

Agenda Item 2: Review of 2014 AGM

**The Minutes of the 8th AGM
of the Prostate Cancer Support Federation (Tackle Prostate Cancer)
held at the Twickenham Stadium, Twickenham, TW2 7BA on 12th June 2014**

1 Roll Call

The following member organisations were represented by the delegates shown:

Aylesbury Vale PCSG	Brian Cole
APPLE	John Burton
Cambridge PCSG	Don Gibbs
Chilterns PCSG	Andrew Scott-Priestley
Coping with Cancer	Erick Holloway
Cornwall PCSG	George Allen
East Suffolk PCSG	Ted Friend
Greater London PCSG	Colin Frith
Haywards Heath and District PCSG	David Barwell
Leighton PCSG	Gary Steele
Norfolk & Waveney PCSG	Noel Warner
Oxfordshire PCSG	George Goldsmith
PCaSO	Roger Bacon
PCaSO Dorset	Allan Higgin
PHASE	David Bell
PROSTaid	Colin Derrick
Cardiff PCSG & The Red Sock Campaign	Keith Cass MBE
Prostate Cancer Support, Kent	Brian Murphy
Purley Prostate Support Group	Terry Garrigan
Reading PCSG	Carmel Howard
Somerset PSA	Brian Smart
Teesside PCSG	Robin Millman
Woking PCSG	Ray Foreman

Apologies were received from David Bell of Phase and Dave Beesley of OPCSG. Dave Beesley was represented by George Goldsmith of the OPCSG.

2 Review of 2013 AGM and Actions

The approval of the minutes of the previous meeting was proposed by Hugh Gunn and seconded by David Smith and carried by the meeting.

The Chairman reported on our achievements since the last AGM as follows:

Early detection campaign

Objectives:

- to get the Dept of Health to institute an awareness programme that encourages men to know their PSA;
- to raise awareness of prostate cancer;
- to raise awareness of Tackle as the only legitimate voice of prostate cancer patients.

Possible activities:

- Update the Real PCRMP
- Nationwide publicity campaign pushing benefits of knowing your PSA
- Dept of Health lobbying – e.g. for adoption of the Melbourne Consensus
- Accelerate Riskman
- GP education campaign to encourage more widespread testing
- Major expansion of the GFCT awareness and PSA testing days, directly supported by Tackle

- Development and operation of one or more full mobile testing units (á la Man Van)

3 Officers' Reports

Chairman's Report, Sandy Tyndale-Biscoe

The Chairman talked about the development of the Tackle brand which had resulted in increased press coverage and improved recognition of the charity as the patients' voice. He also reported that we had an updated and improved website, providing better support to patients. He informed delegates that we had been instrumental in Frank Chinegwundoh being elected as co-chair of the Department of Health's Prostate Cancer Advisory Group. He talked about the charity's role in campaigning, including battles with NICE. Finally he informed the delegates that he would be stepping down from the role of Chairman at the next AGM. The Chairman expressed his gratitude to all those who had contributed to the work of the Charity over the last year and thanked PCUK for sponsoring the conference.

Treasurer's Report, Hugh Gunn

The Treasurer reported that funds received during 2013 were £89k Restricted and £5k Unrestricted, resulting in a total income of nearly £95k which with £38k worth of Gifts in Kind, brought the total received to £133k. Total Expenditure was £105k.

4 Chief Executive's Report, Rowena Bartlett

The Chief Executive reported that in the previous year our members had told us that the priorities for them were:

- Early Detection
- Educating Clinicians
- Supporting Support Groups

She informed the delegates that during 2013/14 we had done the following things as steps towards achieving those aims:

- Established a Clinical Advisory Board
- Established a Regional Structure of Groups
- Sat on the Prostate Cancer Advisory Group
- Sat on the Cancer Campaigning Group
- Campaigned on Enzalutamide, Radium 223, Degarelix
- Worked with other agencies to improve things for patients and their families
- Produced three new leaflets for Groups
- Launched a new website and set up Social Media
- Achieved celebrity endorsement
- Raised funds

She promised that during 2014 we would build on this to:

- Raise awareness of the issues that face patients and get things changed
- Raise awareness of the importance of early detection and get more men tested
- Work with Groups to have a stronger voice
- Produce more leaflets for Groups
- Help Groups with setting up their own websites
- Help Groups to get preferential rates for insurance and other things they need
- Raise more money to do all these things

5 Elections

Hon Chairman

Ken Mastris took the Chair for the election of the Chairman

The Election of Sandy Tyndale-Biscoe as Chairman was proposed by Ken Mastris and he was duly elected.

Hon Secretary

The Election of David Smith as Secretary was proposed by Ken Mastris and he was duly elected.

Hon Treasurer

The Election of Hugh Gunn as Treasurer was proposed by Ken Mastris and he was duly elected.

The following candidates stood for election as Trustees:

Roger Wotton
Rob Banner
Frank Chinegwundoh
Ken Mastris
Gary Steele
Allan Higgin

The following were elected as Trustees:

Rob Banner
Frank Chinegwundoh
Ken Mastris
Roger Wotton

6 Ratification of Appointed Trustee

The ratification of the appointment of Erik Friis-Scheel to the Board of Trustees in the position of Finance Director for a period of three years was proposed by Brian Smart and seconded by Andrew Scott-Priestley and was carried by the meeting.

7 Amendments to the Constitution

The following amendments were proposed by George Allan and seconded by Roger Bacon and was carried by the meeting.

Summary of substantive changes

1. Clause 5(1): deletion of the words struck out below:
(1) Power to raise funds and to invite and receive contributions provided that in raising funds the Trustees ~~shall not undertake any substantial permanent trading activities~~ and shall conform to any relevant requirements of the law.
2. Clause 10: inclusion of the following new term:
(10) The role of an Officer or Trustee is both voluntary and unpaid. Travel expenses will be reimbursed; standard class public transport at cost, car travel at 40p/mile, use of taxis to be authorised by CEO, Chairman or Treasurer. There is no per diem or reimbursement for meals. Lunches will be provided for Board Meetings.
3. Clause 13: inclusion of the following new term:
(5) Matters agreed under voting arrangements specified under Paragraph (13) (4) shall become the collective responsibility of all Trustees, whether present at the meeting or not. Trustees wishing to publicly express contrary views may only do so with the prior agreement of the Chairman.

8 Any Other Business

There was no other business

9 Reports from Regional Co-ordinators

Regionalisation

Roger Wotton talked about the aims and benefits of regionalization as follows:

Aims

- To improve communication across the Federation, in particular to achieve better linkage between the grass roots and the top table of the organisation
- To support the Federation as "The voice of prostate cancer patients and their families"
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Benefits

- For the Federation, this will improve governance through a strong regional voice and a sharper focus on campaign management
- For support groups, this will allow for better networking opportunities, a degree of resource sharing and the identification and promotion of best practice
- For individuals, this will make it easier for their voice be heard and to be better informed.

Roger informed delegates that we had asked our members what the most important issues were for them and they told us:

- Avoiding “Postcode Lottery” in care pathways; understand CCG role in primary care
- More help for those with advanced disease; improved support and better conversations
- Attracting newly diagnosed men to existing groups; Setting up new groups in target areas
- PSA testing; help with local events; choosing the best approach; financial support?
- Relationship with PCUK; who does what; the bigger picture, including Macmillan
- Need to improve awareness by GPs as first contact; better publicity at point of delivery
- Avoiding “Postcode Lottery” in care pathways; understand CCG role in primary care
- More help for those with advanced disease; improved support and better conversations
- Attracting newly diagnosed men to existing groups; Setting up new groups in target areas
- PSA testing; help with local events; choosing the best approach; financial support?
- Relationship with PCUK; who does what; the bigger picture, including Macmillan

Roger told them that the next steps would be for us to:

- Identify “best practice” in raising GP awareness from existing support groups; assemble briefing pack for general use
- Draft a note to all CCGs outlining the importance of linking with local support groups and the need to understand how choices are made for PC pathways; Work with PCUK
- Maintain an action programme for other priority challenges raised by Regions

PLUS:

- Offer a simple website template and hosting solution for all groups wishing to have a web presence; level of interest?
- Improve our existing communication to avoid similar messages coming from multiple sources; be clear about who is getting what
- Plan for a series of Regionally based meetings, building on where these already exist; develop executive role of RFPs as a governance improvement

Roger showed a chart showing how Prostate Cancer UK and Tackle work together, explaining that there was room for both charities.

10. Open Forum

This was a session for members to air their views and issues during which the following subjects were discussed:

- Heads you win – tails we lose – dealing with NICE
- How is the NICE guidance on Enzalutamide being interpreted by commissioners and what should we do about it?
- Other campaigning for advanced PCa sufferers
- GP education
- NICE Quality Standard development
- Tweets for Fathering Sunday

11 Close

The Chairman closed the Meeting by thanking the delegates.