

Newsletter

Autumn 2017

New Prostate Scotland website launched

Prostate Scotland has launched a new website to provide information about prostate cancer and disease, its symptoms and treatments. The website, at www.prostatescotland.org.uk provides a wealth of helpful information for people with prostate disease as well as prostate cancer, is aimed at men and their families coming new to the topic, as well as those diagnosed. With information for people wanting to find out about symptoms or worried about prostate disease, there are also videos by doctors about treatments as well as patients sharing their own experiences. One special feature is the resource centre containing downloadable booklets on all the prostate diseases making them universally accessible. There is also an improved resource for supporters of the charity who do everything from running marathons and climbing Munros to holding quiz nights.

Robert Wilson Chairman of Prostate Scotland said: "We were delighted to launch this new website during prostate cancer awareness month to enable people across Scotland to have access to information about prostate cancer and disease. With nearly one in two men likely to get prostate disease at some stage in their lives, and one in ten men prostate cancer and a projected increase in incidence there is a vital and growing need to ensure that men and their families have access to information and support."

"We would like to acknowledge and thank the Freemasons from across Scotland for their kind donations which have assisted and helped enable this new website, as well as support many other projects. We have very much appreciated the support and partnership with the Grand Lodge of Scotland and Freemasons across the country, which is enabling us to create greater awareness of and reach many more men and their families with information and help about the most common cancer in men. We would like to also thank Union Digital for their creativity, expertise and skill to enable us to develop



this new multi-functional website".

David M. Begg Grand Secretary of the Grand Lodge of Scotland said: "Since we started contributing to Prostate Scotland in 2012 we have contributed almost £340,000 to the campaign. We also participate in distributing leaflets and brochures to all our Lodges in Scotland, which has led to increased awareness of the disease and its symptoms, resulting in a significant number presenting themselves to their doctors for early treatment of the disease."

Since its' launch the Prostate Scotland website has been awarded a top accolade from independent website reviewer Feedspot, which out of many thousands rated the Prostate Scotland website as being one of the top 50 best prostate cancer websites in the world.

Robot-assisted prostate cancer surgery on the map

Our very successful Blue Horizon Robot Appeal, raised £2.8m to support robotically-assisted prostate cancer surgery in the east and west of Scotland

Following its recent introduction in Edinburgh, Glasgow and Aberdeen robot assisted prostate cancer surgery is now very much on the map in Scotland.

A significant contributor towards the progress in the east and west of Scotland was the Blue Horizon Robot Appeal which was Prostate Scotland's largest fundraising appeal to date and successfully completed in November 2016. The announcement of the conclusion of the Appeal coincided with the launch of robotic prostate cancer surgery at Edinburgh's Western General Hospital. Inau-

gurated by Health Secretary Shona Robison MSP, the technology assists surgeons treating prostate cancer patients across the south and east of Scotland.

The £1.4m da Vinci SI Surgical System, operated by surgeons, has already helped to save the lives of 150 men with prostate cancer since its introduction last year in Edinburgh. It was jointly funded by Prostate Scotland, the Scottish Government and health boards from the SCAN (South East Scotland Cancer Network) regional network. Significant contributions also came from the Robertson Trust, the Barcapel Trust, the Grand Lodge of Scotland, the Sir Tom Farmer Foundation, Scottish Rotary Clubs, and from private donations by members of the public. Earlier in March 2016 at the



Queen Elizabeth University Hospital in Glasgow, a robot for prostate cancer surgery for the west of Scotland was launched as the result of a partnership between West of Scotland Health Boards, the Scotlish Government and Prostate Scotland, and so far has helped to save the lives of over 200 men since its introduction.

• Thank you to all of our volunteers



We've had lots of fantastic support from all of our volunteers over the past couple of years to whom we'd like to say a huge thank you.

We had a Prostate Scotland information stand at the Ideal Home Show in Glasgow for the first time over last year's Spring Bank Holiday in May, as well as one at the 50+ Show in Novermber, where our volunteers kindly gave up their time to help raise awareness and provide information; and a group of volunteers from Stirling Rotary Club held a stand in aid of us at

Gardening Scotland at Ingliston.

Thank you to Gordon and Lorraine Turnbull, Stephen Bird, Roddy McLean, John Fulham, Gerry Gallacher, Sarah Whalen, Alasdair Ferguson, Billy Mathieson, Walter Moodie, Alison Walker, Mike Brown, Charlie and Frances Hogg, Paul Farrell, Megan Miller, Lucy McAneny, Lucille Paterson, Stuart Watson, Walter Moodie, Lynn Grierson, David Ridd, Bruce Loughlin, Iain Annand, Jim Sommerville, Alex Dalgettie and Stirling Rotary Club. From our PAGES group, (Prostate Scotland Advisory Group) we'd like to thank Alan McNeill, Ben Thomas, Brian Corr, Scott Little, Lesley McKinlay, Peter Phillips, Graham Hollins, Rob Lester and Roy Partington and the wider reading group. We've provided more information about the different volunteering roles available within Prostate Scotland on our new website which can be found at prostatescotland.org.uk/support-prostatescotland/volunteering.

PRESTONFIELD

Prestonfield Annual Burns Supper

Prestonfield have announced that their 2018 annual Burns Supper will once again be held in aid of Prostate Scotland.

Next years' event will be held on the 25th January 2018. Tickets cost £50 per guest for a three course Supper and entertain-

ment, and can be booked by calling 0131 662 2323. We're delighted to report that the event was recently listed by Culture Trip as one of the best Burns Suppers in Scotland.

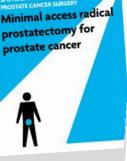
The event follows on from the very successful 2017 Prestonfield Burns Supper which was hosted by broadcaster, presenter and Prostate Scotland Ambassador Grant Stott, with Burns aficionado Cammy Goodall giving the Immortal Memory. Comedians Simon Evans made the Toast to the Lassies, with Rhona Cameron delivering the reply. The fabulous Auction and Prize Draw raised over £16,000 in aid of Prostate Scotland.

Prostate Scotland would like to thank James Thomson and Prestonfield for their generosity in holding the event in aid of Prostate Scotland.

New leaflets and guides

Prostate Scotland has continued to add and update to its series of leaflets and guides. The

Spotlight guide on Minimal Access Radical Prostatectomy was produced to coincide with the launch of robotic surgery following the Blue



Horizon Robot Appeal. We have also added several other Spotlight On Guides. The Table Talkers were updated recent-

Prostate Aware

Prostate Disease
A major issue but a little known problem...
Signs to look out for

- and during the night

 Needing to urinate without
- Needing to urinate without much warning
- to urinate

 Prostate problems can
- Prostate problems can
 often be treated so

Check it out





SCOTIAND Prostatescotland.arg.uk

PROSTATE CANCER
Is it in the family?
Is it time to check it out?

ly and are a very useful resource at our Workplace Initiatives and at fundraising events. The Explanatory Guide to Early prostate cancer now has additional information, and with funding from the Grand Lodge of Scotland, we produced a handy wallet sized guide to 'Prostate Canceris it in the family?' Our 'Raising Awareness' card was generously supported by Rotary Clubs across Scotland. These can all be read on screen, downloaded for printing at home, or ordered in bulk from the resources page on our website.

Keeping in touch

We're delighted that so many of you want to stay in touch, and if you'd prefer to receive your copy of the newsletter by email, Facebook, or read it on our website rather than receiving it by post, do let us know by filling in our contact form. You can find the form on our website at <u>prostatescotland.org.uk/contact-us</u>. You can also call us on 0131 603 8664 or email us at info@prostatescotland.org.uk If you have any suggestions for articles you'd like us to include in the next newsletter, we'd be happy to hear from you.

 Research shows survival rate gap affecting people with cancer from more deprived areas

A study undertaken by the Information Statistics Division of NHS Health Scotland with Macmillan Cancer Support has found a significant gap between survival rates of cancer patients depending on whether they lived in deprived or less deprived areas of Scotland. The study found a particular gap for prostate cancer patients.

Commenting on the study a spokesperson for Prostate Scotland said: 'The gap between survival rate from cancer from people in deprived and non-deprived areas highlighted in this recent report is a very significant worry and means that everyone engaged in the cancer community needs to redouble efforts to ensure that people from the more deprived communities have access to information and awareness about prostate cancer and its symptoms. We have been taking forward a range of initiatives across Scotland in both urban and rural areas to reach out and build awareness of prostate cancer and its symptoms amongst all communities with an emphasis on reaching harder to reach and deprived communities.'

• Study on Abiraterone for advanced

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A recent study as part of the STAMPEDE trial has indicated that adding the drug Abiraterone to hormone therapy at the start of treatment for advanced prostate cancer improves survival by 37%, according to the results of one of the largest-ever clinical trials for prostate cancer. The results were presented at the 2017 American Society of Clinical Oncology (ASCO) Annual Meeting in Chicago, US, and published recently in the *New England Journal of Medicine*.

The results from the Cancer Research UK funded STAM-PEDE trial could in the future lead to a change in the standard care for men with advanced prostate cancer, potentially making Abiraterone a first-line treatment alongside hormone therapy. Such a change in Scotland would however most likely require approval of SMC, as Abiraterone is currently only available following hormone treatment.

Prostate cancer cells usually depend on testosterone to grow. Standard hormone therapy blocks the action of male sex hormones, halting the disease. Abiraterone goes further and shuts down the production of the hormones that fuel prostate cancer's growth.

Prof. Johann de Bono of the Institute of Cancer Research and an author of the study said:

'These results show that Abiraterone used at the start of treatment had clear benefits for patients...Abiraterone is already now being used before chemotherapy, at an earlier stage than initially had been the case, and it's really exciting to see that it could start benefitting patients as soon as they are diagnosed. I hope that the data from this trial will soon result in a change of practice in the clinic.'

Ten tremendous years for ELPCSG



On 22 March 2017, the West Lothian Branch of the Edinburgh & Lothians Prostate Cancer Support Group organised a tenth anniversary celebration event coinciding with prostate cancer awareness month.

With over 120 people in attendance, including representatives from West Lothian Council, Lothian Health Board and other health charities, West Lothian Branch founder Charlie Hogg gave an update on how the group started and its progress to date.

Professor Rob Jones, Director, Cancer Research UK, Clinical Trial Unit, Beatson West of Scotland Cancer Centre was welcomed to the event, and talked of the advances in chemotherapy treatment for men with prostate cancer, and the success of new drugs.

Professor Alan McNeill, Consultant Urological Surgeon at the Western General, Edinburgh and a Founder Trustee of Prostate Scotland spoke of the importance of the Edinburgh & Lothian Prostate Cancer Support Groups. Professor McNeill emphasised the close working relationship between the support groups and the health boards, having referred many of his patients to the groups. He also spoke of the valuable role of the 'Buddies' support system which is managed by the support group. Charlie Hogg said "The success of the support group has been achieved because of the help given to each man from their specially selected member buddy to see them through making a choice of treatments on offer and giving them support all the way through their months of recovery."

For more information on the support group contact Charlie Hogg on 01506 845981 or email charliehogg@blueyonder.co.uk



Prostate Scotland & NHS Fife

Prostate Scotland and NHS
Fife worked together to
raise awareness. As well as
holding Workplace Initiatives with NHS Fife over the
past year, the awareness
campaign also included advertising at local bus shelters for men to be prostate
aware during prostate cancer awareness month.

Workplace Initiatives

The Prostate Scotland Workplace Initiative to deliver information and awareness of prostate disease and cancer through workplaces has gone from strength to strength. Mae Bell, our Information and Advice Coordinator has travelled to a wide range of workplaces to deliver information and awareness of prostate disease and the work of Prostate Scotland. Mae has spoken at several Safety & Health Awareness Days - a new initiative set up by the construction industry through the Health & Safety Executive. Prostate Scotland has provided each attendee on-site with information packs to take away and the opportunity to ask questions at our exhibition stand.

Our Toolbox Talks and Workplace Initiatives continue to be well attended, with events with organisations such as SanDisk, Registers of Scotland, Carillion, Police Scotland and Glasgow Caledonian University; regional councils including East Dunbartonshire, Wishaw and Dumfries & Galloway; and construction company Morrisons on sites in Elgin, Largs, Girvan and Rutherglen. Attendance has been excellent and feedback from workplaces very encouraging. If your business or organisation would like to raise awareness and provide information for their employees on prostate disease and prostate cancer, and what Prostate Scotland can provide to help you do this, then please go to



Cupcakes kindly provided by Ishbel Anand for Registers of Scotland

our website at prostatescotland.org.uk/for-professionals, call us on 0131 603 8663, or email info@prostatescotland.org.uk.

Greater treatment options for men with BPH

The past few months have seen a significant increase in the number of surgical treatment options for men in Scotland with Benign Prostatic Hyperplasia (BPH) who require surgery. In addition to the 'gold standard' Trans Urethral Resection of the Prostate (TURP), a number of health boards have introduced laser treatments and one board has introduced the new Urolift system.

Green Light Laser treatment (GLL) which is used to vapourise tissue blocking the urine flow is now available in NHS Lothian at St. John's Hospital, Livingston; in NHS Ayrshire and Arran at Ayr University Hospital, and is being trialled in NHS Fife at Victoria Hospital Kirkcaldy.

Another form of laser treatment called HoLEP (holmium laser) which trims off tissue blocking the urine flow is also available in NHS Forth Valley and in NHS Tayside at Dundee. Green Light Laser treatment for BPH is also to be found privately at Spire Murrayfield Hospital Edinburgh.

A new minimally invasive form of treatment called Urolift which is different from other procedures, in that it involves using a small tool to place stainless steel 'anchors' or 'tiebacks' to hold back the enlarged tissue that is blocking the urethra (water pipe), has been introduced on the NHS for the first time in Scotland in NHS Fife. It is also to be found privately at Spire Murrayfield Edinburgh.

Prof. Alan McNeill Consultant Urological Surgeon at the Western General Hospital Edinburgh and a Trustee of Prostate Scotland said: 'It is good to see more options for men with BPH who need surgery becoming available across Scotland as many men ask about the newer less invasive treatments'.

Prostate Scotland has produced an information guide on treatment for an enlarged prostate by TURP, GLL and HoLEP which is available via prostatescotland.org.uk/resources, or by contacting Prostate Scotland. A booklet about the UroLift procedure is currently in production.

Medical news

The Scottish Medicines Consortium have decided to make Cabazitaxel (Jevtana®) available via the NHS in Scotland for men with advanced prostate cancer after standard chemotherapy has failed. The decision in December 2016 followed a resubmission after the medicine had been turned down earlier in June 2016 and in 2011. The SMC assessment process included engagement with and submissions from prostate charities and clinicians.

Prostate Scotland commented that: 'This is a helpful and welcome decision for men with advanced prostate cancer as recent research has shown that the administration of Cabazitaxel for men with advanced prostate cancer after failure of standard chemotherapy can have benefits and may lead to longer survival. We are pleased that the Committee have agreed to approve Cabazitaxel for men with advanced prostate cancer where standard chemotherapy has failed as the option of being able to access this treatment (where it is

clinically indicated) could be helpful (particularly for men with visceral metastases), as there are not that many options for men in these circumstances'.

The decision on Cabazitaxel follows earlier decisions in 2016 and 2015 by SMC to make Enzalutamide and Abiraterone available pre-chemotherapy as well as post chemotherapy for men with advanced prostate cancer.

Prostate Scotland

Patron: Sir Tom Farmer CVO CBE KCSG DL Chairman: Robert Wilson Company Secretary: Alison McNeill Treasurer: Mary Hallam Trustees: Alan McNeill, James Thomson OBE, Anna Gregor CBE, Alan C McLaren, Julia Miller, Graeme Conn

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