

NEDPSA

North & East Devon
Prostate Support Assn

Newsletter

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The Cedars in Barnstaple , pictured above, provided a perfect setting for our first foray into the depths of North Devon for our quarterly Association meeting in July.



For those not wishing to venture so far, the West Cliff Hotel in Sidmouth provided a very pleasant alternative for the Exeter Group's recent coffee morning. Details of both events inside.

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A REAL BREAKTHROUGH THIS TIME?

The University of Surrey has announced the discovery of a biomarker, Engrailed-2 (EN2), that is considered to be a major breakthrough in the diagnosis of prostate cancer.

A simple urine test, it detects between 60 and 70% of prostate cancers on its first use and rarely gives a positive result in patients with no prostatic disease. This is about twice as effective as PSA.

In only 4% of cases is a signal generated where cancer has not then been confirmed by a needle biopsy (which doesn't mean that the result is wrong in that the biopsy doesn't always pick up the cancer) This is roughly 10 times better than PSA.

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It is anticipated that the regulatory barriers could be sorted out within the next 18 months and the test could then be available for wide-spread use.

Lesley-Ann Simpson of the Chestnut Appeal passed this information on to us and she is very excited about the development and will be visiting the University in the near future to update herself on the situation and see if the Chestnut Appeal could start rolling it out.

This follows their mass PSA testing exercise that they carried out in March in conjunction with the Graham Fulford Trust and the Kidderminster Group. They hired the Guildhall in Plymouth and tested 301 men. The results were sent away for testing and 8 of these proved positive and required further investigation and treatment.

In contrast the EN2 test will produce a result straight away so that advice and counselling can be given on the spot. It is also interesting to note that the test is seen as complementary to the PSA test which is the standard tool for tracking the progress of prostate cancer after diagnosis.

Thanks to Lesley-Ann for bringing this to our attention.





Exeter Chiefs

The West Country's Premier Rugby Club

Exeter Chiefs are now regularly attracting crowds around the 10 000 mark for their Premiership Games. Their new stadium has ensured that it is an attractive venue in keeping with the quality of play on the field. They surprised everyone last season, their first in the Premiership, finishing well up the table in contrast to the doomsayers who had predicted an early return to the National League by way of relegation.

The club and ground have both been built up and developed on sound financial policies but conscious all the time of their social responsibilities they have put back much in to the local community. One way of doing this was to help Charities by either paying them to provide Parking Supervisors on match days or else allow them to do a "Bucket Collection" at half time during matches.

A few of us have done our bit on the Bucket Collections and in fact have enjoyed the experience as it comes with free entry to watch the game. The demand from Charities was however so great that we were being rationed and could only get one game every other year.

That however has all changed now with the creation of the Exeter Foundation. This started with the Exeter Chiefs and a group of Exeter businessmen who wanted to create a focus for the future of the city and its surroundings, for the benefit of all citizens. Its main aim is to provide the City of Exeter and its surrounding areas with a 'Civic Trust' that will promote the community and pursue the vision of people who live and work here. The Foundation will act as a fundraising body with a commitment to the future prosperity of Greater Exeter, and also as a vehicle for promoting collective civic pride.

To that end The Chiefs have adopted a new system whereby charities are being asked to provide two collectors each for every home game

and at the end of the season all that they have collectively gathered is divided out equally between the participating charities. They trialled it last year with 17 charities invited to sign up and the amount distributed amongst them was in excess of £50 000!

This year, through the good offices of Lee Manley, we were asked if we would like to join in as one of beneficiaries of the Foundation for the current season. That was an offer too good to refuse. It will however require a commitment from our members. As it stands at the moment there are 17 home games (League and Cup) but if progress is made in the cups or playoffs it could be more.

“enjoy watching a good game of rugby; raise funds for the Association - all at the same time!”

Lee is co-ordinating all the volunteers so if you can help please contact him on 01392 251 620. If during the season he is away then Roy Quastel(01392 876 001) and John Perratt (01395 513 611) will be looking after the shop for him. Volunteers need not in fact be members of our Association, friends (possibly those with an interest in Rugby?) male or female can all help.

Of pressing concern is the first match which is in fact a pre-season friendly against the Welsh Scarlets on Saturday 27 August. The season proper opens a week later but the first Premier League home game is on Saturday 10 September versus the Newcastle Falcons.

Please think about it; give Lee a ring; enjoy watching a good game of rugby; and raise funds for the Association - all at the same time!





AT THE WESTCLIFF HOTEL, SIDMOUTH



THE EXETER GROUP INVADES SIDMOUTH AGAIN.

On the 16th June over a dozen members and spouses of the Exeter group returned to The Westcliff Hotel at Sidmouth where they met with some members of the Sidmouth group. In total 19 people were gathered for a very welcome get together and gossip.

After enjoying, very politely, served coffee and biscuits in the large clean lounge, the group split up, some members staying to continue the gossip side of things whilst others braved the showers and went out for a lovely walk around the nearby Connaught Gardens and Jacob's Ladder, with fantastic views of the East Devon Jurassic Coast.

Then, back to the hotel again where 12 members remained for lunch from a wide and varied bar meal menu and more gossip after which we all dispersed and headed home.

Once again, Tony and Val Hanson organised the day, which really does bring everyone together and bond people who are afflicted with the problem of why we are in this 'Social Club' in the first place.

It's just a pity that this time they had no influence over the very showery weather, but a very enjoyable day out nonetheless.

Many thanks to you, Tony and Val.

Graham and Joyce Sluman.

On the previous page we see some of those who came along and, on the back cover, even more of them! These photographs were taken by Ian Mitchell

The next meeting of the Exeter Group will be a coffee morning on Thursday 15 September at 39 Clyst Valley Road, Clyst St. Mary, EX15 1DD commencing at 10.30 am. All welcome

A timely reminder also for the Ladies Group who will be setting out on their afternoon cruise from the Quay in Exeter down the canal and river to Exmouth on Tuesday 6 September. Partners and/or spouses are very welcome and bookings should be made through Dinah Quastel on 01392



SIDMOUTH

We met on 11 July at our usual venue, the Royal York and Faulkner Hotel, with 21 present and four apologies. The usual announcements of forthcoming meetings were made and David Jannaway talked about several new drugs and a recent trial into resistance exercises which concluded that these exercises were more beneficial than walking or running in strengthening the bones.

Our speaker was Gerry Gillespie, Oncology Support Specialist, Force Cancer Charity. Gerry told us that Force was set up over 20 years ago and initially called Friends of the Radiotherapy Centre in Exeter. One of the first research projects looked at how to cut off blood support to ovarian tumours.

Force was the first to fund Brachytherapy within the Royal Devon and Exeter Hospital and led the way with chemotherapy pumps. Patient Support, working with nurse specialists followed. A project recently begun entitled "Some of the things I would like you to know" helps people to put their memories together for their families. Gerry spoke movingly of how one young man, who had been given a poor prognosis and had retreated inside himself, was gradually encouraged to talk and, with Gerry's help, create a sort of memory book for his loved ones.

The official opening of the Force Cancer Centre in Barrack Road took place six years ago. Since then almost 80,000 visits to the centre have been recorded and visitor numbers continue to rise (up 17% in the last six months). This beautifully designed centre is the venue for numerous support groups, and provides services including complementary therapies, relaxation and anxiety management, support and counselling, and an expressive art group. A benefits advisor is also available. An annual sum of £850,000 has to be raised to facilitate this work. The centre has now reached 'break point' and extra space is needed so Force has launched an appeal to raise £350,000 to enable a further extension.

Gerry is in his eleventh year of working for the Force Cancer Charity, four of those in the support team. His talk was much appreciated, particularly as he had spoken about a serious subject but punctuated his

talk with some lovely humour. One member commented that it was the best the group had enjoyed so far.

The next meeting in Sidmouth will take place on TUESDAY (not the usual Monday) 4 October at 10am. The change of day is to accommodate our speaker, Jane Billing, Urology/Oncology Nurse Specialist. Jane comes to us once a year and this is probably our most useful meeting, as she will update us on the latest news for prostate cancer patients. Come with your questions! Everyone welcome!

Jennifer and David Jannaway.

BARNSTAPLE

Sunday June 12th might have been the wettest day of the year so far but it did little to deter a hardy bunch of North Devon members from attending an “indoor barbecue” at Badger’s Drift in Braunton. Thanks to the sterling efforts of our hosts, Richard and Lesley Banbury, all went swimmingly (excuse the pun) and was much enjoyed by all who attended.

Our hosts provided a super venue and also laid on some excellent food and fine wine. Not even the intermittent wailing of their super-efficient smoke alarm could spoil their occasion! Thanks to their generosity, the event raised the princely sum of £60 to be donated to NEDPSA funds.

In July, the quarterly meeting of the association was held in Barnstaple for the first time (see separate report on page 12) and went down extremely well. We look forward to hosting the event again next year.

Our next social event will be a cream tea at “Carillion” in Barnstaple with Rod and Pat Bissett on Saturday 3rd September. This will be followed by a pub quiz in October and a pre-Christmas lunch in November.

Hopefully, some of our members will be able to squeeze in a visit to the ISCA Centre for the next general meeting on 20th October as well!

Tony Lowe

01598 740331

TORRIDGE

Six members attended the NEDPSA General Meeting held at " The Cedars ", Barnstaple on 21 July, 2011.

It was interesting to note that funding still seems to be controlled by the 'suits' of various PCT's and not by the specialist consultants and their colleagues who I feel have the knowledge and experience to prioritise more accurately.

I read an article in a national daily on 21.07.11 which stated that the number of cases of Prostate Cancer has risen in the last year from 30,893 to 34,593 ----- an increase of nearly 12%.

There are up to 5 possible new members for the Torridge Group. It is anticipated that the group will meet the new members at a meeting scheduled to be held during the week commencing Monday 24 October 2011.

Ron Cave.

THE TORCH BEARER

He has done it before - and he can do it again!

Gerry Crocker, 90 years young and a member of the Sidmouth group, has been nominated to carry a torch in the London 2012 Olympic Games, some 64 years after he carried the flame in August 1948 when the Olympic Games were last staged in London.

All this came to light when Gerry undertook a sponsored 90 minute walk along Sidmouth Esplanade raising more than £900 for the Royal British Legion and for the occasion he carried a torch. Not any old torch but the very one he used more than 60 years ago.

He was a Chief Petty Officer in the Navy at the time, and was invited to run on behalf of the Royal Navy/ Royal Marines Athletics Club, Plymouth Command. His section of the Torch Relay was between Alphington, Exeter and Hembury House in Peamore and afterwards all the runners were allowed to keep the torches they had had so proudly carried.

Unknown to Gerry, his name was put forward to take part in next year's 70 day torch relay by his wife Viv and their daughter Jill. He only found out when he received



an e-mail saying that he'd been entered into the ballot.

Viv said she'd put Gerry forward as a 'joke' but we think it would be great if he were selected and if so, the Sidmouth Group will be out in force supporting him.

Here we can see Gerry, above, preparing to set off on his run way back in 1948; and then on the left, with his historic Torch, as he got ready to do his Charity walk back and forth along the Esplanade in Sidmouth for 90 minutes. One minute for every year of his age!

ASSOCIATION MEETING – APRIL

By Ian Mitchell

We broke with tradition this month by holding the meeting in Barnstable at the Cedars Hotel instead of the usual venue at ISCA in Exeter.

The meeting was extremely well attended by more than sixty people including half a dozen new members.

The chairman opened the meeting by welcoming the new members and giving them a brief rundown of the group history and aims before introducing Ruth Burrow who has taken over from Ann Branson as the initial contact for new members. She explained what her role entailed and what advice she could give to new members.

Roy Quastel then reassured us that we were still financially solvent and thanked several members who had raised considerable sums by means of running half marathons, organising barbeques and so on.

Our first speaker was Terry Moon who treated us to a very poignant story. Terry had gone out to India in the early nineteen fifties to seek his fortune as a tea planter. Very soon after arriving, he met and fell head over heels in love with a local girl, swept her off her feet and married her.

However at this time the Raj still ruled in India and it was considered very bad form to marry “out”. She must have been a remarkable lady because she eventually won them over and became accepted by the expatriate community. They went on to have three children, two girls and a boy, who attended boarding school in Bideford.

Eventually Terry and his wife tired of being separated from their children and decided to return to Devon. She had by this time been diagnosed as diabetic and had also undergone a heart by pass. Despite this she remained incredibly focussed on her domestic responsibilities and when Terry was diagnosed with prostate cancer she gave him her total support.

When he went for treatment at Exeter she always accompanied him despite being subject to recurring heart attacks and Terry having to reverse roles and act as her carer. Sadly she died shortly after his treatment had finished.

The main point Terry wished to emphasise in rounding off his speech was the debt he owed not just to his wife but also his G.P. - a woman, and his consultant also a woman. Despite prostate cancer being a man's problem we are all deeply indebted to the women in our lives and those who work to eradicate this disease.

After this we had a short open session where members had a chance to bring up anything close to their hearts.

A concern was raised that personal details were being leaked to commercial organisations. The chairman agreed to raise this matter at the next liaison group meeting. Several members recounted their experiences of keyhole surgery about which they were all very positive.

It was proposed and agreed that the group should send flowers and our best wishes to Dr Sheehan who is currently ill. For those who do not know her, she is the Consultant Oncologist at the RD&E and responsible for the treatment of many of our members and has been a strong supporter of the group from day one.

We then dispersed for a tea break with the chance to meet some new acquaintances from opposite ends of the county and then after the break it was something completely different.

Derek Jerome, the Director of Clinical and Technical affairs at Galilmedical, gave a fascinating talk on the history of cryotherapy from it's early beginning up to the present day.

Cryotherapy is the science of destroying tissue by freezing it at ultra low temperature and although early attempts at treating prostate cancer were somewhat crude the science has now been refined until it now seems like an effective alternative to the more commonly used radiotherapy, chemo or surgery.

Unfortunately NICE, the body which decides what treatments can be made available on the N.H.S., has not yet given it the all clear but it certainly looks as though it might well be one for the future. Derek was an impressive speaker and answered a host of questions about the procedure with a great deal of authority.

Mervyn then closed the meeting by thanking the speakers and also Tony Lowe for his efforts in putting together such an enjoyable and interesting meeting.

BUDLEIGH EXMOUTH

David Warner who got the Budleigh/Exmouth Group started and has kept it running ever since has to give up the reins for a while. Family business requires him to move away from the area although he hopes (as do we) that it will be for a short while.

If all goes to plan he could be back in Budleigh sometime early next year. We wish him well; thank him for his efforts on behalf of the Association; will maintain contact with him; and look forward to his speedy return.

In the meantime Nigel Tucker will take over the reins and their next meeting will be some time in October at their usual venue, Tidwell Manor. Soosie Cole, the Specialist Nurse in Bladder and Bowel care at the RD & E, is expected to be the speaker and for those who missed her in Exeter last October this is another opportunity not to be missed.

For further details or enquiries you can phone Nigel on 01395 232834

MOVEMBER IS COMING

Over the last few years the **Movember** (Mo for moustache and November) movement has been growing in strength. What is it?

It is a campaign to create awareness of Prostate Cancer and on Movember 1st, guys register at Movember.com with a clean-shaven face and then for the rest of the month, these selfless and generous men, known as Mo Bros, groom, trim and wax their way into the annals of fine moustachery. Supported by the women in their lives, Mo Bros raise funds by seeking out sponsorship for their Mo-growing efforts. Last year, world wide it raised £48 million.

Mo Bros effectively become walking, talking billboards for the 30 days of November and through their actions and words raise awareness by prompting private and public conversation around the often ignored issue of men's health.

You don't have to do it with them, why not just do your own Moustache thing in November and send us a photo (before and after) for the next edition of this newsletter!

DATES FOR YOUR DIARY

Wednesday 31 August - Tiverton/Cullompton/Honiton Lunch at the THREE TUNS, Silverton at 12.30 pm. Please phone Ken or Sylvia Trow on 01392 841603 for details.

Saturday 3 September - Barnstaple Group are having a cream tea at "Carillion" in Barnstaple with Rod and Pat Bisset. Further details can be obtained from Tony Lowe (01598 740331)

Tuesday 6 September - Ladies Group Afternoon Cruise to Exmouth (partners/spouses welcome) - Early booking essential, please phone Dinah if you are coming - 01392 876001

Thursday 15 September - The Exeter Group are having a coffee morning at 10.30 am at 39, Clyst Valley Road, Clyst St. Mary (EX15 1DD). For further details contact Tel Tony Hanson 01392 874254.

Tuesday 4 October - The Sidmouth Group meets at the Royal York & Faulkner Hotel at 10.00 am for a morning with Jane Billing. Details from David or Jennifer Jannaway (01395 567159).

Thursday 20 October - Association Meeting. ISCA Centre 10.00 am. Speakers - Dr. Rajaguru Srinivasan, Clinical Oncologist from the RD&E - "**An update on hormone therapy and chemotherapy**" followed by Malcolm Gamlin, Chairman of Prospect (Bristol & District Prostate Cancer Support Group) - "**The work of the Prostate Cancer Charity**".

October (date to be advised) - Budleigh/Exmouth Group meet at Tidwell Manor at 10am for 10.30. Speaker Soosie Cole, Specialist Nurse, RD&E. Tel Nigel Tucker 01395 232 834 for further details.

Tuesday 1 November - Movember - get growing!



The Exeter Group, or at least those who didn't brave the weather outside, enjoying their trip to Sidmouth.

