

## **Federation Holds Successful Workshop – *Promoting Patient Power***

Thanks to the generosity of the Graham Fulford Charitable Trust, a very successful workshop, entitled “Promoting Patient Power” was held in Leamington Spa on 16<sup>th</sup> October, 2008. It was attended by over 40 people, representing 21 member organisations.

The day was introduced by John Dwyer, Chairman of the Federation, and by our sponsor, Graham Fulford. They reviewed the history of the Federation and explained that the purpose of the workshop, which was to build on the very positive response to the Inaugural Conference in April, and moving the Federation forward.

The programme had two themes. One was to encourage discussion amongst delegates to progress ideas about what the Federation should seek to do, and how it should be organised and funded to achieve its aims. The other, in order to attract delegates, was a set of presentations on hot topics including PSA Testing and prostate cancer research priorities.

### **Way ahead workshop**

Federation Secretary Sandy Tyndale-Biscoe opened the session and explained the process for the interactive workshop, in which delegates were divided up into groups and given 45 minutes to discuss any aspects of the Federation’s structure, aims or modus operandi and then come up with a prioritised list of five key issues that should be taken forward by the Federation’s Trustees.

At the plenary session following the various *rapporteurs* presented an unstructured list of the topics and issues. This can be broken down into the following broad areas:

- **Awareness, early detection and reduction in death-rate:** raise awareness of prostate cancer with both the public and the profession; seek equality with breast cancer awareness; run a campaign – leaflets/ information, books/ posters; encourage early detection, education of GPs, promoting new tests, e.g. PCA3, and research leading to screening; influencing research directions for treatments; campaigning for access to new drugs; influencing patient pathways as developed by Networks and PCTs; monitoring implementation of the NICE Guideline.
- **PCSF public profile and recruitment:** raise the presence/ profile of the Federation; improve the website; maintain a register of supporting professionals; encourage collective power; run a major event in London/ Parliament; advertise membership benefits; look for early success; find a high profile patron.
- **PCSF management:** get the funding onto a firm footing – budget activities, identify funders; capturing new patients / increase membership; establish professional relationships with organisations.

- **Services to members:** publicise information on available clinical trials; prepare handbook for forming groups; personal experience survey; buddy scheme; study and advise on impact on families.

The list above will be taken as a guide by the Federation Trustees in planning the future directions of the Federation.

## **Afternoon Session**

After lunch delegates were treated to two presentations on prostate cancer issues.

In the first, Mr David Baxter-Smith, Consultant Urologist from Kidderminster, gave a fascinating and informative presentation on how, supported by the Graham Fulford Charitable Trust, he has conducted a series of increasingly popular PSA Testing sessions throughout the country. He first explained why, despite the controversy over the test and its shortcomings, it is his firm belief that, used intelligently, the PSA Test is the only way to identify prostate cancer at a stage where it can reliably be expected to be cured. He went on to describe the process by which the sessions were set up. To ensure that there is proper follow-up of results he writes to all men tested, giving the results and explaining what should happen next. Such letters are colour coded: green, amber and red. In the case of red letters, where a suspicious PSA level has been found, Mr Baxter-Smith recommends the man consults his GP urgently, but also gives his own contact details so that the man can discuss the implications of the findings.

In all, in these sessions, 6,788 men have been tested, 426 red letters issued, and 152 cancers found and treated.

The presentation was very well received, and many delegates were interested in setting up their own testing sessions. During questions, Graham Fulford explained how these could be made self-financing.

The final session was entitled “Getting patients’ voices heard in setting priorities for Prostate Cancer Research”. Sandy Tyndale-Biscoe described how, after a request from the Prostate Cancer Research Foundation (PCRF) for patients to complete a research priorities questionnaire, very little response was achieved, primarily because the questionnaire was written with researchers in mind, and too detailed for a “consumer” to assess. He had prepared an alternative “Top Ten Questions in Prostate Cancer” questionnaire, which has produced good response, and a picture is beginning to emerge of what patients feel are the big issues. An exercise is now under way, with the PCRF, to get a consensus view on priorities for research. This should complete some time later this year.

The Workshop closed with thanks to Graham Fulford for generously sponsoring it. It was generally agreed to have been a most enjoyable and informative occasion, and to have progressed development of the Federation.