

NEDPSA

North & East Devon
Prostate Support Assn

Newsletter

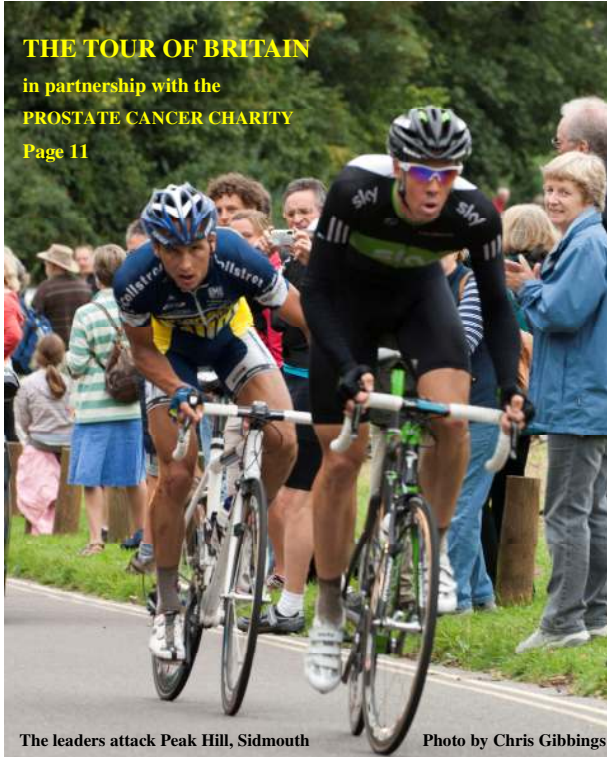
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THE TOUR OF BRITAIN

in partnership with the
PROSTATE CANCER CHARITY

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The leaders attack Peak Hill, Sidmouth

Photo by Chris Gibbings

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A BUSY COUPLE OF MONTHS!

Last month we had to expand the newsletter from 12 to 16 pages (got to be in multiples of 4) and this month we have had to keep it the same to include everything that has been going on.

There is no space for chatty articles or amusing little anecdotes just room for what everyone has been up to in the last couple of months. All the heavy stuff we leave to the experts and you can read that in the "Prostate Matters" publication that we send out together with this, our own newsletter.

Talking of "Prostate Matters" we did ask at the last ISCA meeting for members who want to receive notices and/or this newsletter by e-mail. The idea is that we can save a considerable amount in postage and stationery by doing so and there has been a reasonable take up. Please bear in mind though that we always send out the "Prostate Matters" with it so if you opt for e mail you will get both of them as attachments.

If you haven't subscribed to this yet and want to do so then please email Tony Lowe. His address is shown opposite.

THE AUSTIN HEALEY CLUB

Amongst their social and other non motoring activities the Club raises a fair amount for good causes and at the end of each year sends out cheques to one or two selected charities.

Lee Manley, who many of us have seen driving around in his magnificent Austin Healey 3000, is a member of the local club and last month we received a generous donation of £250 from them. Thanks Guys!

Incidentally Roy Quastel our Treasurer tells me that we have just received a Gift Aid refund cheque of £135.58 so the scheme does work. Thanks to everyone who co-operated in this respect.



PEOPLE WATCHING IN EXMOUTH

I have to confess I sometimes hurry past street collectors. But since I met so unexpectedly the disease which is diagnosed annually in 35,000 men in the UK alone, the plea for volunteers to help out our local group caught my eye.

You're not actually supposed to catch the eye of passers-by as you stand there with your collection box according to the strict guidelines issued by the organisers, and you're certainly not supposed to rattle it under punters' noses in that brazenly cheery fashion adopted by some charity hawkers. But I couldn't help studying the faces of people who did stop to put money in the box as I waited outside Exmouth's Tesco Superstore on Salterton Road yesterday.

And lots of people did stop. Even if it was just a few coppers, they paused on their busy way, giving me a few seconds' reflection on what had made them decide. For the young ones who I'd thought wouldn't notice me, was it a father or a grandfather who'd been diagnosed or even died from prostate cancer? Was the old lady in her 70s who silently pushed a £20 note in the slot before hurrying away still remembering the best friend or the husband she lost?

I started off trying to look a bit pathetic and grateful. And yes, it seemed to work as the collection boxes got heavier and heavier. But it was also fun to find myself joking with complete strangers about this annoying disease which comes out of the blue. The hour's stint that my friend Annie and I did passed quickly and easily.



We are grateful to Tesco PLC for its permission to use the Exmouth Superstore for its October collection day and a total of £483.26 was raised. "We're delighted with the result of the collection and would like to thank all those who contributed," commented David Warner. "The amount raised was more than double what we collected last time and shows not only that people know more about prostate cancer as a potential killer but also that they are more aware of the treatments that are offered nowadays."

Michael Downes

<http://budleighbrewsterunited.blogspot.com>

INTRODUCING HIS WORSHIP

YOUR ASSOCIATION SECRETARY Ian Mitchell

Family and Politics have long played a part in Ian's life and he clearly excelled in both. Six children, seventeen grandchildren and nine great-grandchildren bear testimony to the first and a Mayoral year in 1996 to the second.

And he is still a young man having been born in 1939 in Lanarkshire. Educated at Hamilton Academy, best known for their oddly named football team, he joined the R.A.F. in 1956 and served for five years as an aircraft engine fitter. On demob he moved to Largs in Ayrshire and worked for the S.S.E.B. at the Hunterston Nuclear Power Station for about ten years before leaving Scotland for fresh pastures. Unfortunately he still has that native dialect which immediately identifies him as from the wrong side of Hadrian's Wall.

It was then in Shropshire where he met and married Joyce and quickly got round to raising their family. This kept them very busy, very happy and very poor. Eventually Joyce persuaded him to move to Devon since most of her family lived around Exeter and a recent return visit to Telford has convinced him that it was a very smart move. He worked for many years as a Lab Technician at Howmet Engineering in Exeter and for a time with British Rail.

He joined the Labour Party in 1980 and in 1990 was elected to represent Pinhoe Ward on the City Council which he did until 1998 when he became disillusioned with New Labour. During his term as Mayor he had one unforgettable experience when on a very busy day he hurried into the Guildhall to greet a party from Terracina, our twin town in Italy. Ian had prepared some notes beforehand including an opening greeting in Italian. Surprisingly this didn't go down too well so he just assumed that his Italian accent left something to be desired. It was later



pointed out that it was in fact a party of academics from Brazil visiting the university!

He was diagnosed with prostate cancer in 2003 and treated successfully with radiotherapy at the R.D & E. hospital. His father died of throat cancer, his sister from breast cancer, Joyce lost a kidney to cancer and recently one of their daughters has been diagnosed with breast cancer so he is only too familiar with the disease. These experiences have taught him the value of support organisations such as ours and his acceptance of the long vacant position of Secretary is his contribution to the aims of the Association.

Now retired he enjoys the social activities provided by NEDSPA not forgetting the hours spent on the computer getting it to do what he wants in his Secretarial role and then there are the Civic functions that he is able to attend in his capacity as Honorary Alderman of the City of Exeter. The rest of his time is filled, as we can guess, babysitting or attending to the odd jobs about the house that used to take about two hours but now tend to take several days, if indeed they get finished at all.

TORRINGTON

Regretfully, I have to report the death of the Rev. David Sherriff BD. He departed this life on Sunday 1st August 2010. He and his wife Vivienne were strong supporters of the group and welcomed us into their home on several occasions for our meetings.

We were guests of Barnstaple on 19th August for a talk entitled **A PSA ROLLERCOASTER** by Alan Grimsley. I will not go into detail because I am sure that Tony Lowe will be covering it in his report. Suffice to say it was a very enjoyable presentation about very important matters. Nonetheless, it was at times hilarious. The man is a natural !

A pleasant lunch was enjoyed at the "Merry Harriers" on 28th October. Ten people attended with 3 apologies. There were various topics discussed including the format for future meetings - Anyone for skittles ?

Ron Cave

SIDMOUTH

We met at our usual venue on 20 September with sixteen of us and three apologies. After the usual announcements of our next meeting and the next Isca meeting, David Jannaway gave us the latest information he had gleaned from the internet. T

his included acupuncture for hot flashes which is proving beneficial for men on hormone therapy; two drugs in the news – Abiraterone and MDV3100 entering late phase trials are looking promising; the vaccine Sipuleucel-T will soon be approved by the FDA; and a phase 3 trial of the supplement Selenim has shown negative results.

David then introduced Tony Lowe who leads the Barnstaple group. Tony told us he had a history of prostatitis, had been feeling unwell, passing some blood when he consulted his doctor. After diagnosis he was offered “containment or cure”, surgery or radiotherapy? He opted for surgery and then told us in graphic detail, of the problems following his surgery. As he said, “Cancer OK, Continence big problem”.

We will not go into the gory details here but will just say that as he told his tale, there was wincing and pained expressions, we all felt for him! John Perratt relieved the tension by saying Tony had made him feel “thoroughly queasy” which provoked much needed laughter.

Tony had his prostatectomy in 2004 so has been battling for 6 long years. He took part in the Snowdon 500 Challenge in May 2009, raising a large amount for the Prostate Cancer Charity. Modestly, he said this was “a bit tricky”, referring to his waterworks problem, not the climb itself. I think we were all rather shocked to hear of the aftermath of his surgery but very impressed by his cheerfulness and fortitude.

Tony’s talk was by turns shocking, interesting and ultimately, inspiring. We wish him well for the future.

Our next meeting is on TUESDAY 23 November, not the usual Monday; this is to accommodate Jane Billing, Urology/Oncology Nurse Specialist. Any member is very welcome to join us at the Royal York and Faulkner Hotel, the Esplanade, at 10am.

Jennifer and David Jannaway

Budleigh and Exmouth

19 Members attended our meeting at Tidwell manor on 12 October (plus 4 apologies) to welcome Dr. Denise Sheehan as our guest speaker. She is already well known to many of us as the Consultant Clinical Oncologist at the RD&E Exeter. Details of her interesting and informative talk are set out in Michael Downes’ article below. As expected, Dr. Sheehan’s discourse prompted a host of questions, all of which received expert replies and we are grateful to her for sparing the time from her busy schedule to come and speak to us.

David Warner thanked all those who participated in the one day collection at the Exmouth Tesco store the previous week and announced that the total collected was £483.26 more than twice the amount raised at our last collection in 2007. In addition we dealt with several enquiries and handed out a good quantity of leaflets - a splendid effort by all concerned. Brian Bolt was also congratulated on raising £675 from donations by friends and relatives at his and Linda’s ruby wedding celebrations. This money is being divided between the Chestnut Appeal and a Breast Cancer Charity.

It was also announced that Michael Downes has volunteered to act as our linkman with the press, so we look forward to our activities becoming even more widely known in this area in future.

Our next meeting will take place on a date to be arranged in January or February next year.

David Warner

BARNSTAPLE

The group’s latest meeting was held at the usual venue of Fremington Parish Hall. Following a brief but substantial discussion on local business matters, we were joined by Mervyn Reed, David Jannaway and members of the Torridge Group to listen to our guest speaker, Allan Grimsley.

Allan proved to be a fine orator and caused great amusement with his tales of learning to fly. So much so that we began to wonder what the connection was with prostate cancer! However, as the story unfolded

it eventually became clear what a rocky road Allan had travelled since his diagnosis. This included some tense encounters with NHS consultants, a brief but encouraging flirtation with complementary therapy and finally a dramatic course of treatment with Tomotherapy.

This is essentially a very sophisticated form of radiotherapy but since there are only 6 machines in the UK, it's not readily available on the NHS. As Allan pointed out, his cure is not yet complete but nonetheless he's made a remarkable recovery from a very gloomy starting point and is optimistic about the future. If you want to know more about Allan's experiences, you can read a full account in the February edition of the association newsletter.

A Pub Quiz was held recently and our next event will be a pre-Christmas lunch at the Williams Arms, Braunton on 25th November. We're looking forward to a full attendance!

Tony Lowe 01598 740331

LOOKING FOR THE X FACTOR IN RADIOTHERAPY

On the face of it there's always good news from the front line in the battle against cancer, and it's impossible not to be optimistic about the final outcome. That was certainly the underlying message from clinical oncologist Dr Denise Sheehan, who spoke to the Budleigh & Exmouth Group about her work with radiotherapy for dealing with prostate cancer.

The story of radiotherapy as a treatment for cancer has been one of steady progress since the early days following the German physicist Wilhelm Röntgen's discovery of X rays in 1895. With no way of accurately judging either the amount of radiation to kill a tumour, or the precise area to be targeted effectively so as to avoid damage to surrounding tissue, it was a very hit or miss affair.

It seems that ignorance was bliss for both patients and doctors in those early days: while the angry red patch of skin which followed a course of radiotherapy was a sign that the treatment might have worked it also hid all the possible side-effects of the radiation.

Not until the late 1950s was a more accurate approach possible with the introduction of the linear accelerator, now used for Intensity-Modulated Radiation Therapy (IMRT), and only in the last 30 years has proper investigation of a tumour prior to radiotherapy been possible thanks to the CT scanner.



Ironically there's a bittersweet element to all this of course. How many of us have lost a friend or relative to cancer only to read, often just a few years later, of an improvement in treatment which would have made all the difference.

Similarly, as radiotherapy for the treatment of prostate cancer becomes ever more sophisticated, improvements in delivery or the amount of radiation to a tumour mean that the cancer is more likely to be eliminated for good. And the side effects suffered by patients who underwent treatment only a few years ago are now less likely to occur thanks to the advance of science. Some previously irradiated former patients listening to all this were by now wondering whether they'd received the right dose!

Funding, as always, seemed to be crucial, Dr Sheehan implied. There is, she told us, a national shortage of medical physicists, the people needed to develop scanning techniques for improved targeting as well as to devise ways of finding out if a particular patient will respond badly to a particular type of radiotherapy.

As for the immediate outlook in radiotherapy techniques Dr Sheehan said that High-dose rate brachytherapy (HDRB) was "a developing field." Inserting and then removing a source of high energy radiation directly within the tumour, using radioactive wires, means that delicate areas such as the urethra can be avoided, reducing the likelihood of side-effects like incontinence. The technique has been used in combination with external beam radiotherapy in the past, but it seems possible that HDRB on its own could be used in the future.

For a cancer patient with little medical knowledge but lots of trust in the doctors one can only feel enormous admiration for oncologists like Dr Sheehan who play such an important role in the fight against this killer disease.

Michael Downes <http://budleighbrewsterunited.blogspot.com>

THE TOUR OF BRITAIN

IN CONJUNCTION WITH THE PROSTATE CANCER CHARITY

The Tour of Britain Cycle Race, in partnership with the Prostate Cancer Charity, started in Rochdale on 11 September and finished a week later in London with two stages taking place in the South West.

Stage 4 (171km) started in Minehead and finished in Teignmouth. Considered the hardest stage, the route took the riders across Exmoor on to the Blackdown Hills, up Peak Hill out of Sidmouth and then for 40 km along the edge of Lyme Bay to the finish. Stage 5 (178km) the next day set off from Tavistock and finished in Glastonbury passing over Dartmoor and on to Moretonhampstead, Cullompton and Ilminster.

By coincidence the Tiverton Group were holding their monthly lunch in Silverton on the day stage 5 passed through and we were able to join the locals cheering the cyclists as they sped by together with the support vehicles and Police outriders - one blink and you missed them!



The professionals may have taken the limelight but two weeks earlier 1,500 amateurs tackled the same Stage 4 route raising funds for the Prostate Cancer Charity. There were in fact 3 stages open for anyone to have a go. This one in the South West and the others in London and Stoke on Trent.

Close to 5,000 all told took up the offer and such was the demand that they had to be set off in intervals to avoid too much congestion. The sheer volume of riders did however create a few traffic problems and one or two complaints were made but on the plus side £300 000 was raised for the Charity. That's worth a bit of inconvenience, surely!

Three local Councillors, Chris Wale, Roger Giles and Stuart Hughes also played their part being sponsored to ride the final section from Sidmouth to Teignmouth. David James and Daley Thompson also came along in support on what was a great day for everyone.

Roy Quastel

“ on the plus side £300 000 was raised for the Charity ”

NOT A LOT OF PEOPLE KNOW THAT!



Elephant polo?

You've got to be kidding? Well, apparently not.... It seems that Scotland really did become world champions in this most esoteric of sports in 2005.

If you didn't know that then you were in good company because neither did any of the other contestants in the Barnstaple Group's recent Pub Quiz! Despite the slight eccentricity of some of the questions, most of the teams scored well and, in a tight finish, "The Famous Five" squeezed across the line by a short head to claim first prize.

As one of the group's regular social activities, this event went down particularly well and in the process made a handsome profit of £163 to be donated to NEDPSA funds. Many thanks to all who gave their support and particularly those who donated raffle prizes.

THE LADIES GROUP

Our second visit to the Turf Hotel across the Exe from Topsham on 18 August was again a great success.

The weather and food were good and, this time, we were accompanied by several partners who otherwise were going to wait around Topsham for our return – the ladies enjoyed their company!!!



ASSOCIATION MEETING - OCTOBER

After the usual admin matters, Mervyn introduced our first speaker, Graham Fulford founder of the of the Graham Fulford Trust. Graham is a firm advocate of PSA testing and referred to the 'Great Debate' put on by the Prostate Cancer Support Federation on the subject of screening. Six specialists were required to speak, 3 for and 3 against screening. Those in favour were sincere in their case whilst those against it were quite happy to argue the case but would just have happily argued the opposite! We are all aware of the fallibility of the PSA test, the possibility of unnecessary anxiety and treatment but, as Graham pointed out, all of this applies equally to breast cancer and the recently introduced screening for bowel cancer.

In association with the Kidderminster Support group Graham's charity has organised meetings throughout the country where men are invited to have their PSA taken. The results of the test are first of all examined by their in-house urologist who then passes on the findings in the form of a coded letter. A 'green' letter will say that all is well but an annual test is recommended; an 'Amber' indicates a slightly elevated PSA and is one to watch with a suggested further test in 3 months; finally the 'RED' strongly advises the recipient to see their Doctor straightaway for further investigations.

To date they have tested 13 496 men of whom 12 019 (89%) were 'Green' and 621 'Amber'. The remaining 856 were 'RED' of whom 289 were confirmed cancerous by biopsy and went on for treatment. It is difficult, faced with these figures to argue against the case for screening on any other basis other than that of cost. Unfortunately the cost is considerable and in these straightened times the concept stands little chance of acceptance.

There was however good news as Graham told us about 2 new developments. The testing undertaken by his Charity included a 'free to total' test. If the free PSA is more than 18% of the total then it is more likely to be benign. As an illustration of this 284 of the Charity's 289 confirmed cases were below that mark. As such it is something of a breakthrough but the cost of the test doubles and it is not routinely done by the NHS.

The second possible breakthrough comes from a 'PSA watch' ma-

chine produced by Mediwatch plc. Its cost is negligible (£'000s) compared with conventional testing equipment (£'0 000 000s) and with recent refinements it is starting to give comparable results. Graham looks forward to the day when such machines become fixtures in Tesco or Boots so that men can have a test whilst their wives get on with the shopping.

He would be happy to carry out a PSA Testing evening in Exeter if asked - something for the committee to consider!

After coffee the second part of the meeting was pure joy!

Soosie Coles, the Specialist Nurse in Bladder and Bowel Care is another one of those gems that seem to crop up all over the RD&E. There can be few parts of the body less likely to be the subject of lively debate in open forum but the question and answer session after her talk could have gone on quite cheerfully for hours.

She described how their small unit had developed and the service that they provided. The time devoted to individual patients, accessibility and the follow up by phone clearly indicated a patient focused and caring service - specialist nursing at its best. Her favourite clients though came from post op radical prostatectomies and many of those present could vouch for the wonderful care that they had received at a time of considerable distress in their lives.

After outlining the most common problems that she encountered, she followed this with a detailed explanation of the procedure and workings of an artificial sphincter. These can revolutionise a patient's quality of life so much so that, had she been selling them I would willingly have bought one - and I don't even have a problem!

Her referrals mostly came from the wards, G Ps or outpatients but she also accepts self referrals and left her contact telephone number for anyone wanting to see her. I am sure she will be in great demand and once again we were reminded of how lucky we are to have so many talented and caring people at Wonford.

DATES FOR YOUR DIARY

Tuesday 23 November - The Sidmouth Group meets at the Royal York & Faulkner Hotel at 10.00 am with Jane Billing. Details from David or Jennifer Jannaway (01395 567159).

Thursday 25 November - Barnstaple Group meeting at the Williams Arms, Braunton. Further details can be obtained from Tony Lowe (01598 740331)

Wednesday 15 December - Tiverton/Cullompton/Honiton Lunch at the THREE TUNS, Silverton at 12.30 pm. Places are limited and filling up quickly so Please phone Ken or Sylvia Trow on 01392 841603 to see if they can squeeze you in.

Thursday 16 December - Ladies Group Xmas Lunch at the Catering Department Exeter College (partners/spouses welcome) - ***SORRY FULLY BOOKED***

Thursday 6 January - Exeter Group New Year Lunch at the Langstone Cliff Hotel, Dawlish at 12.30. The lunch will consist of 4 courses and coffee at a cost of £15 a head. Those interested should contact Tel Tony Hanson 01392 874254. Cheques payable to T A Hanson and must be sent to 39 Clyst Valley Road, Clyst St. Mary. EX5 1DD to be received before 15 December.

Thursday 20 January - Association Meeting. ISCA Centre 10.00 am. Speakers: Malcolm Crundwell, Consultant Urologist from the RD&E Wonford and Carmel Fanconi on behalf of the Expert Patient Programme.



Michael Downes and David Warner doing their bit at TESCO, Exmouth



Lunch at Turf Lock