



A Man's a Man for A' that

SUPPORTING MEN WITH PROSTATE CANCER

Winter 2008 Newsletter (Issue No 10) • Edinburgh and Lothian Group • Prostate Cancer Support Scotland (PCSS) • www.prostatescot.uk

In this Issue:

- Scottish Conference
- Fund Raising
- Upcoming Events
- Group Meetings
- Christmas Party
- Prostate Issues Making the News
- In Brief

Scottish Conference 2009

March 12th Edinburgh, the major event of the 2009 calendar during Prostate Cancer Awareness month. Held at the prestigious Playfair Library in Edinburgh. On the platform will be Lord Steel our patron, Nicola Sturgeon (Minister for Health) and many eminent physicians. More information below.

Chairman's Message

by Malcolm Goldsmith

Christmas and the New Year is traditionally a time for celebration, family visits, enjoying children and grandchildren and generally feeling good about things. For many people though, it is a time of sadness, pain or anxiety. A time when people may have to live without their partner for the first time, or when they are struggling with deteriorating health and fearful for the future. As each Christmas and New Year approaches we are conscious of those of our membership who have died during the year and of those who are just coming to terms with their diagnosis. Wherever you are in your journey with cancer, remember those who are struggling and if you are fortunate enough to be one of those who can truly celebrate and enjoy this season – have a wonderful time for it is a precious gift that you have been given.

Editor's Note

by Larry Foster

The past few months have been a frenetically busy time for the Group. Organising the National Conference in March, full and busy meetings in Edinburgh and Livingston, attending local authority Men's health awareness events, setting up new processes etc. I pay tribute to my fellow committee members who form a team which gels magnificently and gets things done efficiently under the able stewardship of Malcolm Goldsmith. I would like to acknowledge on behalf of the Committee the contribution over the years of Chris Garner. Chris has resigned from the committee after many years of valuable contribution e.g. initiating this newsletter, setting up the

continued on page 2 ▶

Scottish Conference – March 12th Edinburgh

Our Scottish Conference being held on March 12th from 9.30 am at The Playfair Library in Edinburgh promises to be the highlight of Prostate Cancer month in Scotland. The theme is Prostate Cancer Prevention, Awareness, Detection, Diagnosis, Treatment and Support. We are honoured that our patron Lord Steel will give an address as will the Secretary of State for Health and Wellbeing, Nicola Sturgeon. The programme includes a panel of eminent medical specialists, the PC Charities as well as sessions to develop support for patients. This is the event of the year, so if you would like to be invited, talk to Peter Phillips (01316648858) or go to our Conference web site www.edinburghconference2009 and you

can register there. Alternatively email PCSSeandL@googlemail.com.

There is no charge for the event, lunch is included as well as some healthy freebies from supporting organisations. Check it out!



Playfair Library, Edinburgh

Things that go "P" in the night (or did we forget to mention the free wine!)



Malcolm & Larry being shown around Axel's lab at the MRC

21st January 2009 @ 5.30 pm – MRC – Little France (ERI site)-Lab & lecture Tour

Axel Thomson, well known to us at the Group, is a Research Scientist at the Medical Research Council facility at the ERI site. Along with Tony Riddick (consultant surgeon from St Johns), Axel will discuss the health issues of diseased prostates and describe symptoms and their treatments. The anatomy of the prostate will be revealed and also how science is being used to treat the disease. Find out how well you know your Prostate and enjoy a glass of MRC laboratory wine..!

Axel Promises to Provide a Pleasurable Presentation of Prescient insight into Prostatic issues!

To reserve a place go to... www.crb.ed.ac.uk/letstalk/



Fundraising – Justgiving

Our Support Group has now signed up to Justgiving, which is the HMRC approved global charity donation web site..6000 charities registered. How does it work?

Firstly it's easy, quick and tax-friendly and lets people donate to PCSS on-line.

To make a donation or to raise money for PCSS...

All you have to do is go to the Justgiving PCSS web site... www.justgiving.com/pcss

1) Select option for making a donation (single or regular payments)

OR

2) If doing an event, select option for raising money by:

a) Register for an account selecting PCSS as your charity.

b) Add a title, message and photo and set up your own web page. Email your page's address to

everyone you know and start collecting donations on-line! Justgiving transfer donated funds to the PCSS bank account automatically, so you don't have to chase cash or cheques. Note though that Justgiving allows for payments to be made off-line also for those not on line.

About Gift Aid

Under the Gift Aid scheme, PCSS can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. Also between 6 April 2008 and 5 April 2011, the government will also give UK charities an extra 3% of all eligible donations. Charities often miss out on this extra income because it is too expensive to process the paperwork on small donations. Justgiving has solved this problem by automating the process of Gift Aid reclaim so that every £1 donation is worth more, and costs less to administer. All of Justgiving's processes have been audited and approved by HMRC.

What do I have to do?

When you donate, you will be asked to confirm whether or not you are a UK taxpayer. Please note that tax can only be reclaimed on donations made by individuals who pay UK income tax at least equal to the amount reclaimed on their donations in the current tax year. If in doubt, contact the helpdesk at Justgiving. Your Justgiving account helps you claim tax relief by keeping an accurate record of your donations. Simply print out a copy of your donation history and attach to tax return.

What if I am not a UK taxpayer?

The Gift Aid scheme is unique to the UK. If you are not a UK taxpayer, you can still make a donation through Justgiving, but your donation will not attract Gift Aid.

Donations not using Justgiving...

We are of course delighted to receive payments directly not involving the Justgiving process..if you wish to make a donation or regular payment, please contact Charlie Hogg.

Group Meetings

Lifestyle Group

I am sure that those who attend the bi-monthly meetings of the Prostate Cancer Support Group at Maggie's Centre find them of tremendous help and interest. However, by nature, such large gatherings do not give one the opportunity to discuss at length what may be small details but important to each of us. The end of meeting availability of "specialist" discussions with fellow patients in different treatment situations is a great help.

However, the Lifestyle group was set up by Chris Garner – who, unfortunately, has recently had heart surgery (but is recovering well) – hence my

current involvement. Firstly, this group meets at Maggie's Centre on the last Wednesday of each month at 2.30pm.

It meets to exchange ideas, experiences and suggestions on a very broad and casual basis. We do not simply confine ourselves to the prostate as many have other additional problems from joint surgery to heart operations. Anything can be "thrown into the pot". But obviously our prostates are the main item.

I have never left a meeting without some reassurance or some useful ideas.

For example, the use of honey as a sleep aid had been discussed by a main speaker at a previous main Maggie's meeting. We brought up the anti reactions caused by some. Many of us take Saw

Palmetto in various herbal medicines. Brought up was the fact that taking this within two weeks of having a PSA test could distort the PSA results. Brazil nuts are a great source of selenium – that is if you do not have a violent skin reaction. Diets, alternative medicines etc. are all discussed with the value of members' own experiences. We have even directed a worried potential knee transplant patient on a MUCH happier path.

The whole value is the exchange of ideas in a relaxed and casual atmosphere and I feel there are many who are happier to discuss their personal worries and experiences in a smaller group such as Lifestyle...

Why not come along?

Alan Robertson

► from page 1 Editor's Note

Lifestyle Group etc. Chris went into hospital in December and had a successful heart bypass. We all wish him a speedy recovery and look forward to seeing him fit and well soon.

You may have noticed the new name for our Group newsletter. We ran a competition and thanks to you all for the great ideas (some unprintable!) from members. In the end we elected to go for the suggestion from Malcolm (no, it was not a fix..), that wonderful Rabbin Burns line "A Man's a Man for A'that". This is in fact the theme title to our Conference in March during UK Prostate Cancer awareness week.

Malcolm donated his winning bottle of vino to the Christmas party raffle.

Not everyone is aware that PCSS is an Association of PC support groups in Scotland. Association sounds a bit like the mafia, but no horses' heads here..it's a loosely coupled but aligned organisation (is that too much management speak?) comprising self-help groups throughout Scotland. The web site gives more detail on the organisation structure.

Check out also the lab tour and talk at the MRC laboratories at Little France on January 21st. Malcolm and I have done the tour, it's fascinating. The evening starts at 5.30 pm and with free wine! See page 1.

Donations and sponsorship have been fantastic. Our new facility with "Justgiving" makes it easier

for all members to raise funds using internet technology. More on donations on page 3.

You will notice that our communication efforts are moving with the times and we can now communicate with members via email. This is obviously less expensive for the Group so if you are on email and have not given us your address please do so if you wish to receive communications this way.

I am always pleased to hear of anything newsworthy for our newsletter... please email or call me.

Finally, I wish you all a very happy and healthy New Year.

Larry Foster

Funds Raised...

We have had a particularly successful few months from our members and friends. Many thanks to all that contributed.

Nicol Family Walk

The fantastic sum of £2000 (with gift aid) was raised by the family of Graham Nicol who died in 2006 from prostate cancer. Graham was a very active member of the committee of our Support group and a major contributor. The Nicol family and friends walked from Cramond Brig to South



The Nicol Family on their walk

Queensferry on the 28th September 2008 to commemorate the life of Graham, a much loved husband and father. Graham was very keen to raise public awareness of the importance of early diagnosis, and the family hope that the money will be used to support the Group and in the drive to find a cure for prostate cancer. This walk was the first to use the Justgiving web site set up to make donations and sponsorship easier.

Martin Clark Pentland Walk

Martin Clark from the group raised the magnificent sum of £1200 with a further £500 being given by the Royal Bank of Scotland. Martin and friends walked across the Pentland Hills...well done... Martin enjoyed



Malcolm and Larry receiving a cheque for £2000 from Martin Clark

it so much he is now planning a fund raising event next year...rumour has it that this will be by taxi though...

Jim Woodhead's Coast to Coast bike ride..

Jim's coast to coast bike ride from Workington to Newcastle (134 miles) on 23-25 June raised £515 in aid of Group Funds... well done Jim... wish we had a picture of you in your lycra...

The Royal and Ancient Order of the Buffaloes

We were very pleased to accept donations from the ROAB (known as the Buffs), Tranent Lodge who raised collectively £170



Peter Phillips receiving a cheque from Alf Robinson

from a sponsored walk near Edinburgh. Picture below shows Alf Robinson of the Buffs presenting the cheque to our Deputy Chairman, Peter Phillips at a Lodge meeting.

The Royal Antediluvian Order of the Buffaloes – Newtown Lodge

Charlie Hogg was invited to the Christmas Social of the above and presented with a generous cheque for £1100. This is the second donation following the sponsored walk in May. A note of sadness was that Bill Johnson, who was instrumental in raising funds and helped with the Livingston Group had passed away from lung cancer having already overcome prostate cancer.



Charlie Hogg receiving £1100 cheque

Prostate Issues making the news

Chief Medical Officer's Report on Cancer in Scotland

Reported 3 December 2008 by Harry Burns, Scotland's Chief Medical Officer, was the fact that cancer rates could soar to unprecedented levels within the next decade if people do not start adopting healthier lifestyles. The report concludes that if trends remain unchanged then bowel and breast cancer will rise and prostate cancer was projected to rise from 2420 cases to 3207, an increase of 33%... It also went on to say that from 2015 to 2019 the figure could show a growth rate of cases of up to 58%.

Zometa (for advanced and metastatic cancer)

Our submission for Zometa to be made available on the NHS throughout Scotland is now on the website of the Scottish Parliament.

We acknowledge the help and support with this submission from Alan McNeil (Consultant, Western General Hospital, Edinburgh) and Professor Alan Rodger of the Beatson. Watch this space..

Abiraterone

Many members may have seen press notices and comment over the past few months about a new drug for aggressive prostate cancer which some have said is 'potentially the most significant advance in the field for over 70 years'. Members of the committee have been finding out as much as they can about it and there is a short paper available. If you want a copy of this, please contact a committee member or email our general contact address (pcsseandl@gmail.com). More news about this will no doubt be available at our Conference in March. However, Sheila Liggat, Specialist Nurse at the Western points out that whatever the outcome of the current clinical trials, the availability of the drug for general use is unlikely to be for some years yet.

Nordic study results

Findings from a 10-year study in Scandinavia suggest that combining hormone treatment with radio therapy gives the best result for PC that has started to invade surrounding tissues. The results have to be digested fully but it is a very positive development.

In Brief

- Six of our members have been videoed talking about their cancer and treatment for the Prostate Scotland website..this will be launched at the Scottish Parliament on February 3.
- Another good resource is the South East of Scotland Cancer Information Network (SCAN). www.scan.scot.nhs.uk
- We are considering running a jazz band fund-raising evening in Edinburgh in the spring of 2009..this will be with a well known 17 piece big band plus suitable refreshment.. more information early in the new year.
- www.after-cancer.com This is an interesting site with a great deal of advice for post treatment cancer patients.
- The Committee supported Edinburgh Council Men's Health initiative by attending an event at Blindcraft in Edinburgh to raise awareness of PC with their disabled employees. (www.blindcraft.co.uk)
- Prostate Scotland has produced an excellent guide to Laparoscopic Radical Prostatectomy at the Western Hospital Edinburgh. Available at the Maggie's Centre.
- Travel insurance options were detailed in the last issue of the newsletter and we have been made aware also that Age Concern have a good range of policies for cancer patients. Maggie's Centre in Edinburgh have up-to-date information.



Recent meetings in Edinburgh at Maggie's Centre

September 4

Again a large turn out in Edinburgh for what was a sensitive subject (Impotence & Incontinence) presented by Alasdair Innes, Specialist Nurse Practitioner. Alasdair had talked earlier in the year in Livingston and similarly presented this time in a lively and open manner. Erectile Dysfunction was discussed and the various medical solutions to deal with this problem. Drugs such as Viagra, Levitra, Cialis were described as well as invasive treatments such as Muse and Caverjet. A demonstration was also given of a vacuum pump. Group members were able to contribute with their experiences of ED and incontinence.



Sheila Liggat- Specialist Nurse, holding court at the meeting

November 6

The meeting was opened as usual by our Chairman, Malcolm Goldsmith who gave an update with support from Peter Phillips on the status of the Conference next March as well as updating everyone on the current level of donations. Following this, three members gave illustrated talks on their own experiences and journey with PC. Jim Woodhead started proceedings with a lively illustrated talk covering his diagnosis, subsequent radio therapy and hormone treatment. Larry Foster followed and discussed his diagnosis via the Protec study, the connection with a mountaineering accident in 2005 and subsequent keyhole surgery in 2007. Finally, Martin Clark presented his philosophy and thinking behind his decision to opt for watchful waiting. Following the presentations, group discussions were held on various interest areas such as surgery, radiotherapy, advanced cancer treatment, lifestyle etc. A very lively and full meeting. Copies of the presentation material are available from Larry Foster the Editor.

December 4 – Christmas Party

The Christmas party. A great night and turn out despite the weather. We were all very pleased to see our Clinical Nursing Specialists friends there from the Western and St Johns. Thanks to them all for their contributions during the year were made by Malcolm and Charlie and special thanks were

made to Sheila Liggat who will be retiring from the NHS in the new year and has been involved with Group for the last ten years. Some excellent mulled wine was supplied and organised by the hostess with the mostest, Frances Hogg. She also organised the Quiz which was hijacked by the bonus points being awarded for the Chick Murray impersonations from Jim Woodhead and Martin Clark, clearly wasted talent but stick to the day job guys! Stuart Robertson provided a couple of musical quizzes with his impressive talent on the keyboard. A donation of £500 was made by the Group to the Edinburgh Maggie's Centre and also to Seonaid Green for her sterling work and for making us so welcome at our regular meetings.



Stuart entertaining on the keyboard



John Bishop delivering another rib tickler...



Chick Murray special guest



Frances keeping all fed and watered

Recent meetings in Livingston at the Macmillan Centre

August 6

Livingston Group host regular thriving meetings and, although not as big in numbers, has always had a good turn out. We were pleased to have at this meeting Tony Riddick, Consultant from St Johns who discussed various aspects of prostate cancer treatment including the recently announced Abiraterone. Contributions from the floor followed and a lively discussion ensued around these new drug treatments and their clinical trials. Peter Phillips contributed with his experience and knowledge of treatments for advanced cancer. Tony Riddick also discussed current PSA screening, biopsies etc. and the fact that these procedures do not always give infallible results. Jill Davis, Specialist Nurse discussed new screening procedures that are under development based on urine samples. She also stated that our Awareness campaign in Livingston had resulted in more referrals for PC and consequently more men diagnosed. Side effects of treatments were discussed as well as incontinence and the benefit of pelvic floor exercises both pre and post treatment.

October 6

Axel Thomson, scientist from the MRC (Medical Research Council) at the ERI site attended and presented a fascinating insight into his team's research into prostate cancer. For more information, take a look at the event Axel and his team are running at the MRC site on January 21st 2009 which will include a lab tour (see events).

Upcoming Group Meetings in 2009

Edinburgh Support Meetings

All on Thursday at 7 pm at the Maggie's Centre
February 5, April 2, June 4, Sept 3, Nov 5, Dec 3

Lifestyle meetings are held in Edinburgh with Alan Robertson and Advanced Cancer group with Peter Phillips. These are held once a month. Please contact Alan and Peter for more information.

Livingston Support Meetings

The next meetings are at 7 pm at the Macmillan Centre, Livingston
January 21, March 18, May 6, Aug 5, October 14.

Useful Contacts

General Enquiries
pcsseandl@gmail.com

Malcolm Goldsmith, Chairman
01314419881 mcg@malcy.net

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

Charlie Hogg
01506845981 charliehogg@blueyonder.co.uk

Alan Robertson
01620826978 robertson488@btinternet.com

Larry Foster, Editor Newsletter
01313376027 lwfoster@btinternet.com

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