

**Minutes of the Annual General Meeting the Prostate Cancer
Support Federation held at Staffordshire University, Stoke-on-
Trent Campus on 25th April 2009**

1. Roll Call

The following Member Organisations were represented by the Delegates shown:

Cancer Support Dudley: Peter Allen
Chilterns Prostate Cancer Support Group: Mike Basnett
PCaSO: Mike Hollingworth
PCS : Pauline Bowden
PCS Bolton: Norman Lomas
PCS Leighton: Janet Addenbrooke
PCS North Staffs: Clive Stevenson
PCS Oldham: Robert Healey
PCS Wirral & North Cheshire: Lance Yates
PCSA Central England: Brian Atkins
Prospect: Prostate Cancer Support Group (Bristol): Richard Firth
Prostaid: Hugh Gunn
Prostate Cancer Support Group, City & Sandwell: Bob Tidmarsh
Prostate Cancer Support Group, Kidderminster: David Baxter-Smith
PSA: Alan Ashmole
Reading Prostate Cancer Support Group: Roger Bennett
Shropshire Prostate Cancer Support Group: John Sugden
Somerset Prostate Support Association: Brian Smart
South East Cancer Help Centre: Terry Garrigan

2. Chairman's report

John Dwyer, the Chairman of the Prostate Cancer Support Federation, gave his report. He felt that the Federation had had a good first year. The Promoting Patients Power workshop in October, kindly sponsored by the Graham Fulford Charitable Trust, was a successful example of what the Federation could do.

He described our involvement in other Advocacy areas, particularly with commenting on the NICE Guideline, and the Revision of the PCRMP. The latter did not go well, but has stimulated the Federation, with the support of Prostate UK, to produce our own single page leaflet, "The Real PCRMP" and he encouraged all Member Organisations to distribute this to their local GPs.

He went on to discuss the importance of the Federation being closely in touch with progress and direction of Research. He argued strongly for the prioritisation of translational research into predictive modelling; making use of existing markers and nomograms, to estimate the probability of a patient having prostate cancer and the outcome of treatments. The presentation on the James Lind Alliance Priority Setting Partnership illustrated the problem well. The Federation has representatives on NCRI committees so we are well in touch.

The Federation provides two main resources to its Member Organisations: the web site and the Help Line. The latter is being transferred from PSA operation to the Federation office in Manchester. This will be managed by the PCS Administrator Darrell Baguley from our office at Stockport in the future. Alan Ashmole will continue to send out packs of information to callers, but this will be rebranded as Federation material and local contact details will be included as well as the Information Booklet *Knowledge Empowers*, which is a Federation Badged version of the PCaSO booklet of the same name.

The Chairman then went on to discuss our very important liaison with prostate cancer patients across Europe through Europa Uomo, where we are represented by Mike Lockett. Our aim is to show that cancer patients are speaking with one voice across Europe, to make sure the fight against cancer will remain high on the EU's and our individual country's agenda after the elections.

He finished his report by thanking Prostate UK for sponsoring the 2009 Annual Conference and providing funding for the Prostate UK Grants. He also thanked Graham Fulford for sponsoring the Promoting Patients' Power workshop in October. Finally, he thanked the outgoing members of the committee for their hard work over nearly 5 years to get the Federation running.

3. Treasurer's report

Hugh Gunn, Hon Treasurer of the Prostate Cancer Support Federation gave his report. The Charity started the year with £5,250 in the bank and ended it with £6,257. Excluding Prostate UK Grants, which are cash neutral, the following are the significant income items:

| | |
|------------------|--------|
| Affiliation Fees | £1,296 |
| Donations | £54 |
| Ferring | £465 |
| PCS | £3,500 |
| GFCT | £500 |

Again, excluding Prostate UK Grants, the following are the significant expenditure items:

| | |
|--|--------|
| Committee Expense | £1,636 |
| Printing (Prostate Matters, Inof sheets) | £2,227 |
| Tele Conference | £283 |
| National voices | £25 |
| University of London Union | £480 |
| Accountancy Fees | £571 |

These figures suggest an overall surplus of £1,007, which would be encouraging, but they do not tell the whole tale, and in reality the Federation is reliant on a number of significant grants from individual organisations which cannot be expected to be repeated reluctant.

There was then a discussion about membership fees. It was proposed that a membership fee amounting to £100, or £1 for each member that a Member Organisation has, whichever is the lower, would be levied. This was put to a vote of Delegates, and with one abstention and none opposing, duly passed.

4. Secretary's report

Sandy Tyndale-Biscoe, Hon Secretary of the Prostate Cancer Support Federation, gave his report. Membership was now 40 Patient-led Member Organisations, an increase of 5 over the past year. The Federation has 3 Organisation Members, a reduction of 1 over the year, represented by 1 new member the Prostate Cancer Research Foundation, and 2 resignations: The Prostate Cancer Charity and Macmillan Cancer Support. These resignations were triggered by the advocacy stance being taken by the Federation on PSA Testing.

He reported that the Prostate UK Grants had been well supported, the full amount of £2,500 had been shared between 12 Member Organisations as shown in the following chart:

| | | |
|---|---|------|
| West Wales P Ca Support Group | Running 2 awareness events | £250 |
| Chilterns P Ca Support Group | Design & printing of info leaflets | £250 |
| SE Cancer Help Ctre | Help with meeting costs | £250 |
| PROSPECT | Update of Web site | £250 |
| PCaSO Dorset | Postage of newsletters etc. | |
| Prostate Project (Guildford & Frimley Park) | Production of leaflet | £150 |
| Prostaid | Roll-up banners | £250 |
| PCSA CE | PSA Testing evening | £250 |
| The Prostate Cancer Support Group - Northern Region | Meeting running costs | £250 |
| PDA Campaigners | For presentation software to produce awareness material | £250 |
| Prostate Cancer Support Group, Reading | PC and Beamer | £100 |
| PCS Oldham Branch | Leaflets | £250 |

5. Elections:

a. Chairman

Sandy Tyndale-Biscoe was elected as Hon Chairman

b. Officers: Secretary and Treasurer

Mike Lockett was elected as Secretary

Hugh Gunn was elected as Treasurer.

c. Trustees

The following were elected as Trustees:

Keith Hobby – PCS
John Dwyer – PCS
David Smith – PCaSO
Roger Bacon – PCaSO
Graham Fulford – GFCT
Rob Banner – Prostaid

d. National representatives

The following volunteered to fill the posts indicated:

European Representative - Mike Lockett
Medical Advisor - David Baxter-Smith
Newsletter Editor - Roger Bacon
Grants Secretary - Sandy Tyndale-Biscoe
Fund Raising/Sponsorship - Rob Banner
Website maintenance - Sandy Tyndale-Biscoe
Helpline coordinator - John Coleman
Development/Recruitment - Graham Fulford
Membership secretary - Alan Ashmole
Representatives on National groups: NCRI; PCAG; PCCA; NICE - David Smith/ John Dwyer
Political Liaison - Tom Stuttaford
Education/Research coordinator - John Dwyer

6. Amendments to the Constitution

The incoming Chairman introduced a revised version of the Constitution. The main thrust of the changes were:

1. To change the name clause to refer to “The name of the Charity” rather than “The name of the Association”. This requires Charity Commission approval which has been sought.
2. To clarify membership. The word “member”, where it refers to an organisation that is a patient-led organisation that is a member of the Federation, has been replaced by the term “Member Organisation”, and the grammar changed where necessary.
3. Remove the distinction between member organisations that are registered charities and those that aren't.
4. Clarify and simplify rules for Delegates.

After a brief discussion it was proposed by Mike Lockett, seconded by David Smith that the new Constitution be adopted. This was passed on a show of hands with none opposing.

7. Any other business

The Chairman informed the meeting that the 2010 AGM would be held on 24th April 2010, at the Penny Brohn Centre in Bristol. The meeting closed with a vote of thanks to Prostate UK for sponsoring the Conference.