

**Minutes of the Annual General Meeting the Prostate Cancer  
Support Federation held at Staffordshire University, Stoke-on-  
Trent Campus on 25<sup>th</sup> 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 24<sup>th</sup> April 2010, at the Penny Brohn Centre in Bristol. The meeting closed with a vote of thanks to Prostate UK for sponsoring the Conference.