

Edinburgh & Lothian Prostate Cancer Support Group

Minutes of the Annual General Meeting

Thursday 7 June 2018 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 Larry Foster, Charlie Hogg, David Milner, Ian Manderson, Iain Sime, Roddy McLean and Mike Shaw.

2. Registration

There were 36 members present, including four new members.

3. Minutes of AGM on 8 June 2017

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

4. Chairman's Report

Ian Hay (IH) reported as follows:

2018 has again been a good year for the group with continued success in supporting our members and in promoting our activities to their advantage.

Our committee members have served the group well over the year but past chairman Rob Lester has decided not to stand for re-election. Rob's contribution to our group has been immense. As his vice chairman I saw at first hand the outstanding work he did on our behalf. He has continued to serve us for three years since then, and has kept us all abreast of developments in cancer related treatments while also acting as a buddy - a role in which he will continue to serve. We are hugely indebted to Rob and wish him well as he takes more time to travel the world. Past chairman Mike Shaw remains as a committee member but is still on leave of absence until his new home is fit for occupation. He hopes to return to active involvement with the group in the autumn. Over the year I have had dedicated support from all our committee members for which I am very grateful. I would also wish to acknowledge the work done by other supportive members including Eddie McGill, Bob Scott and Stuart Malcolm on meeting evenings here at Maggie's. Thanks also to Bob for his provision of home baking treats at our meetings!

Our Walking Group, so expertly organised by Iain Sime, has had another very successful year. The next walk is on Tuesday 26th June and new walkers will be warmly welcomed to join these walks which are well planned, not taxing and very sociable. I wish to record on behalf of the group our appreciation of Iain's dedication and meticulous planning of the walks.

Our finances remain healthy in the very capable hands of Jim Woodhead as you will find out when he makes his report. We have already witnessed this evening a very generous donation from Isla Campbell and her family and friends. We are very grateful for this and for all the kind financial support we have received over the year.

Our bi-monthly meetings continue to be very well supported with Maggies at times almost bursting at the seams! In September 2017 we had our special Murrayfield event which was attended by nearly 140 members, their families and friends with the theme being 'Fit for Treatment - Fit for Life'. Speakers included Dr Anna Campbell of Edinburgh Napier University; Yvonne Macintosh from Maggies; Audrey, Byron and Ryan from Edinburgh Leisure; and Chris Paterson, the legendary Scotland International Rugby player. We were also entertained by the Caledonian Kickers line dancing ensemble and enjoyed good food and excellent company.

At our November 2017 meeting our main speaker was Lynne Connolly, Marie Curie Palliative Care Nurse Specialist. Alasdair Ferguson gave a demonstration of our new website and we reflected on the organisation and success of the Murrayfield event.

Alasdair Innes, Clinical Nurse Practitioner from NHS Lothian was the main speaker in February 2018 when he told us about new local developments and responded with clarity and humour to the many questions addressed to him. Gareth McAteer (Patient Research and Policy Co-ordinator with Prostate Scotland) told us about some innovative patient-led research which he was to be conducting on behalf of Prostate Scotland and he was delighted to enrol many members of our group to assist in the research.

Our April 2018 meeting was addressed by Professor Nick Leslie of Heriot Watt University when we learned a lot about ongoing research particularly P-TEN. Our members Chris Wrigglesworth and Iain Annand gave us very interesting backgrounds to their personal experiences of 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 2018 through to April 2019.

a) Buddying

There has been a slight drop in buddy requests but our more recently trained buddies have been kept fairly busy. We have three volunteers for buddy training which will be arranged in the autumn and hopefully some others will come forward as it is important that buddies are fully aware of current treatments. Training will take place at Maggies and will be conducted by Andy Anderson. The recent introduction of GDPR will impact on our Buddy system - in the way we conduct it and maintain records.

We will update buddies as soon as possible on what will be required in future. Grateful thanks are due to all our buddies who are a great credit to our mission of patients supporting patients.

b) West Lothian meetings

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

"It has been a very busy year as normal, however, much of the time was taken up by our support for a campaign to stop the local council from closing the Ability Centre where we hold our meetings. After a local paper campaign plus STV coverage we were successful in stopping the proposal. The meetings we hold continue to have good numbers with 65 being the average attendance. The new members continue to attend to gain support from our successful buddy programme. We had eight new members at our last May meeting.

We received substantial donations this last financial year of £6225. This was a remarkable spell of some large unexpected donations. We decided we needed to do something different and in agreement with our members we donated £2000 to Prostate UK to support prostate cancer research in Scotland. We continue to reach out with our publicity material to all types of organisations in West Lothian about our buddy programme and are involved in briefing MacMillan volunteers based in the Partnership Centres throughout West Lothian about the role of our support group. The contact with our members regarding the new GDPR regulations has resulted in a 98% yes return of our 90 members."

c) External activities

RL reported that the past 12 months have been eventful thanks to increased media interest in prostate cancer. This has been due to the publication of significant research information throughout the year which included such news as the improvement in biopsy techniques with the use of MRI scans (MRI targeted biopsies), the increased knowledge of the genetics involved in prostate cancer with blood tests that can tell much more about how the tumour is behaving (liquid biopsy) and renewed

interest in ultrasound scanning as way of differentiating aggressive cancer from more stable forms. Also there was much press interest in celebrities who have gone public on their diagnosis and treatment of prostate cancer including the actor Stephen Fry and the broadcaster Bill Turnbull.

Perhaps the news that created most public attention was the publication of UK cancer mortality statistics in February 2018, showing that there were more deaths from prostate cancer than breast cancer.

The Prime Minister then announced in April 2018 that a government fund of £75 million would be made available for research on prostate cancer.

Finally we continue our close association with Prostate Scotland and congratulate them on winning the 'Health Charity of the Year Award' for 2017.

d) Administration

AF reported on membership and administration of the group over 2017/18 which he said had been a challenging year.

The first challenge was the collapse of our well-used website in summer 2017 which hastened the development of a new website - this was launched in October 2017 and we hope you are all now familiar with it. (just Google "Edinburgh Prostate Support"). Our new website is now usable from mobile phone or tablet as well as desktop computer or laptop, and users can find lots of information about our meetings both here and in West Lothian, about local and national developments in prostate cancer treatment, breaking news from the press about prostate cancer, photos of some of our activities (e.g. the walking group) upcoming events of interest and links to reputable and reliable sources of support. Plus of course information about our Buddy programme.

The second of our major challenges in 2017/18 was GDPR (General Data Protection Regulation). GDPR required us to contact all the people on our mailing list to ensure they still wanted to hear from us, and this I did. We knew we would lose some members, particularly those who have not been in touch with us for many years, but to date we have had 152 positive responses (as of today). This is a very good result and we can now be sure the people on our mailing list do want to hear from us.

In both of these projects – website and GDPR – the group received enormous support from Lesley Duncan – a work colleague of committee member Iain More so thanks to Iain introducing us. Thanks also to David Milner (unable to be here tonight) for efficiently taking the minutes of all our meetings.

IH asked for a proposer and seconder to accept the above reports – proposer: Iain Annand, seconder Frank Letham.

5. Financial Report

Jim Woodhead (JW), our Treasurer, prepared a written report of the Group's accounts for the year 1st April 2017 to 31st March 2018. Donations of £7,759.38 over the year were received, with expenses for both Groups totaling £11,933.55. Excess receipts and payments amounted to minus £2573.72. The opening year bank balance was £13,534.95 and the closing year bank balance was £10,961.23, so the finances of the group remain healthy (although not as healthy as last year – the main reasons being expenditure associated with the Murrayfield event and increased donations. Acceptance of the accounts was proposed by David Patterson and seconded by Bob Scott. 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 Ross Swinton and seconded by Bill Platts.

6. Election of Chairman

Ian Hay has agreed to continue to act as Chairman of the Group. His continuing role was proposed by Derek Howie and seconded by Bob Geddes.

7. Election of Committee Members.

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

Ian Hay

Charlie Hogg

Mike Shaw

Jim Woodhead

Roddy Maclean

Iain More

Alasdair Ferguson

Support for all these names was proposed by Des Brogan and seconded by Robin Carmichael, and approved by the members.

As previously intimated, Rob Lester has decided to step down. Iain Annand and Ian Manderson have agreed to join the committee. This was put to the group and proposed by Bob Scott and seconded by Ian Gilroy.

8. Election of Trustees

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

Ian Hay

Charlie Hogg

Mike Shaw

Rob Lester

Jim Woodhead

Alasdair Ferguson

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

9. ELPCSG Patron

It has been felt for some time that it would be beneficial to the group to have a patron, the main criteria for a patron would be:

- A non-member acceptable to both Edinburgh & West Lothian Groups
- Someone who is a respected member of the community, may be a well-regarded medical or scientific professional, and who will give our group added credibility
- Someone who is genuinely interested in prostate cancer, and will promote our charity
- Someone happy to be invited to attend our Annual General Meeting, and to participate in or lead other major events as appropriate

IH indicated that Dr Anna Campbell of Edinburgh Napier University had agreed to take on this role, and this proposal met with unanimous approval from the members (Dr Campbell was our speaker prior to AGM)

10. Any Other Competent Business.

Finally Ian Hogarth proposed thanks on behalf of the members to the Chair, Ian Hay and to other members of the committee.

There being no other business the meeting was concluded at 20.45.

Alasdair Ferguson

(standing in for David Milner, Minute Secretary)