

Inaugural Conference Prostate Cancer Support Federation 28th April 2008

The Inaugural Conference of the Prostate Cancer Support Federation (the Federation) was held at Imperial College, London on 28th April 2008. It was attended by approximately 55 representatives of 24 patient-led support organisations.

The conference was opened by John Dwyer, Chairman of the Federation, and Professor Mustafa Djamgoz, Professor of Cancer Biology, Neuroscience Solutions to Cancer Research Group, at the Imperial College, London who were hosting the conference.

John Dwyer briefly outlined the background to formation of the Federation and explained the purpose of the conference which was to broaden the membership and establish a *modus operandi* for the Federation to act as a voice for all prostate cancer patients across the UK. Mustafa Djamgoz then explained his department's interest in prostate cancer and why they were supporting this conference.

Morning Session

The first speaker of the morning was **(Brig) John Anderson**, Chief Executive of Prostate UK, the sponsors of the conference. He emphasised the strength of groups 'coming together' and he explained that Prostate UK not only promote awareness of prostate diseases through a range of leaflets, but give money for research, pay for medical training and fund seminars to educate GPs and nurses in all matters relating to the prostate. He felt support groups play an important role in helping newly diagnosed men come to terms with a diagnosis and because of this, Prostate UK are offering grants to support groups who are members of the Federation, and have a particular expense that needs funding.

The second speaker was **Dr Chris Parker** from the Institute of Cancer Research, Royal Marsden Hospital, whose talk was entitled **Advanced prostate cancer: recent developments and future prospects**. He kicked off with a discussion about the most appropriate terminology to be used for that stage of the disease commonly referred to as "hormone refractory prostate cancer", which is not an accurate term for a complicated situation which may be amenable to a number of hormone related treatments. He suspected that a more accurate term might be "castration independent" disease; it was made clear by the audience that this would not be a popular term with patients.

He stressed the importance of the 'multi- disciplinary team' meetings that now take place to discuss the care and treatment options available to patients. This *team* approach is of great benefit.

He went on to discuss the treatment of *advanced disease* and some of the newer drugs coming through the trials system – *Dexamethasone*, a steroid, has been given to men whose PSA has started to rise after the standard treatment with Zoladex and Casodex has failed, and some have experienced dramatic improvements using this drug.

Two chemotherapy drugs, *Docetaxel* and *Mitoxantrone* are now in more common use. The former has been shown to improve quality of life even in older patients thought to be 'too old'. An example was shown of an 86 year old who responded well. *Strontium 89* trials, held 15 years ago, have proved the benefits of this treatment; back then it was thought to be

expensive at £1000 a shot, but now that is cheap! and can have dramatic effects on quality of life.

Dr Parker concluded his talk with news about new drugs which will hopefully become recognised as standard treatment for advanced prostate cancer – *Abiraterone* has had good response in trials, most men experiencing a drop in their PSA and bone density improvement. *Alpharadin*, *Radium 223* is showing early evidence that it improves bone marrow and a phase 3 trial is recruiting patients now. These are all entering clinical trials, and one of the problems that he continues to see is difficulty in recruiting men, particularly to randomised trials, where the common belief is that those randomised to the control arm of a trial (i.e. those who do not receive the intervention being trialled) are somehow missing out. He emphasised that in all cases a trial participant who does not receive the drug or procedure under trial will nonetheless still receive the best **proven** treatment. He asked the audience to encourage men to participate in these trials.

The third speaker of the morning, offering a *neuroscience solution*, was **Prof. Mustafa Djamgoz**, Professor of Cancer Biology, Neuroscience Solutions to Cancer Research Group, at the Imperial College, London who reported on his research into gene therapy and his quest to identify at diagnosis whether a disease is indolent or dangerous (the ‘*pussycat or tiger*’ dilemma). He showed a gene map, which immediately identified how difficult the task is when it comes to looking at cells and genes.

A simple equation was shown – *gene > protein > signal > function* and the professor said that if one of these goes wrong it results in disease. His research had been looking at electrical *signalling* to identify cells that show metastatic progression compared to those showing non metastatic. His *gene* research has identified embryonic cancers and in passing observed that it can be seen why salt is very bad for prostate cancer sufferers. He finished his presentation by thanking all the charities and companies involved in the funding of his research, two of which were present, PCaSO and Prostate UK.

Business Session

After lunch the conference got down to the business part of the day with **John Dwyer**, the current Hon Chairman, in the Chair.

Roll Call

A roll call of organisations represented at the meeting was taken (see Annex A). **Sandy Tyndale-Biscoe**, the Acting Hon Secretary, explained that, for the purposes of this inaugural meeting, and pending any decisions about membership fees and other constraints that might deter organisations from joining, the assumption being made was that any eligible organisation present wished to be treated as a member. Representatives of each attending organisation had received copies of the Constitution and Rules, which stated that, as currently implemented, there was no effective distinction between Full Members and Associate Members, and that, in particular, each such member had exactly one Delegate with one Vote. Voting cards had been issued to the nominated Delegate for each member organisation.

Chairman’s Review

The Chairman then reviewed the history of the Federation and outlined the kind of issues that he hoped would be taken up and progressed by the committee. Although the Federation will be run by a *central committee* voted in annually by group votes, it was hoped to form regional

committees made up of representatives from member groups, who could then provide feedback on specific issues and identify targets and direction.

Finance

Mike Lockett, Acting Hon Treasurer, gave an overview of financial issues explaining how money from a fund raising event at Dummer Golf Club, several years ago, had been 'ring-fenced' to provide initial funds for the Federation to be launched. There was now around £5,250 left which will shortly be transferred into a Federation account newly opened following achievement of charity status.

A discussion ensued about membership fees payable by groups, with several options put forward. It was decided to form a sub-group of volunteers to look into and recommend to the main committee the best format for membership. The following volunteered to form this group: Brian Cooley (PCSA Central), Keith Hobby (PCS Cheadle), Philip Barnard (PSA).

Prostate UK Grants

Sandy Tyndale-Biscoe outlined a scheme, to be funded by Prostate UK, whereby Full and Associate Members of the Federation can obtain small grants (of the order of £250), for such purposes as equipment purchase, advertising, web space design and purchase etc. An application form for these grants will be made available on the Federation Web Site (www.prostatecancerfederation.org.uk).

Elections

Election of Trustees, officers and committee then took place. The following were elected as Hon Officers:

Chairman – John Dwyer (Prostate Cancer Support)
Secretary – Sandy Tyndale-Biscoe (PCaSO)
Treasurer – Hugh Gunn (Prostaïd)

The following committee members/trustees were elected:

Brian Atkins (PCSA Central England)
Philip Barnard (PSA)
Jim Stansfeld (PCaSO)
Roger Bacon (PCaSO & Prostate Matters South)
Mike Lockett (Prostate Cancer Support)
Keith Hobby (PCS Cheadle)

Immediate Work Programme

There was a brief discussion on the immediate work programme, which will concentrate on the following:

- establishing a membership register;
- getting the National Help Line up and running;
- development of a Federation Newsletter – Prostate Matters, an evolution from Prostate Matters South, a collaborative newsletter produced by patients groups across the South Coast of England;

- development of a regional structure, based around the catchment areas of the four founder members, viz: PSA: London; PCaSO: South coast; PCSA: Midlands; PCS: North West; to which could be added Wales and the North East.

Details will be worked out by the new committee. There was comment from the floor that the Federation should not become just a talking shop. Action is needed, e.g. on advocacy regarding the lack of any prostate cancer screening programme. The Chairman noted this, and promised that the Federation, under his leadership, will be very active.

Close

There being no further business the Chairman declared the Business part of the conference closed at 3pm.

Afternoon Technical Session

The afternoon technical session commenced with **(Mr) John Anderson**, Consultant Urologist at Sheffield Teaching Hospitals and Secretary of BAUS, the British Association of Urological Surgeons whose talk was entitled **Prostate Cancer Diagnosis – can we do better?**

Statistics show that 70% of diagnosed men are still living after 5 years and early diagnosis allows greater choice of treatments. He asked *What are the problems?* Patients tend to present with urinary symptoms with high anxiety levels due to uncertainty of benign or malignant diagnosis. PSA results can be misleading and it has its limitations, as no symptoms can accompany a high PSA and it does not always identify the need for biopsy, a large number of patients are over-diagnosed. He felt the PSA test could be better used by recording the *velocity and doubling time* by regular tests being made, and relating the readings to *age and prostate volume*.

Education and public awareness is needed. People should be aware of high risk factors such as close relatives with prostate cancer, and African origin. Prevention such as supplements – selenium, Vit C & E, Lycopenes and dietary modification should also be made more aware.

Whereas the PSA test can be used to accurately monitor a cancer's development once identified, the new biomarker PCA3 is useful to those who need further investigation following a negative biopsy, as it is proving more accurate in detecting a dangerous tumour.

The final talk of the day was given by **Prof Louis Denis** a urologist from the University of Antwerp who is secretary of the European Coalition of Prostate Cancer Patients, **Europa Uomo** and also a prostate cancer sufferer. Europa Uomo, which is “a federation of patient led independent not for profit NGOs” was launched 2002-2004 by the European School of Oncology & Oncologic Centre Antwerp. He reviewed the reasoning behind why such an organisation was needed, which in many ways reflects the requirements for and development of the Federation now being launched.

He emphasised the two aspects of Health Care: First, optimal medical treatment which is the responsibility of professional groups, and patients need information and education. Secondly Holistic Patient Centered Care, which is the responsibility of patient organisations, addressing equality and quality of life, and needs advocacy and research.

Europa Uomo stands for three things:

- Development of individualized prostate cancer treatment based on optimal medical treatment and personalized cancer care.

- Reduction in over-treatment in indolent cancer.
- Reduction in under-treatment in lethal disease.

Europa Uomo has a number of projects under way, including the Patients Passport (available to Federation Members) and a book, “*A Woman’s Guide to her Man’s Prostate*”, which will be published shortly.

He said that solving the problem in the senior adult males is a key ambition of Europa Uomo. This involves clear distinction into low risk and high risk prostate cancer, treatment selection on health status and life expectancy, and recognition that effective, palliative chemotherapy is not the end but the beginning where hope is key to the balance of treatment and care.

His final comment related to the emphasis often placed on the connection between prostate cancer and lower urinary tract symptoms (LUTS). Current advice recommends doctors to suspect prostate cancer whenever a patient presents with LUTS. In fact, the evidence suggests that less than 30% of patients presenting with LUTS have prostate cancer. A large proportion of patients with early stage prostate cancer do not have LUTS. Recognition of this fact would transform the PSA debate.

Conference Close

John Dwyer, Hon Chairman of the Federation, closed the meeting by thanking all those who attended, but particularly Prostate UK, who have generously sponsored both the event and the management effort in developing the Federation to its current status, and Prof Mustafa Djamgoz for providing the conference facilities.

Annex A – List of Patient-Led Organisations Represented

The following organisations, considered eligible for full or associate membership, were represented at the Conference and are therefore deemed to have joined the Federation as full or Associate Members (exact categorisation to be determined when Charitable Status is ascertained):

Organisation Name	Catchment Area	Contact	Address	Post Code	Phone	Email	WWW
APPLE (Association of Prostate Patients in London)	London	Sam Chaplain	1 Southwood Gardens, Ilford, Essex	IG2 6YF	0208 550 0600	s.chaplain@btinternet.com	
Bolton PCS Group	Lancashire	Ian Jackson	7 New Court Drive, Edgerton, Bolton, Lancs	BL7 9XA	01204 300454	dorianjackson@btinternet.com	
Cancer Support Dudley	Dudley	Beverley Hart	Cancer Support, The White House, 10 Ednam Road, Dudley, West Mids	DY1 1JX	01384 877895, 01384 231232	info@support4cancer.org.uk, petersallen@btinternet.com	
Cheadle PCS Group	Cheshire	Keith Hobby	“Oaken Gates”, Ladybrook Road, Bramhall, Cheshire	SK7 3NE	0161 486 9288	Keith Hobby c/o Darrell Taylor-Brown <darrell@prostatecancersupport.org>	
Chiltern Prostate Cancer Support Group (CPCSG)	Chilterns	Andrew Scott-Priestley	Fairfield House, High View, Chalfont St Giles, Bucks	HP8 4HH	01494 874722 (H)	andrew@cnconsultancy.com	
Dorset Cancer Network User Involvement Partnership	Dorset	Tracy Street	Victoria House, Princess Road, Ferndown, Dorset	BH22 9JR	01202 850631	tracy.street@ferndown.nhs.uk	
Leighton Hospital Prostate Cancer Support Group	Cheshire	Gary Steele	58 Cherry Crescent, Winsford, Cheshire	CW7 1EE	01606 553097		
Norfolk and Waveney Prostate Cancer Support Group	Norfolk	David Haines	The Corner House, 2 Peacock House, Easton, Norwich	NR9 5JD	01603 881 213	david.haines2@btinternet.com	
North Staffs PCS	North Staffs	Ken Smedley	68 Ravens Lane,	ST7 8PS	01782 722168	kensmedley@hotmail.co.uk	

Organisation Name	Catchment Area	Contact	Address	Post Code	Phone	Email	WWW
Group			Bignall End, Stoke-on-Trent				
PCaSO Dorset Branch	Dorset	Gordon Woodward			01202 892775	<gwoodward@talktalk.net>	
PCaSO Prostate Cancer Network	Central South Coast	Sandy Tyndale-Biscoe	PO Box 66, Emsworth, Hants	PO10 7ZP	0845 650 2555	info@pcaso.com	www.pcaso.com
PCSA Central England	Midlands	Brian Atkins	2 Shelley Gardens, Hinckley, Leicestershire	LE10 1TA		Brian Atkins <brian.atkins@ntlworld.com>	www.psatest.co.uk/
PDA Campaigners	Kent	Paul Grainger	33 Epps Road, Sittingbourne, Kent	ME10 1JD	01795 478199	grainger932@btinternet.com	
PHASE	NE London	Alan Cheetham			01708 229020	alan@thecheethams.co.uk	
Prospect: Prostate Cancer Support Group (Bristol)	Bristol	Malcolm Gamlin	41 Brook Farm Close, Nailsea, Bristol	BS48 4YJ	01275 859419	malcolm.gamlin@talktalk.net	
Prostaid	East Midlands	Rob Banner	17 Torrington Close, Wigston Magna, Leics	LE18 2RY	0116 2888188	rob@wigston.net	www.prostaid.co.uk
Prostate Cancer Support	North West	Mike Lockett	Mansion House Chambers, 22 High Street, Stockport	SK1 1EG		info@prostatecancersupport.org	www.prostatecancersupport.org/
Prostate Cancer support Group Reading	Reading	Roger Bennett	52 Deanfield Road, Henley-on-Thames, Oxon	RG9 1UU	01491 576044	saroban@btinternet.com, vinvivuk@yahoo.co.uk	
Prostate Cancer Support Group, City & Sandwell	Midlands	Heather Wilkins	Sandwell General Hospital, Lyndon, West Bromwich	B71 4HJ	0121 507 3381	Heather.Wilkins@swbh.nhs.uk, Sharon.Leahy@swbh.nhs.uk	
Prostate Cancer Support Scotland	Scotland	John Duncan	Algo Business Centre, Glenearn Road, Perth	PH2 0NJ	01738 450415	supportprostate@tiscali.co.uk, <johnsylvie@btinternet.com>	
PSA	London & South East	Malcolm Perry				info@prostatecancersupport.info	www.prostatecancersupport.co.uk/
South East Cancer Help Centre	South East	Ms Terry Garrigan	112 Higher Drive, Purley, Surrey	CR8 2HL	020 86680974	<info@sehc.org.uk>, <terrygarrigan@hotmail.com>	
South Liverpool Cancer Support	Liverpool	Arthur Jeffrey	107 Elm Hall Drive, Mossley	L18 5HY	0151 7242201		

Organisation Name	Catchment Area	Contact	Address	Post Code	Phone	Email	WWW
Centre - Prostate group			Hill, Liverpool				
The Prostate Cancer Support Group - Somerset	Somerset	Peter Loader	Woodlands, Chaffcombe, Chard, Somerset	TA20 4AP	01460 62935	Petergloader@btinternet.com	
The Prostate Project	Frimley	Mac Derwig			01483 811878	jan317@btinternet.com	
Woking PSA - North West Surrey	North West Surrey	Roy Sowersby	5 Pantiles Close, St Johns, Woking	GU21 7PT	01483 832120	roy.sowersby@ntlworld.com	

Annex B – List of Patient-Led Organisations wishing to be members but not at the Conference

The following organisations, considered eligible for full or associate membership, expressed a wish to join the Federation but were unable to be represented at the Conference. They are deemed to have joined the Federation as full or Associate Members (exact categorisation to be determined when Charitable Status is ascertained):

Organisation Name	Catchment Area	Contact	Address	Post Code	Phone	Email	WWW
Droylsden PCS Group	Manchester	David Mitchell	12 Rainow Avenue, Droylsden, Manchester	M43 6HW	0161 285 2721	david.mitchell90@ntlworld.com	
Guys and St Thomas	London	Netty Nichol			020 7188 7339	Janette.Nichol@gstt.nhs.uk	
Leeds PCSG	Leeds	David Padfield	1 Laurel Court, Possett, Yorks	WF5 8QA	01924 275985	djpadfield@yahoo.co.uk	
North Durham Prostate Cancer Support Group	Durham	Stafford Scholes	38 College View, Esh Winning, Durham,	D87 9AB	0191 373 4958	staffordscholes@yahoo.co.uk	
P.C. Southeast Cheshire	Cheshire	Robin Pritchard	Holly House, 3 Oakhurst Chase, Alderley Edge, Cheshire	SK9 7QT	01625 585753	rbn.pritchard@ntlworld.com	
Shropshire Prostate Cancer Support Group	Shropshire	John Gear	Greenside, Limekiln Bank, Telford	TF2 9NU	01952 613487, 07975 855247		
The Prostate Cancer Support Group - Northern Region		Pauline Bagnall / Margaret Charlton			0191 293 4142	pauline.bagnall@nhct.nhs.uk	
Tynedale Prostate Cancer Support Group	Northumberland	Malcolm Ferries	56 Peth Head, Hexham, Northumberland	NE46 1HQ	01434 609455	elrondofez@clara.co.uk	
West Wales Prostate Cancer Support	West Wales	Philip Burr	Helyg-y-nant, Pentrecwrt, Llandysul, Carmarthenshire	SA44 5DG	01559 363154	mailto:gniven@edencoe.fsnet.co.uk	

Annex C – List of Organisations contacted but not at the Conference

The following organisations, believed to be patient-led and therefore potentially eligible for Full or Associate membership, were contacted before the Conference, but for various reasons declined to attend:

Group Name	Phone	Email
Furness Prostate Cancer Support Group	01229 889768	annebooth53@hotmail.co.uk
Oldham PCS Group	0161 303 0403	
Wirral and North Cheshire PCS Group	01928 722832, 01829 740847	richard.c.coy@ukgateway.net
The Bay Prostate Cancer Support Group	01524 32736	gniven@edencoe.fsnet.co.uk
Lister Prostate Cancer Support Group	01462 684732	bradleys2@tesco.net
Chesterfield prostate cancer support group	01246 512596	
Southend and East Essex Urology Cancer Support Group (Cadgers)	01702 385369	ann.tull@southend.nhs.uk
Prospect - Prostate Cancer Support Group Kent	01322 428614	alan.welsby@btopenworld.com
South Devon	01392 402747	karen.green@rdehc-tr.swest.nhs.uk
Central England Leicester	0116 2588258	
York Prostate Cancer Support Group	01904 725848	bryan.metcalfe@virgin.net
Procure (Prostate Cancer Support Group)	02920 750420	
Derriford Prostate Support Group	01752 245228	vanessa.wilcox@phnt.swest.nhs.uk
East Suffolk PCSG.	01473 404735	john.dent20@ntlworld.com
East Surrey Hospital Prostate Cancer Support Group	01737 768511 ext. 6901	jj24@sweethaven.biz
PSA Eastbourne	01323 749258	graham.hatfield@btopenworld.com
Edinburgh & Lothian PCSG	0131 4419881	meg@malcy.net
Fife PCSG	01592 873221	jim.mavis@cowie48.fsnet.co.uk
Forth Valley PCSG	01324 629003	
Glasgow Area PCSG	0141 5869936	petermcalear@hotmail.co.uk
Hull	01482 669631	
Jersey PCSG	01534 855040	garth@localdial.com
PSA Kent	01634 849032	iantnoble@blueyonder.co.uk
Kidderminster & District	0562 66593	<david.baxtersmith@btinternet.com>
Merthyr Prostate Support Group	01685 722112	telizton@aol.com
Sutton Coldfield Prostate Cancer Support Group	0121 686 6491	
North and East Devon Support Group	01392 277295	beardm@tiscali.co.uk

Group Name	Phone	Email
North East Essex PCSG	01206 742964	lucy.powell@essexrivers.nhs.uk
Freshford Health Centre Prostate Awareness Group	01371 810060	smithj83@aol.com
North Wales PCSG	01745 823822	
Mount Vernon Cancer Network Prostate Cancer Support Group	01923 844014	
Nottingham Prostate Cancer Support Group	0115 984 3448	re.oldroyd@btopenworld.com
Perth and Kinross PCSG	01764 684581	andy@prostatescot.fsnet.co.uk
Torbay Prostate Support Association	01803 843806	peterh@talktalk.net
Berwickshire & Borders PCSG	01750 20523	ian.w.mitchell@lineone.net
Cornwall Prostate Support Association	01872 253143 (Debbie Victor)	cpsa@rcht.cornwall.nhs.uk
South Wales (Progress)	01633 270430	progress.prostatecancer@ntlworld.com
Prostate Support Association (North East)	01287 625686	coolerking5@aol.com