

NEDPSA

*North & East Devon
Prostate Support Assn*

Newsletter

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Don't forget. March is Prostate Cancer Awareness Month. Let us all do our bit to spread the word!

THE
PROSTATE
CANCER CHARITY

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AWARENESS MONTH

The years seem to flash by and once again Prostate Cancer Awareness Month has crept up on us. This year we are very grateful to the Prostate Cancer Charity, as always, for all their work in promoting awareness but in addition for their permission to use the artwork for this year's theme on the front and back pages of our Newsletter.

It certainly adds a touch of class to this edition, don't you think?

Now start asking yourself what you can do to support the campaign. There are lots of ideas on their website

<http://www.prostate-cancer.org.uk/get-involved/event/pcam>

Some are a bit extreme, like joining their Sky Diving Team - I will give that one a miss - but there are plenty more. First of all why not sign up and order your awareness and/or fundraising materials now. They contain everything you need to raise awareness and raise money - from toilet door stickers to event tips.

Join in the Day of Action Campaign for the end of the month if you like but most of all do your best to spread the word. Awareness and knowledge is half the battle.

If you are not on the internet you can get all the necessary details by phoning the Prostate Cancer Charity on this number - **020 8222 7141**. They will be happy to answer all your questions and requests.

We are also pleased to see that once again we have the support of Marks & Spencers (M&S) again this year. Last year they did a great job throughout the month in all of their stores throughout the country - even on their outlets on the Motorway Services.

Please show you gratitude by popping into their stores even only to see what they are doing this year. Whilst you are there why not buy a pair of socks or let your wife go loose with your credit card. Let them know how much we appreciate what they are doing. So inspired, we can then help out by playing our part, no matter how small.



ADAM GIFFARD

Adam Giffard died peacefully at his home near Barnstaple, surrounded by his loving family, on 31st December 2010 at the age of 76.

He was born in London on 3rd June 1934. Despite the fact that his parents divorced when he was still a toddler he had a happy childhood, especially with his mother's Scottish side of the family, and his stepfather Donald whom he loved very much.

Much to his confusion Adam became Viscount Tiverton at the age of 10 when his grandfather died. Even at that age he was uncomfortable with such a title, fearing that fellow pupils might befriend him for his title rather than for him as a person. He maintained his distaste of hereditary titles throughout his life.

His father, a member of the Royal society, was a scientist with a brilliant mind while his stepfather was something of a lovable roué with a love of boats, a passion which he passed on to Adam who had great admiration for these two contrasting characters throughout his life.

Adam inherited his father's intelligence; he was incredibly bright and multi-talented, going on to Cambridge University and growing into something of a Renaissance man – a polymath.

Adam spent much of his adult life in the States. Having attended film school in New York he became a well respected documentary cameraman. It was through his film work that he met Joanna in the early 1970s and they married in 1976.

They bought an old cider mill so that Adam could realize his dream of making British-style, alcoholic cider, at that time illegal in the States. In between rebuilding a whole new structure within the mill, so that people could watch it in action, he also got the New York legislature to amend the law so that his product became legal.

Adam loved a challenging project which he would see through to absolute completion. A three-storey water-mill with a 24ft wheel in Milford, Pennsylvania was the next project some 14 years later. This one took four years to finish. A fully functioning mill with new leat, demonstrating corn grinding, and a collection of shops was the result – a business that is still going strong today.

Adam's final task in the States was to load into a 40ft container the family's possessions for the return to the UK in 1990

Back in England Adam showed his immense versatility, working for a time for Dorothea Restorations repairing listed buildings and bridges. His next project was growing reeds for sewage treatment. He re-searched and devised how to grow reeds from seed, which had not been done before.


Renewable energy was next on the list. He surveyed across Exmoor for possible hydro-power sites and then developed wood chip and pellet heat systems, one of which he installed to heat the family home. Robin Cotton, his partner in the wood heat industry, remembers two of Adam's wise sayings: "things are never as good as they seem... and never as bad as they seem" and "never invest in anything that eats or rusts".

In 2003 he discovered on a Worcester river a barge hulk, called *Darby*, originally built in Appledore in 1903. He brought it down by tug with a plan to refurbish it and use it for touring the French canals. He was unable to finish it, and his final act was to find a sympathetic new owner to bring it to fruition. .

Adam was diagnosed with prostate cancer in 2000 and given two or three years to live. He survived for ten and typically became more knowledgeable about his condition than his doctor could ever hope to be.

He survived a catastrophic accident in late 2009, suffering a 25ft drop while riding a quad bike, breaking vertebrae, neck bones and ribs. After months of intensive care and huge determination on his part he learned to walk again.

Adam is survived by his wife Joanna and daughters Emma and Sarah and will long be remembered as a stalwart of NEDPSA from its very early days and a founder member of the Barnstaple Group. He provided much useful information and encouragement to many Association members and will be sadly missed by all who knew him.



**things are never as good as they seem
.....and never as bad as they seem**

SIDMOUTH

We met on 23 November at our usual venue, the Royal York and Faulkner Hotel with 19 members and four apologies. Jane Billing, Urology/Oncology Nurse Specialist, was our speaker.

Jane had recently attended the BAUS Section on Oncology Annual Meeting at the Olympia Conference Centre, London, which was entitled **Prostate Cancer: The Way Forward** so we were privileged to hear the latest news on the treatment and management of prostate cancer. We are always so grateful to Jane for the information she brings and her expertise in handling our concerns.

We held another meeting on 14 February with 22 members and 2 apologies. We were to have had a speaker from Cancer Research UK but she had to cancel. After the usual announcements of dates for forthcoming meetings, both Sidmouth and the Isca centre, we handed out questionnaires from the Prostate Cancer Charity who are researching fatigue. John Perratt spoke about the January Association meeting for those unable to attend.

The extra time given us by our speaker's non-appearance gave us an opportunity to introduce new members and invite them to talk about their treatments.

One expressed his surprise that no-one else in the group had had an orchidectomy which prompted discussion and another told how he had requested a genetic test for the prostate cancer gene which proved positive. This gentleman had then monitored his PSA over a 10 year period before opting for treatment recently.

A long-standing member cheered us all when he reminded us of his 16 years of treatment which have included several courses of chemotherapy during the last seven years. He looks the picture of good health! As always, there was much humour to alleviate the worries and positive attitudes prevailed.

Our next meeting will be on Monday 9 May at 10am at the hotel. Newcomers are very welcome to join us.

Jennifer and David Jannaway

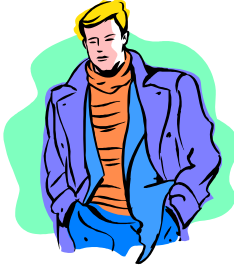
Telephone 01395 567159

LADIES GROUP

Following our successful Christmas Lunch at the Exeter Catering College, we are going there again for lunch on Wednesday 23 March. Partners/husbands/better-halves/toy-boys are most welcome to join us.

If you are interested and have not already confirmed with me that you are coming, please ring on 01392 876001.

Dinah Quastel



EXETER GOES TO DAWLISH

On the 7th January the Exeter group held a 'Christmas Dinner' at the Langstone Cliff Hotel at Dawlish Warren.

Unfortunately, the adverse weather took its toll of those attending as the snows and winter ailments caused some half a dozen members to cancel.

In the event, ten hardy souls did manage to get there and we all enjoyed an excellent four course meal served in a very grand dining room and expertly served by very attentive staff.

After the meal we were not at all hurried to vacate and so we all went on to enjoy some good conversation and putting the world to rights over coffee, before finally dragging ourselves away and heading home.

The event was organised by Tony and Val Hanson and the downside for them is that, despite the weather, it was so successful they will have to organise another one for next year and perhaps use their influence and arrange some better weather.

Graham and Joyce Sluman

Mike and Moyra Pulman.



BARNSTAPLE

Our annual pre-Christmas lunch took place at the Williams Arms in Braunton on 25th November and was much enjoyed by all who attended. Sounds like it could be a good venue for next year!

As the New Year dawned, we weren't quite sure what to do next, so the group held an informal meeting in February to work out a plan of campaign.

The only firm commitment so far is a visit to Marwood Gardens on Sunday 8th May followed by a lunchtime barbecue, generously hosted by Richard and Lesley Banbury. We also have some interesting ideas for future social events later in the year although details have yet to be finalised.

On a more formal note, there will be a prominent display of NEDPSA material in the foyer of Barnstaple library at the end of March. Bearing in mind that this might attract some interest from outside the group, there will be a "drop-in" coffee morning at the Royal and Fortescue Hotel on Thursday 14th April for existing and potential new members. Please drop-in if you can!

Tony Lowe

TORRIDGE

Torrige held a meeting which was followed by a game of skittles at Frithelstockstone (!) Village Hall on 10 February.

Those attending had an enjoyable time. Many thanks to Edward and Velve Ley for arranging the venue and providing refreshments.

Ron Cave.

HONITON

Flushed with his success last year Paul Godfrey, son of our Vice Chairman Brian, is again running the Great West Run and will be raising funds for NEDPSA. Look out for him - he is the guy in the Orange Suit!

Budleigh and Exmouth

There were 17 members (and 5 apologies) at our meeting at Tidwell Manor on 23 February 2011 when our speaker was Tricia Heard of the Macmillan Cancer Support. She told us that the Charity originated 100 years ago and went on to give details of the wide range of activities they undertake in support of cancer patients. These include the funding of the well known Macmillan Nurses, the provision of information booklets and leaflets, organising cancer support groups, financing doctors, dieticians and specialist advisers on all aspects of cancer, as well as offering grants and financial support to individual patients.

She emphasised that the help of Macmillan Nurses is not restricted to the final stages of cancer treatment but is available at all stages from diagnosis onwards. In our own area, they operate in close liaison with Hospiscare and avoid overlapping. After dealing with members' questions, Tricia was thanked for giving us such an interesting and informative talk.

One of our group, Elaine Raymond, is competing in the Great West Run on 1st May and there was a good response to a request for sponsors. The money she raises will go to NEDPSA and the Chestnut Appeal.

David Warner produced and distributed copies of the latest print of the NEDPSA leaflet and also drew attention to recent press reports, including the announcement a fortnight ago that US scientists have now cracked the genetic code of prostate cancer, opening the way to a new understanding and treatment of the disease. Also some amusement, and no little incredulity, greeted the news from the Institute of Cancer Research that men with longer index fingers than ring fingers were a third less likely to develop prostate cancer than men with longer ring fingers! Research has established that the relative length of fingers is determined before birth and is thought to relate to the levels of testosterone a baby is exposed to in the womb.

Our next meeting has been scheduled for Wednesday 4 May at 10 am for 10.30.

David Warner

Telephone 01395 442707



Scenes from the 'Ladies' Xmas Lunch at the Catering School, Exeter College



The Exeter Group Xmas Lunch

Tony Hanson and Lee Manley getting stuck into the pudding at the Langstone Cliff Hotel, Dawlish Warren. If you look carefully you can see the snow on the cars outside.

ASSOCIATION MEETING - JANUARY

Mervyn kicked off the meeting with the usual admin stuff and then let us all know that copies of the saucy Chestnut Appeal 2011 Calendar were being offered in return for a small donation. At the start of the coffee break these were being snapped up by the ladies and one was even seen with a large pile under her arm. The Appeal will be delighted to have found such a lucrative market. Thank you, ladies!

Carmel Franconi then spoke to us about the Expert Patients Programme.

This is a programme funded by NHS Devon which provides courses designed to help improve the quality of life for those with long term health conditions. Prostate cancer with its lengthening survival rates, attendant side effects and imposed life style changes qualifies all of us as 'experts' in that we know what it is like to live with the condition, unlike our health care professionals.

The courses are run by trained tutor volunteers who are themselves living with a long term medical conditions and so are well placed to empathise with those on the course who may include Carers whose own health is affected as a result. It aims to help people gain control of their situation and give them the confidence to cope with their problems. Apart from the obvious content like relaxation techniques, healthy eating and exercise, the six week programmes (in sessions of 2 and a half hours each) draw up a plan of action to cover topics like dealing with tiredness; managing symptoms and medication; coping emotionally; problem solving; communicating with family, friends and health professionals; evaluating new health information and monitoring one's own progress.

Courses are run in groups of a maximum of 16 and are designed to run alongside treatments provided by health care professionals and after the completion of the course and a reasonable gap a 'Reunion' is held to see how everyone is getting on. By

“ a 7% drop in GP consultations; 10% fewer outpatient visits; 16% fewer Accident & Emergency attendances; and a staggering reduction of 18% in medicine prescriptions ”

this time of course many friendships have been established and this of course in itself is part of the secret of the courses success. Feedback from these reunions has also been impressive and participants have reported a 7% drop in GP consultations; 10% fewer outpatient visits; 16% fewer Accident & Emergency attendances; and a staggering reduction of 18% in medicine prescriptions. In general it has given people the self confidence to really make a difference to their lives.

Anyone want to go on one of these course could be referred by their GP but could also simply apply themselves by using the free phone telephone 0800 073 0792. Further information can also be found on the website www.expertpatients.nhs.uk. The courses are however limited to those over the age of 18.

Since 2003 14 tutors have been trained in the county (including our own Tony Lowe) but Carmel is constantly on the look out for more. She looked around expectantly and one hopes that as a result of her interesting and informative talk she may have had some success in that area.

After the Coffee Break it was to a welcome return by the popular Malcolm

Crundwell, one of the team of Urologists at RD&E Wonford. He said that he would take questions either at the end of his talk or as and when a subject arose. We were also delighted to hear that he had made arrangements so that he did not have to rush back to the hospital afterwards and so would be available to chat on an individual basis to anyone who wanted to speak to him privately.

He then took us through the latest developments in 4 different areas - Prevention, Screening, Diagnostics and Treatment. Prevention is largely about life-style - diet and exercise, both of which are well establish factors and there was nothing new to report there although there was a tricky question from the audience about the effect of growth hormones on meat and could that be countered by sticking to organic food. Faced with some eminent members of the

“ the successful introduction of Multi Disciplinary Teams (MDT's) ”

farming community, Malcolm felt unqualified to comment on the practice but with a smile he admitted that he knew of no research on the matter.

Screening is of course an old chestnut, not helped by the publication last year of 2 major trials. One of these in the United States indicated no benefits from screening whilst the European trial came up with the opposite view. What is clear though is that it takes an awful lot of screening and follow up investigation to save just one life. He pointed out that half to two thirds of prostate biopsies turned out clear. This led naturally on to diagnostics where a four year trial had just started in Cambridge on a 'Do It Yourself' urine test for PSA levels. Oxford, not to be outdone, is looking at biological profiling in order to develop more accurate diagnostic tests. The necessary procedures unfortunately mean that we are looking at a five year time scale before anything positive can come out of it.

When it came to treatment Malcolm commented on the successful introduction of Multi Disciplinary Teams (MDT's). After their introduction some years ago it appears that survival rates are up and more patients are expressing satisfaction with their treatment pathway. Initially the meetings were fitted in around the specialists' schedules but now the whole of Monday mornings have been set aside for these meetings where all factors are taken into account and fully discussed. In response to questions it was confirmed that these meetings were not only for new cases but also were used where there was a recurrence of a problem. He also confirmed that the people from North Devon were not only included in the scheme but in fact had a bonus with one meeting in Barnstaple followed up by another in Exeter.

Open prostate surgery was still being performed in Exeter, but there were options for Keyhole prostatectomies in Taunton and Robotics in Bristol. Cryotherapy had been restricted to Guildford although Bristol now had the facilities for it. Previously NICE had rejected Cryo as a treatment but that decision had been reversed and it was now funded,

“A son is at greater risk if his father contracted the disease at a young age”

like the other treatments, by the Primary care Trust. This led to the inevitable question about the proposed demise of the PCTs and the taking over of their functions by GP practices but in Devon the existing set up was well geared up for this and he felt that, as patients, we would notice very little difference.

Another recent development is the use of open surgery as a salvage procedure after Radio Therapy. It is not common at present and the surgery is tricky. Intensity Modulation Radio Therapy (IMRT) is also adding a new dimension to Radio Therapy in that it monitors movement during the treatment. He also mentioned Dutasteride which is a drug used for the treatment of benign prostate enlargement. It is not a treatment for prostate cancer but a recent trial suggests that it does play a part in keeping it at bay. One of our members had in fact taken part in the trial and his PSA count had gone down and had stayed static at acceptable levels.

A wide range of questions followed and in particular went into the question of family connections. A son is at greater risk if his father contracted the disease at a young age and this applied more so if his father's brother was the same. Under these circumstances a PSA test for the son would probably be advisable around the age of 45 to 50.

He also answered a question about genes and said that the BRCA gene that that can give rise to breast cancer can be carried by men but there had been no published research as to whether the same applies to women and prostate cancer.

Unfortunately time caught up with us and the proceedings had to be called to a close with many grateful thanks to our speaker for his talk and sympathetic attention to us as real people and not just patients.

As the meeting closed David Beard stood up and wished to acknowledge the role played by Ann Branson ever since the Association came into being. She will be standing down at the next AGM and will be sorely missed. For many members she was their first contact and she was always available for anyone wanting reassurance or advice. Her sympathetic approach and genuine interest in everyone that called was of great value to the Association as a whole as well as to the individual. **Thank you, Ann!**

DATES FOR YOUR DIARY

Wednesday 9 March - Tiverton/Cullompton/Honiton Lunch at the THREE TUNS, Silverton at 12.30 pm. Please phone Ken or Sylvia Trow on 01392 841603 for details

Wednesday 9 March - The Exeter Group are having a coffee morning at 39 Clyst Valley Road, Clyst St. Mary at 10.30 a.m.. For further details contact Tel Tony Hanson 01392 874254.

Wednesday 23 March - Ladies Group Lunch at the Catering Department Exeter College (partners/spouses welcome) - Please phone Dinah if you are coming - 01392 876001

Thursday 14 April - Drop in Coffee Morning at the Royal & Fortescue Hotel, Barnstaple. All welcome to pop in!

Thursday 21 April - Association Meeting. ISCA Centre 10.00 am. AGM followed by Dr. David Jenner on "the GP's Role with Prostates, Past, Present and Future."

Wednesday 4 May - Budleigh/Exmouth Group meet at Tidwell Manor at 10am for 10.30. Tel David Warner 01395 442707 for further details

Sunday 8 May - Barnstaple Group are having a lunchtime Barbecue at Marwood Gardens. Further details can be obtained from Tony Lowe (01598 740331)

Monday 9 May - The Sidmouth Group meets at the Royal York & Faulkner Hotel at 10.00 am. Details from David or Jennifer Jannaway (01395 567159).

Thursday 25 July - Association Meeting at the Cedars Hotel, Barnstaple. Speaker to be advised.



**MAKE SURE THAT
ALL YOUR
FRIENDS AND
FAMILY ARE
AWARE!**

**THE
PROSTATE
CANCER CHARITY**