



A Man's a Man for A' that

SUPPORTING MEN WITH PROSTATE CANCER

Summer 2009 Newsletter (Issue No 11) • Edinburgh and Lothian Group • Prostate Cancer Support Scotland (PCSS) • www.prostatescot.co.uk

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Chairman's Message

Malcolm Goldsmith

The past year has been the busiest in our history. We've had 'full houses' at all our meetings in Edinburgh and the group meeting in Livingston has gone from strength to strength. We've been 'out and about' on several occasions, visiting workplaces and shopping arcades with literature about prostate cancer and talking with concerned people. We've been active in highlighting the post-code lottery that exists in Scotland regarding access to certain drugs for men with advanced metastatic cancer - even getting the matter raised in parliament. We've played a full part in the national PCSS body and several of our members can be seen and heard on Prostate Scotland's excellent website (www.prostatescotland.org). In addition, we played a formative part in organising and hosting the first National Conference. None of this would have been possible without the incredible hard work of the committee - Peter Phillips, Charlie Hogg, Chris Garner, Kerry Napuk, Forbes Craig, Jim Woodhead, John Bishop, Larry Foster and Martin Clark. (Chris and Jim have now stepped down and Mike Shaw and Peter Moles have joined us). John Bishop has accepted the position of joint Vice Chairman with Peter. John will be helping with strategic matters and brings useful past experience to the role. So, it's been a busy year, whether it's been successful is harder to judge. We have been successful only to the extent that we have been able to encourage and support men with prostate cancer. If we fail to give that support then our activities, however impressive, are in vain. We press on, hoping that we actually do offer that support and hope.

Editor's Desk

As Malcolm says in his message, this has been an extremely busy period for us with the Conference raising the profile of screening issues and then these being well reported in the Press (see BBC report - Prostate Issues Making the News, back page). As a support organisation, we support the introduction of a national screening programme but understand the issues and wish to contribute to the debate. The conference was a great success according to delegates and presenters making the hard work very worthwhile.

Besides his role at the helm of our Group, Malcolm has many other time consuming tasks and interests, such as painting and writing (not to mention recovering from a recent TURP!). He has now published his first novel and a submitted review is inside.

I would like to remind everybody that we are always happy to receive some extra help at the Maggie's meetings i.e. setting up furniture, helping with refreshments etc. so don't be shy! We are considering a regular morning meeting once a week for two hours where members can drop in and chat on a more regular and informal basis. This is very much at the discussion stage so any thoughts on this would be appreciated.

Regarding fund raising for the Group, a reminder that our new facility with "Justgiving" makes it easier for all members to raise funds using internet technology. However, we are not primarily a fund raising organisation although we do require funds to keep the group viable for the activities that we plan throughout the year. Monies raised are designed to be used as much as possible for the benefit of our members.

Finally, I echo the welcome from Malcolm to our new committee members Peter Moles and Mike Shaw..both veterans of radical prostatectomy surgery.

Larry Foster

Scottish Conference Report

The Conference, the first PCSS National Conference, was organised by prostate cancer patients primarily for patients and their carers and secondly for those involved from the charities, medical fraternity and government. The conference was a great success with 210 delegates and a full house of top quality speakers. The theme of the Conference was Prevention, Detection, Diagnosis, Treatment and Support. Unfortunately Nicola Sturgeon was unable to come at the last minute due to a crucial health bill in Parliament that day but an able replacement was found with Dr Aileen Keel, deputy CMO for Scotland and head of the task force looking at Cancer in Scotland.



Conference in full swing

The Conference was opened by John Duncan, President, PCSS, Perth, who introduced Lord David Steel, the charity's Patron. Lord Steel talked amusingly about his own experience and recovery from prostate cancer. He had also previously generously raised the profile of the Conference by donating the proceeds from auction of the contents of his attic on the programme "Cash in the Attic". Following his talk, he introduced the keynote speaker and government health representative, Dr Aileen Keel. Questions from

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the floor generated robust exchanges regarding the NHS position on screening i.e. testing using the PSA blood test, which is regarded by the NHS as insufficiently accurate possibly leading to unnecessary diagnosis, anxiety and over treatment. Dr Keel stated "that men over 50 should not be denied a PSA test after discussion with their GP about the pros and cons." Controversy in this area continued throughout the day and another "hot" issue was the apparent post-coding of the supply of the drug Zometa for men with advanced PCa..

We are grateful to Magic Monkey and Pomegreat (www.magic-monkey.co.uk, www.pomegreat.com) for generous donations of Pomegranate juice which were excellent, prostate-healthy alternatives to tea and coffee.



Audience spellbound..

Around 2500 new diagnoses of PCa are made in Scotland each year, and with the ageing population this number is set to increase. Around 1000 men die of the disease each year but the hope is that with earlier diagnosis and improvements in treatment this number will decrease. The Conference organisers (PCSS) were delighted to have presentations providing up-to-date information on the latest treatments and developments from leading professionals in their field as follows:

- Professor Mustafa Djamgoz, Professor of Cancer Biology Imperial College London,
- Dr Robert Jones, Beatson Institute, Glasgow
- Dr Duncan McLaren, Consultant Clinical Oncologist, Western General Hospital, Edinburgh
- Professor Hing Leung, Professor of Urology/ Surgical Oncology
- Professor James N'Dow, Professor of Urology at the University of Aberdeen
- Dr Alan McNeil, Consultant Urologist moderated the Q & A panel.

The leading charities, Prostate Scotland, UCAN, The Prostate Cancer Charity and Prostate Cancer



L to R: "Dr Alan McNeill, John Duncan, Professor Mustafa Djamgoz, Lord David Steel, Dr Aileen Keel, Duncan McLaren"

Support Scotland, presented their objectives, awareness programmes and initiatives.

During the afternoon, PCSS facilitated a unique



Lord David Steel, Patron PCSS

Open Forum of patients and carers proposing local and national actions and voting on priorities around the Conference's theme.

The following top 9 action priorities were voted by patients and carers for local groups and PCSS to



Kerry facilitating the Open Forum

consider and take forward:

- 1) Educate GPs (68 votes)
- 2) Research improved screening test (55)
- 3) Screen families (with PCa histories 49)
- 4) Equal treatment, no post coding (42)
- 5) More awareness in Sport/TV (40)
- 6) Standard PSA offered to all men over 50 without symptoms (37)
- 7) Increase emphasis on diet (37)
- 8) Facilities should be available in Scotland, remove need to travel to England (34)
- 9) Prostate on school curriculum (31)

More information on all the priorities and proposals to action will be published in due course.



Robbie (Peter Phillip's son) helping well with PR

Quotations from those in attendance:

Thanks for your efforts in organising and running a super conference yesterday. I thought it was very successful, and enjoyed hearing the speakers and audience questions.

Dr Axel Thomson – Research Scientist – Prostate Cancer – MRC

Well done to you and your colleagues on organising such a successful conference. You managed to attract an excellent attendance, and there was

no doubt that the audience was enthused and enthusiastic. There is a real opportunity for raising the profile of prostate disease and cancer. Most men (between) 50 and 75 are not aware of what symptoms should be acted upon, and what symptoms can be disregarded - there is a real opportunity to educate chaps about what matters, and what they should be doing.

Dr John Steyn – General Practitioner

Many thanks and congratulations to you and your colleagues on a very successful conference yesterday- it was a very good event.

Adam Gaines – Director Prostate Scotland

Congratulations on organising a very impressive conference.

Dr Rob Jones – Lecturer and Consultant in Medical Oncology and lead clinician on the new drug, Abiraterone Acetate.

I greatly enjoyed the conference. Many congratulations, again, for making it such a success.

Professor Mustafa Djamgoz, Professor of Cancer Biology Imperial College London

I thought it was a great success and all involved are to be congratulated on putting together such a good event that will help bring the cause to the attention of the policy makers.

Dr Alan McNeil, Consultant Urologist, Western General Hospital, Edinburgh

Prostate Issues Making the News

- PCa Awareness month in March was not short of news worthy articles.
- From the UK Prostate Cancer Charity a new strategy for the next six years. Check out on www.prostate-cancer.org.uk/who/strategy.asp
- Reported in April, scientists at the University of Leicester are planning to use a new grant for research into diagnosing and treating prostate cancer using cutting edge nano technology.
- Dave Prowse, Darth Vader actor and star of Star Wars revealed recently that he has completed treatment for the disease and is now raising money for the Royal Marsden Hospital in London where he was treated.
- Mike MacInnes who is well known as an advocate of honey for the health benefits (www.hibernationdiet.com) found our conference very stimulating and reported that he is publishing shortly an essay on a theory that indicates there is a connection between cancers, metabolic stress and neuroscience. Poisonous puffer fish have given further evidence of these connections which in turn link cancer in some cases to obesity. More will be revealed in due course....another fishy story..

- **PSA and Screening.** The BBC reports that "routine prostate cancer screening could cut death rates from the disease by 20%". It said the results from a major study suggest that 2,000 lives a year could be saved in the UK. The study, which involved over 160,000 men aged 55 to 69 from seven European countries, found that men who were screened every four years with a PSA test were 20% less likely to die from prostate cancer compared to men who received routine care. Despite these preliminary results, however, the researchers say that it is too soon to advocate a PSA screening programme. They say that with the benefits comes a "high risk" of over diagnosis and over treatment. They note that to save one life, 1,410 men would need to be screened. Of that same number, 48 would be given treatment that they may not have needed. Ref: www.nhs.uk/news/2009/03March/Pages/Reviewofprostatescreening.aspx
- Dr Anne Mackie, Director of the UK National Screening Committee stated that they will be publishing in June data based on new evidence regarding screening. In Scotland, Dr John Steyn, General Practitioner in Edinburgh is working with Consultant Urologists at the Western General in Edinburgh to establish a Standard Operating Procedure (SOP) that addresses needs of patients and clinicians. It should be noted that whilst GPs can provide advice and counselling on screening and the current PSA test they are not obliged to give the test to every patient who asks for it. This is a very hot topic and we will report more on PCa screening in the next issue, our position as a support group, and the latest from the government and research fields.
- A new development is a test called PCA3 that is becoming available in the UK to specialists looking after men who may have prostate cancer. The test could improve the diagnosis of prostate cancer by reducing the number of unnecessary biopsies of the prostate. Its potential, or otherwise, as a screening test, is unknown. In time it may become standard practice as evidence in its favour begins to accumulate. It is not yet clear at this time whether Trusts or Health Boards in Scotland will have this available in the near future or not.

Dance Band Night Corn Exchange, Edinburgh 🎵🎵

Saturday 17 October 2009. 7.45pm - 12.00pm
A date for the diary! We are running a big band concert and dance band night. £20 per couple with superb 17 piece band/orchestra playing well known popular music and dance numbers to get you on your feet. There will be a bar and other surprise entertainment. This will be a night to relax and enjoy a drink and a dance. The event is unofficially known as "Guys and Balls!"

Group Meeting Reports

Recent meetings in Livingston at the Macmillan Centre

January 21

Julia Bain gave an excellent presentation about the work of the West Lothian Benefits Advice team of Macmillan.

The Centre is based in Bathgate but also responds to requests for advice from other parts of Edinburgh and visits the Edinburgh RI and Western Hospitals regularly. The message was given that if any PCa patients are having difficulty with benefits as a result of their cancer then they should talk to an adviser who can help with matters such as grants, financial issues, energy (heating etc) and over and under payment of benefits. Other issues such as general welfare, employment and travel costs can all be potentially helped by the Centre. It was well reported by Macmillan in the Herald newspaper on the 17th April " that some 4416 people in Scotland received payments from Macmillan Cancer Support, almost 400 more than the previous year. More than half (55%) of grants awarded by Macmillan were used to pay gas or electricity bills and the charity urged the UK Government to extend the winter fuel payment, which gives extra money to cancer patients". For more information on how Macmillan can ease hardship contact Julia on 01506 776277 or email macmillan@westlothian.gov.uk.

March 18

Charlie Hogg opened proceedings with a welcome to new members and then gave a summary of his experiences of the Conference. Other members contributed with feedback as did Peter Phillips and Alasdair Innes, Specialist Nurse Practitioner. The priorities and outcomes from the Open Forum were discussed and overall feedback was very positive about the event. A general group discussion followed with members in their own interest groups of surgery, radio therapy etc.

May 6

Despite Chelsea playing Barcelona in the European Championship, a good turnout to listen to Karen Campbell, present (and demonstrate) how to strengthen the pelvic floor muscles. Karen (a trained Physio) works with men and women at the WGH Edinburgh, to help with post intervention issues such as incontinence. Great talk and enthusiastically received. Karen is away to have a baby shortly, we wish her well and she will be back in due course in a part time capacity.



Karen demonstrating with pelvic model

Also at the meeting was Rosie Hall from Macmillan, West Lothian who gave an insight into her role as an Information and Support nurse for all cancer patients. Her tel. no 01506777604.

Recent meetings in Edinburgh at Maggie's Centre

February 5

Sarah Scott and Trish Chambers presented their development work on a research study titled "Pilot Decision Support Study in New Diagnosed Breast and Prostate Cancer Patients" based at the Edinburgh Cancer Centre, Western General Hospital. The programme (called Decision Navigator) is designed to help patients write down their concerns and questions for their doctor with regard to treatment options. The aim is to increase patients' understanding of their condition allowing them to participate in an informed way with the decision making and thus to increase their satisfaction with the choice of treatment made.

The next part of the evening was devoted to a very interesting talk from Dr A Milliken, about how he, as a GP, approaches treatment with patients. He is also trained in naturopathy and covered a great deal on this subject in the short time available. Dr Milliken is an advocate of organic foods, non dairy (no surprise), vegetables, varied and steamed ideally, cooked meat but not too much red meat, tomatoes (lycoprene content), fish and fish oil and organic eggs (free range) etc. In his opinion the message was to essentially try to reduce toxicity in the body and maintain a good balance of appropriate nutrients and minerals.

April 2

A busy, well attended meeting which commenced with members discussing and sharing personal experiences and views in specific interest groups e.g. surgery, radio therapy, hormone treatment, watchful waiting, lifestyle and advanced cancer. Following the Interest meetings, the AGM was held with Malcolm our Chairman presenting in his usual eloquent style the activities of the group in the past year and some of the challenges ahead. It has been a great year with many achievements culminating in the Conference in March. Malcolm covered the structure of the group and core objectives (support, awareness and relating to professionals) reiterating that it is a group for patients run by patients. Much has been achieved such as excellent PR and awareness raising and also attendance at various health information events providing help and guidance where necessary. Campaigns such as wider provision of Zometa were also launched. Our excellent connections with the MRC in Edinburgh and Axel Thomson's research team there were highlighted.

The committee and Chairman were reinstated and thanks given to Jim Woodhead and Chris Garner who have stood down. Welcomes were given to Peter Moles and Mike Shaw who have recently joined the committee and also to new clinical specialist nurse Scott Little, who will be available at our meetings in the future along with Rita O'Dea. Kerry Napuk our Conference Organiser then gave a summary of the Conference and the results of the Open Form Priorities facilitation part of the Conference.



Awareness



Committee Members presented to Rotary Club meetings about the disease.

Awareness activities have been keeping the Group busy particularly during March, Prostate Cancer Awareness month.

Charlie Hogg, Frances Hogg and Ron

Jackson from the Livingston section were busy in Marks and Spencers in West Lothian publicising the disease and the support charities and issued well over 1000 leaflets. Local MSP Angela Constance gave her support to the campaign which was well reported in the West Lothian Courier. Also, Angela Constance has entered the

Edinburgh and West Lothian marathons this year and has agreed to wear a running shirt with our logos etc.

As reported earlier, Prostate Scotland, the awareness charity has produced an excellent web site (www.prostatescotland.org) that is a resource for patients and concerned men. This was launched at the Scottish Parliament in February this year by Prostate Scotland and MSPs. Also in attendance were Malcom and Larry from the committee.

Our conference raised a great deal of awareness and PR before and after the conference and articles were published on the STV web site, in the Edinburgh Evening News, Forth Radio, Scottish Sun, Daily Record, Scotsman and Scotland on Sunday newspapers.. copies of the articles are available if required.

Group Activities

Other Groups

Committee members Larry and Peter attended Borders and Glasgow meetings recently to compare ideas, learn from each other and share ideas and experiences.

Video Stars

Six of our members have been videoed talking about their cancer and treatment for the Prostate Scotland website (www.prostatescotland.co.uk)

Scotland against Cancer Conference

Glasgow – March 20

Peter Phillips represented PCSS at the recent Scotland against Cancer Conference in Glasgow. Extracts from Peter's report as follows:

It was an excellent conference covering all aspects of the fight against cancer in Scotland. Nicola Sturgeon offered smart and logical answers to questions from patients, health professionals and other politicians. NS said she was keen to find new protocols that work. From the success of breast and cervical cancer screening, NS understands the importance of early detection and stated that bowel cancer screening was under consideration. Nothing about PCa screening though.

After NS, Professor John Frank, an eminent epidemiologist explained that he studies factors affecting the health and illness of populations.

Discussion Groups followed. There were 8 groups; you can see them on the website www.scotlandagaincancer.org.uk.

While waiting for the discussion group to start, I met a 26 year old patient with brain cancer. He was a walking miracle, given only months to live, he has survived ten years so far. Guess what, he is involved in support group work. Better than us, he does it on his own, traveling round Scotland to start groups. He spends 2 or 3 days in an area, hanging around hospitals and soliciting for trade. This lad has his own system of supporting brain cancer patients, his groups are small and only contact each other

if desperate. Later I met a Novartis representative and gained good insight into the organisation. Good contact for lobbying, more to come from this. By 3pm I was bushed, so decided to check out Larry Foster who was at the Men's Health Cancer Forum same day (not as high profile, smaller but talked about PCa awareness for men)

All in all, a worthwhile event which will definitely have an effect on cancer treatment in Scotland for the immediate future.

Peter Phillips

Book Review Review of Family Ties

We all knew that our chairman was a man of many exceptional talents but I think we were all taken by surprise to discover that he also had a novel in him and could find the time to write it. "Family Ties" charts the lives of a mother and her family. The mother is widowed for the second time soon after the First World War. She is left to raise three daughters on her own under very difficult circumstances. It turns out that they are three very different daughters with different aspirations and expectations from life. Victoria follows the most conventional life and appears content to stay in England and raise her family with a caring husband. Libby is the most academic and is the first to go to university and becomes a teacher. She has a much broader view of life, travels to Africa to make her contribution to life and perhaps "find herself". Maggie never seems satisfied with what she has and leads the most varied life. She looks for that elusive element in Spain where she spends much of her adult life. How does Beryl cope raising these three daughters? Will Victoria remain satisfied with her homely approach to life? Will Libby ever find true love? Will Maggie ever find contentment?

To find out read "Family Ties" by Malcolm Goldsmith published by 4M Publications.

(ISBN 978—906557-01-0) (Cost £8.99 on Amazon.)

Group Notices

Sad News

Sadly we have to report that two of our members have died since the turn of the new year. Roddy Mackenzie and Bill Wood who attended the Edinburgh meetings at Maggies. Bill Wood was only able to come to one meeting before he died. Our thoughts are with their families and friends.

Group Meetings remainder of 2009

Edinburgh Support Meetings

All on Thursday at 7 pm at the Maggie's Centre
June 4, Sept 3, Nov 5, Dec 3

Advanced Cancer Group with Peter Phillips. These are held once a month. Please contact Peter for more information. The Edinburgh Lifestyle meetings have been suspended for the time being due to low interest however these will be resurrected if demand is there.

Livingston Support Meetings

The next meetings are at 7 pm at the Macmillan Centre, Aug 5, and October 14.

Web Links

SOME USEFUL WEB LINKS..

www.prostatescot.co.uk
www.prostatescotland.org
www.cancernet.co.uk
www.prostate-cancer.co.uk
www.prostate-cancer.org.uk
www.cancerhelp.org.uk
www.epi.bris.ac.uk/protect/
www.prostate-link.org.uk
www.hibernationdiet.com
www.maggiescentre.org
www.scan.scot.nhs.uk
www.ustoo.com
www.after-cancer.com
www.scotlandagaincancer.org.uk
www.prostatebrachytherapyinfo.net

Useful Contacts

General Enquiries
pcsseandl@gmail.com

Peter Phillips, Deputy Chairman & Advanced Cancer Group
01314534671 scottishflyer@gmail.com

Charlie Hogg, Treasurer & Livingston
01506845981 charliehogg@blueyonder.co.uk

Forbes Craig, Secretary
013144515102 forbes@craig.fsnet.co.uk

Larry Foster, Editor Newsletter
01313376027 lwfooster@btinternet.com

Seonaid Green, Maggie's Centre
01315373131 seonaid@maggiescentres.org

John Bishop, Co-Deputy Chairman
01313377472 JohnBishop@phonecoop.coop

**Julia Bain, Macmillan Benefits Advice
Edinburgh & West Lothian**
01506 776277 macmillan@westlothian.gov.uk