

Edinburgh and Lothian Prostate Cancer Support Group

Minutes of Annual General Meeting held on 8th June 2023 at Maggie's Centre, Edinburgh.

The Chairman noted that a quorum of members was in attendance at the meeting.

1. Apologies

Apologies were received from Ken Howey and David Milner.

2. Minutes of last AGM

The minutes for the AGM held on 9th June 2022 were circulated to members and were proposed by Ian Hay and seconded by Richard Kerr. On a show of hands the minutes of the AGM held on 9th June 2022 were approved.

3. Reports

a. *Chairman's Report*

Iain Annand reported that overall 2022/23 has been a year of consolidation for the group after the effects of Covid. However it is encouraging to see the West Lothian group under leader Charlie Hogg going from strength to strength with their members meetings and profile in the West Lothian Area. The Edinburgh, East and Midlothian Group have found it more challenging attracting members back to face-to-face meetings and this is something the committee is addressing.

Warm thanks were given to Andy Anderson and Lisa Egan at Maggie's for all the assistance given the Group throughout the last year.

Iain reported that this has been his third year as Group Chairman and he has been fortunate to have been given outstanding support from the hardworking and dedicated Committee Members from both West Lothian and Edinburgh, East and Midlothian and he passed on his thanks to them.

b. *West Lothian Report*

The West Lothian report was written by Charlie Hogg and presented by Tom Lambie.

It has been a busy year with our 'Prostate Cancer Awareness Campaign' where we put up local adverts and expanded our poster display in all Surgeries and Council facilities in West Lothian and had articles in our local publications. Alongside the national March UK campaign on 'Prostate Cancer Awareness' we had a very successful stand outside the ASDA Store at the Livingston Shopping Centre where our team and some of our members helped speak to many men & women about this issue and handed out around 300 leaflets on Prostate Cancer PSA testing and the Group Buddy Scheme. We received good coverage in the local Courier newspaper and in a West Lothian GP Surgery Newsletter which is distributed to 211 Surgeries in the area. We also will have an article in the June Council Bulletin Magazine that goes into every household in the area. We highlighted the need to get tested early as Scotland has the worst record in the UK for men receiving their first diagnosis being advanced cancer with a rate of 35% and with 1 in 6 men expected to get Prostate Cancer the work of the Support Group with its excellent Buddy Programme will be more and more needed. All other local Support Groups in the area were made fully aware of our campaign and promised to provide information about our Support Group to individuals using their services.

We recently were asked to give a talk on Prostate Cancer to 4 local Cyrenian Groups in West Lothian and about the help & support provided by our Support Group. From these we identified potential future sources for giving talks to women's groups in West

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Lothian which we see as a potential aid to help get the message around about men needing to get tested earlier.

Our Support Group meetings in West Lothian continue to be well attended with a good mixture of men & women and we have had a good regular intake of new members throughout the year who have benefited from the excellent 'Buddy Scheme'.

c. *Edinburgh Report*

The Edinburgh report was presented by Iain Annand. He reported that whilst it has been a relatively quiet period for the Edinburgh group member meetings have returned to Maggie's. Five meetings were held with an interesting range of speakers including: Dr Rishi Ramaesh discussing the current trial of PET Scans and the advantages in the future of such scans, Dave Clarke who gave an extremely interesting talk on the Mesopotamia campaign during the First World War, Professor Alan McNeill speaking about the development of robotic surgery, our own Rob Lester who gave a talk on his experience with the Stampede trial and two lawyers from Gillespie Macandrew talking about Powers of Attorney and Wills. All the speakers were well received and we are grateful for their time in presenting to members. Members meetings this year also saw a resumption of members giving their own story of their journey with prostate cancer and thanks were given to those who have shared their experience. Attendance at the meetings ranged between 20-30 out of a membership of 186. The committee are making efforts to expand awareness of the member meetings with the hope that attendance numbers will increase. We were again invited by John Lewis Department store at the St. James Quarter to host a stand in March to raise awareness of the Group and thanks were given to Morton Cowie and Graham Marchbank for volunteering to help with the stand. This has led to positive meeting with the management of the St James Quarter with a view of having an awareness stand within the Centre itself in the near future. We are also looking at other such events and will be asking for volunteers to help us man these stands.

Buddy Report - The Buddy report for Edinburgh was presented by Ian Manderson. He reported that in the last year:

- we have supported 25 men who have been diagnosed with prostate Cancer;
- we are dealing with more complex diagnoses;
- we trained a further 6 buddies in February at Maggie's supported by Andy Anderson.

Ian reported that there are now a total of 28 active buddies and he expressed gratitude to all the buddies for providing invaluable insight and hope to men starting their prostate cancer journey which is a trip into the unknown and frightening. Having a friendly voice and being able to hear of your experiences is very reassuring. It is observed that we are short of men who have had EBRT+HT, Brachytherapy+HT and the Brachy/EBRT combination as this combined treatment has produced good results in trials and is being offered to suitable men. It was noted 25 men were supported by the service in the past year and 6 new buddies have been trained.

Walking Group Report - David Milner reported that the walking group has continued to prosper, with a steady rise in new members joining. A variety of walks have been undertaken over the past year each one planned and led by a different member. The

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leaders were thanked for generously devoting their time to devise, plan and lead the walks. Without them, a very valuable resource that the Support Group has to offer its members would simply collapse. Iain Sime was thanked for his continued support of the walking group, after first initiating it in October 2013. For the first 5 years of the walking group's life, Iain devised and led all of the walks, and thanks to his inspiration the walks have continued successfully since then, apart from an 18-month hiatus in 2020-21 due to the pandemic. The walking group is looking forward to its 10th anniversary in October 2023 in a healthy state and with some optimism for the future.

d. Administration

Membership currently stands at 186. The year has again seen us sifting through a number of requests from external bodies looking for participants from our membership to take part in various surveys and members of the Committee have also attended and spoken to an Older Men's Health and Wellbeing group organised by Pilmeny Development Projects in Leith and also a similar health awareness group at Edinburgh College. We have also dealt with requests from Health Bodies seeking input into drugs approval. One of which was the Groups submission to the National Cancer Medicines Advisory Group for the off-label use of Abiraterone for men with high-risk prostate cancer. Whilst our report was well received it was deemed that the drug too expensive, however since the initial submission Abiraterone has now been approved. As in past years the Committee have given priority to circulating those requests associated with our close partners Prostate Scotland, Prostate UK, and Maggie's.

e. External

It was noted the website continues to be managed by Colin Lothian and is updated on a regular basis. Colin was thanked for his considerable efforts in maintaining the website.

4. Financial Report

The Financial Report was presented by Richard Kerr and he was thanked for taking over the role from Jim Woodhead.

Richard reported that for the year ended 31 March 2023 income was £2,394 and expenditure was £4,741 resulting in a deficit for the year of £2,347. The cash balance as at 31 March 2023 was £23,810.

Ian Hay asked whether attention was being given to the cumulative deficit over the past 2 years. Richard Kerr confirmed that the committee are looking at new sources of funds to cover operational costs.

The Annual Accounts were proposed by Gary Tait and seconded by Ian Manderson. On a show of hands the Annual Accounts for the year ended 31 March 2023 were approved.

5. New Group Constitution

Gary Tait presented the rationale for preparing a new constitution for the group including the need to ensure the constitution reflects both "best practice" and the area branch structure. He confirmed there would be no change to the operating function of the group nor the purposes and aims of the group. The new constitution sets out the structure of the group (Members, Group Management Committee, Area Management Committees), option

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to hold meetings via audio or audio-video conferencing and the obligations of Area Branches Committees.

Ian Hay asked why the new constitution did not expressly refer to the Buddies service and Gary Tait replied by confirming that as the Management Committee would have the authority to "carry on activities which further its purposes and aims" then there was no requirement to specify activities in the constitution.

The resolution to approve the new constitution was proposed by Ian Hay and seconded by Keith Dempster. On a show of hands the new constitution was approved. The Secretary was requested to submit the new constitution to OSCR.

6. Election of Chairman

In the absence of any other nominations Iain Annand confirmed his willingness to stand as Chairman for a further year. The resolution to elect Iain Annand as Chairman was proposed by Richard Kerr and seconded by Bob Scott. On a show of hands the resolution to elect Iain Annand as Chairman was approved.

7. Election of Committee Members

It was noted the current committee of Charlie Hogg, Tom Lambie, Ken Howey, Ian Manderson, Richard Kerr, Gary Tait and Keith Dempster are all prepared to stand again as Committee members for next year. The resolution to elect each of these individuals as committee members was proposed by David Patterson and seconded by Bob Scott. On a show of hands the resolution to elect Charlie Hogg, Tom Lambie, Ken Howey, Ian Manderson, Richard Kerr, Gary Tait and Keith Dempster as committee members was approved.

8. Election of Trustees

It was noted the current Trustees are Iain Annand, Charlie Hogg, Jim Woodhead, Ken Howey and Richard Kerr. Jim Woodhead has indicated that he wishes to stand down but Iain Annand, Charlie Hogg, Ken Howey and Richard Kerr have expressed their willingness to continue in the role. The resolution to approve Iain Annand, Charlie Hogg, Ken Howey and Richard Kerr as trustees was proposed by Gary Tait and seconded by Ian Hay. On a show of hands the resolution was approved.

With the resignation of Jim Woodhead both Tom Lambie and Ian Manderson agreed to stand as a Trustee. The resolution to approve Tom Lambie and Ian Manderson as trustees was proposed by Ian Hay and seconded by David Patterson. On a show of hands the resolution was approved.

9. AOCB

Ian Hay thanked the committee for their continued service and suggested they consider the 2024 AGM is held in West Lothian to coincide with a West Lothian meeting. Iain Annand confirmed the committee would consider this proposal.

As there was no further business the meeting was closed.