations received, and breaking news about prostate cancer treatment both locally and nationally. If you do see something in the media or the press please do bring it to our attention.

Acceptance of the Annual Reports was proposed by Bob Scott, seconded by Russell Johnston, and agreed by the members.

5. Financial Report

Jim Woodhead (JW), our Treasurer, prepared a written report of the Group's accounts for the year 1st April 2018 to 31st March 2019. Donations totalling £3934.14 over the year were received, with expenses totalling £5752.43. Excess receipts and payments amounted to - 1818.29. The opening year bank balance was £10,961.23 and the closing year bank balance was £9142.94, so the finances of the group remain healthy.

Acceptance of the accounts was proposed by Ian Manderson and seconded by Bill Platts. 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 David Muir and seconded by David Patterson.

6. Election of Chairman

Ian Hay has agreed to continue to act as Chairman of the Group. His continuing role was proposed by David Milner and seconded by Stuart Bell.

7. Election of Committee Members.

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

Ian Hay
Iain Annand
Charlie Hogg
Jim Woodhead
David Milner
Iain More.

Support for all these names was proposed by Bob Scott and seconded by Colin McClelland, and approved by the members present. As previously intimated, Alasdair Ferguson has decided to step down.

Fortunately, Ken Howey and Bruce Vickery have agreed to join the committee. Their election was proposed by Bob Scott and seconded by Ian Gilroy, and was approved by the group.

8. Election of Trustees

The current trustees are, and subject to the approval of the members were willing to remain, as follows:

Ian Hay
Charlie Hogg
Mike Shaw
Rob Lester
Jim Woodhead
Alasdair Ferguson.

Following a proposal by Iain Annand, seconded by David Milner, the board of trustees was confirmed by a show of hands.

10. Any Other Competent Business

There being no other business the meeting was concluded at 20.10.

David Milner
Minutes Secretary.