

ISSUE No 48

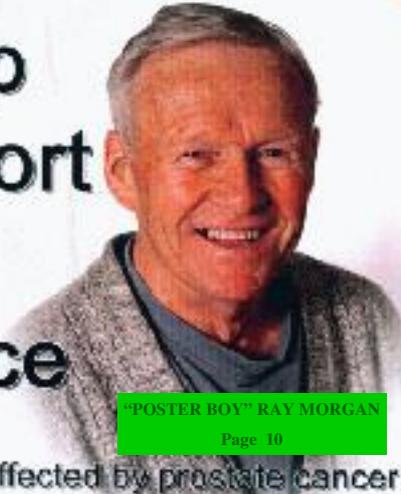
AUGUST 2015

*North & East  
Devon  
Prostate Support  
Association*

# Newsletter

Registered Charity No 1108540  
Patron: Sir John Cave Bt DL

**Help  
Support  
&  
Advice**



**"POSTER BOY" RAY MORGAN**

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for anyone affected by prostate cancer

This edition  
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Exeter  
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## WHITE COAT MEN (AND LADIES)

Most of us grow up with an in built respect for our GPs and this is probably true of the Health professions as a whole. On the other hand ask us who we dislike most on the road and we are likely to come up with the dreaded "White Van Man."

We were therefore shocked recently to discover that statistically, according to the website gocompare.com, the White Coat people have overtaken the van drivers as the most accident prone group of people in the country for the second year running.

It suggests that 27.8% GPs have made a car insurance claim within the last 3 years closely followed by the Hospital Consultants at 26.9%. Only 9.9% White Van Men in contrast have lodged a claim over the same period.

The data does not reveal the most common claims made by each profession, which would indicate whether the high number of bumps and scrapes by health professionals is down to their having to negotiate tight car parks in hospitals and surgeries or whether long working hours results in more serious accidents on the road.

Professor Andrew Smith of Cardiff University's school of psychology suggested that the rate of claims could be due to the stressful job. "Often" he said "when people experience a particularly stressful day, they find that they become clumsy or absent minded as they struggle to concentrate on tasks."

I prefer to think though that the Health Professionals are mindful of their positions and endeavour to keep up their standards and, in so doing, justify the respect that we were taught to show them in the first place.



## EXETER

We thought that we should try one further attempt at a coffee morning for the Exeter Group. After 10 years we do not seem able to attract any younger new members and the older regulars are falling away.

There will be a coffee morning at 39 Clyst Valley Road, Clyst St Mary, Exeter EX5 1DD on Thursday 17th September commencing at 10:30am. All members, especially new ones welcome. Please spread the word around and we hope to see some new friends on the day.

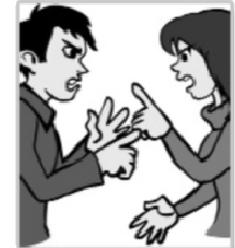
Contact Tony and Valerie Hanson for further details, 01392874254.

## PICK YOUR MOMENT

I sometimes think that this "Patients' Choice" thing is getting out of hand. In practical terms it is more likely to be a choice of where treatment will be offered rather than who does it. It seems however to have got to the stage where some people think that they can demand the Queen's Physician if they want to and see no reason why they don't get him.

Not so long ago I saw that Samer Nashef, the Cardiac Surgeon who helped to produce the Euro-SCORE system for assessing risk in operations has given a series of alarming warnings one of which is that patients are twice as likely to die if they go into theatre the day before their surgeon goes on holiday than the day of his or her return.

Obviously we all have good days and bad days but it does strike me as somewhat insulting to the integrity of our surgeons in such comments and why stop there. If the surgeon had a row with his /her spouse the day before going on holiday that will surely aggravate the situation but does that mean we have the right to know all the gory details?



## MEDICAL DETECTION DOGS

At our Association meeting in Barnstaple we were pleased to listen to Tim Sutton-Woodhouse who came to talk to us about the Charity "Medical Detection dogs" accompanied by his own dog.

Their work is concentrated into two fields - Medical Alerts and Cancer & Bio detection.

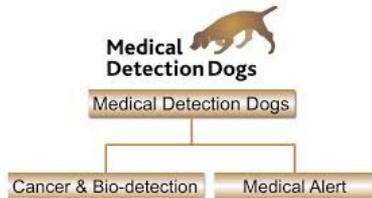
The former is the more advanced and they have had great success in helping patients

suffering from Type 1 Diabetes, Addison's Disease, Narcolepsy, Nut allergies, or pain seizures (but not including epilepsy).

In these cases a trained dog can pick up when there is a problem and alert his owner to the problem such as a drop in blood levels or the the presence of other dangers. One lady for example had a nut allergy which prevented her travelling because of the constant risk especially on airlines but this was overcome when she was provided with a dog to pick up the warning signs.

It takes about 18 months to 2 years to train a diabetes alert dog and so far 51 have been placed. They have a target of 12 -14 placements a year but with a 3-4 year waiting list and a cost of £11,200 per dog it is an up hill struggle and there is no Government funding.

On the other side of the coin is the newer Cancer Detection unit which has received a lot of favourable publicity lately. Based in Milton



Keynes it was given Charity status in 2008 and employs 22 people, mostly volunteers or contributors. They work also closely with many research projects at Universities throughout the country and abroad.



This detection unit has been studying the ability of dogs to detect breast and prostate cancer from breath and Urine samples respectively and they have a multi disciplinary team of eminent academics working with them. They have already published several scientific papers describing recent studies to demonstrate that dogs could identify the unique odours associated with certain types of cancer. A longer term aim is the development of an "E Nose" that will assist in the early detection of cancer through cheap non-invasive test.

These techniques can apply to all gaseous cancers (breast, lung, stomach, prostate etc) and tests so far with dogs have shown success rates in excess of 90% keeping them in line with similar work in the field of explosives and drug detection.

The small but attentive audience were grateful to Tim for coming along and he finished with the usual question and answer session which could have carried on for much longer had there been the time

## ORGAN DONATION

Our second talk at Barnstaple was by Tam Jackson, the Organ Transplant Specialist Nurse from the Royal Devon & Exeter Hospital, Wotton and she gave us a very comprehensive, interesting and at times controversial insight into the organ transplant work.

She started with why such donations were made. They are life saving and the only treatment available for the patient but there are other reasons, financial for example where a kidney transplant is cheaper than long term dialysis. Many people simply want to donate for altruistic reasons and others get comfort for the thought that they have benefited someone else. In fact the donor family are entitled to an outcome letter so that they know the good that has been achieved. NICE Guidelines also encourage people to donate.

She then described the different types of donations that could be made which could add up to a total of 9 people who could benefit from one donor. In the South West however the only operations that can be done are eye and heart transplants although we are also linked in to the National Network. The donations range from soft tissue and organs after

**"a total of 9 people who could benefit from one donor"**

either brain stem or circulatory death.

Three people on average die every day waiting for a transplant amounting to over 1,000 a year but in contrast all of us are more likely to need a donation than likely to become a donor. It is generally recognised that over 90% of the population support donations yet only 30% of them are on the Register. Follow up enquiries have shown that 36% of those who refused to donate regretted the decision later whereas only 6% of donor families regretted that permission was given.

According to the Tissue Act 2004 the next of kin can not override the wishes of a donor. However the NHS Guidelines do allow them to do so with the emphasis being on an informed decision, Obstacles in the way are usually personal or religious beliefs but there are other factors that come into play. Families often want to be consulted as a whole and frequently the media can get involved either for or against. In some cases of sudden death the Coroner may require certain conditions to enable him to carry out his investigation properly although they are usually sympathetic.

The Donor Register then took over the discussion with many of the audience in favour of an "Opt out" rather than an "Opt in" system. This was the case in Spain where donations are at a much higher level than here. The situation here is that in September Wales is going to switch to the opt out and the effect of that will be closely monitored with a view to changing the situation here as well. Tam, interestingly was not fully convinced and said that the discussions with donor families on the subject were the most rewarding part of her work.

Most people on the door register got on to it through the DVLA although the Boots Loyalty Card had attracted a good number. There is even an "i-tunes app" but for anyone wanting to sign up the easiest route is either through the internet or the organ donation telephone number (local call rates apply). Details are given on the right:



0300 123 23 23

organdonation.nhs.uk

## WAITROSE COMMUNITY MATTERS

Waitrose started it all out in Sidmouth for us when we were selected as one of their good causes for their £1 000,00 monthly draw. We were up against Mcamillan in that month but still cleared a handsome proportion of the pay out.

The challenge was then taken up by Ruth Chandler, our hard working Secretary, who organised a spot for us recently on the New Exeter Waitrose Site which as reported last month raised £370 for us as a result of which this copy of our Newsletter has been totally sponsored by that amount.



*"A nice problem for the committee to ponder and our thanks once again go out to Waitrose for their further generosity."*

The good news though does not end there as we were then invited to a Cream Tea Event put on by Waitrose for all the causes that they had helped over the past year. There were about 30 charities represented with the Right Worshipful Lord Mayor of Exeter, Councillor Olwen Foggin being the Guest of Honour.

At the tea they put each charity name in a box and gave a £100 Waitrose store voucher to one lucky charity. NEDPSA was that lucky charity! The voucher has to be spent in Store but I think we can probably put it towards

some raffle prizes and hopefully at least double the face value. A nice problem for the committee to ponder and our thanks once again go out to Waitrose for their further generosity.

Unfortunately the photo does not do the occasion justice but it does show the Store Manager introducing Cllr Olwen Foggin just before the draw of our name from the hat.



## BUDLEIGH AND EXMOUTH

We had a most enjoyable and informative meeting at the Manor Hotel, Exmouth on 4 June when our guest speaker was John McGrath, Consultant Urologist, from the RD&E, Wonford.

Opening the meeting, David Warner thanked all those who had taken part in the highly successful collection at TESCO in April. We have now also received a supply of the recently produced leaflet giving details of NEDPSA. These will be useful for passing on to anyone who may be interested. He mentioned also the almost daily press reports of "breakthroughs" in prostate cancer research which could well bear fruit in future years. One of the most bizarre he had come across was a newspaper report claiming that dogs have been trained to detect cancer by sniffing a patient's urine! Who knows? We may one day see dogs replacing PSA blood tests.

Interestingly this was one aspect of the Medical Dogs Detection talk given at our Barnstaple meeting and further details on this are on page 8.

At the outset of his talk, John McGrath gave details of recent staff changes at the RD&E including a number of additional posts made necessary by the ever increasing workload, especially in the field of robotics. He also emphasised the importance of genetics and of the IMPACT clinical trial which he is leading in conjunction with Exeter University. Progress in genetics is bound to raise ethical problems, such as whether a patient should be told which diseases he has a propensity to face in later years.

Another interesting project he mentioned is the use of light probes for biopsies in place of the solid probes. Apparently the colour of reflected light can be an indicator of the presence of cancerous tumours.

As always his talk prompted a good number of questions mainly this time related to robotics and the genome alphabet. He was warmly thanked for sparing his time to come to us and giving us such an entertaining meeting.

Our next meeting will be on Thursday 8 October when Anne Searle, Genetics Nurse Counsellor will be the speaker.

David Warner Tel: 01395 445 614

## BARNSTAPLE

Our most recent event was the quarterly General Meeting on 16<sup>th</sup> July. Held as usual at The Barnstaple Hotel, we welcomed Tim Sutton-Woodhouse from the Medical Detection Dog charity and Tam Jackson, Specialist Nurse for Organ Donation from RD&E. The meeting is reported in more detail elsewhere in this newsletter, so I'll keep my comments brief.

Suffice to say that both speakers provided some useful insights into two interesting but contrasting subjects, which occasionally generated a bit of lively debate. Sadly, attendance was extremely poor. Since we started holding annual meetings in Barnstaple, attendances have gradually slumped from a peak of 66 in 2011 to a mere 15 at this year's meeting. Whilst July is a busy month for many and people clearly can't be expected to attend every meeting that takes place due to other commitments, the figures are still hugely disappointing.

As a result I will not be arranging a July meeting in Barnstaple next year. However, if anyone else wishes to take up the challenge they're welcome to do so.

Tony Lowe

01598 740331

## “POSTER BOY” RAY MORGAN

Featured on our front cover this edition is the very first NEDPSA poster which saw Ray Morgan's good looks spread all over our area.

He and his late wife Sheila lived in Tiverton and the Cullompton / Honiton members used us to go along to their house for coffee and biscuit evenings before they settled on the lunches at the 3 Tuns (now moved to the Ruffwell Inn, Thorverton).

He first came to Tiverton as an evacuee on the outbreak of war, spent most of his working life as an engineer in the town and in retirement was active in the Museum where his voice can still be heard in many of the 'Talk Over' Exhibits.

We are sorry to record his recent death and our sympathy and condolences are with his family at this time

## DATES FOR YOUR DIARY

**Wed 2 September - Tiverton/Cullompton/ Honiton**  
Lunch at the Ruffwell Inn, Thorverton at 12.30 pm.  
Please phone Sylvia Trow on 01392 841603 for  
further details

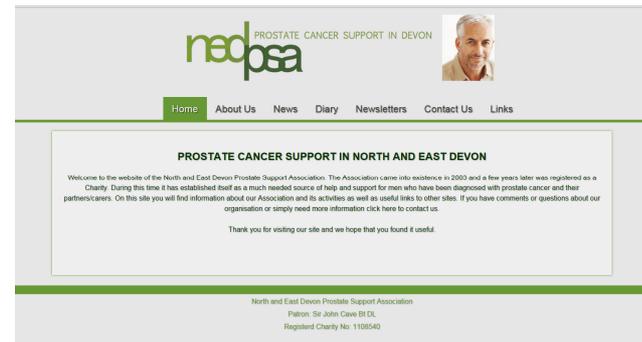
**Monday 7 September - The Sidmouth Group**  
meets at the Royal York & Faulkner Hotel at 10.00  
a.m. with Bill Lankaster founder of the Sidmouth  
Living with Cancer Group. Enquiries to Terry Fuller  
(01404 46996) or Jennifer Jannaway (01395  
567159)

**Thursday 17 September - Coffee Morning** at 39,  
Clyst Valley Road, Clyst St Mary EX5 1DD at  
10.30a.m. Enquiries Tony & Val Hanson 01392 874  
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**Thursday 8 October-** The Budleigh/Exmouth  
Group meets at the Manor Hotel, Exmouth. The  
speaker will be Anne Searle, Genetics Nurse  
Counsellor. For more information phone David  
Warner on 01395 445 614.

**Thursday 18 October 2015 - Association Meeting**  
at the ISCA Centre, Exeter. Speakers be a  
representative of PALS and Miles Goldstraw, a  
recently appointed urology consultant at RD&E.

## NEW WEBSITE



Above is a snapshot of the Home Page of our new website which has recently gone live.

The main aim has been to keep it clean and simple, although the key point is the ease with which we can maintain it. So far I've created/edited all the content (often by copying & pasting from other publications!) with no difficulty. In fact, anybody who has the ability to create a basic Word document can do it!

It is important to keep it up to date, in particular the Diary of events and bits of news that crop up from time to time. It also has a page devoted to our Newsletters and the "Prostate Matters" newsletter issued by the Tackle Charity.

The "Links" tab will also take you to other web pages of interest to us plus one or two video links including some from "You Tube." We hope to develop this more and perhaps even put videos of our own presentations on it.

Please have a look at it ([www.nedpsa.org.uk](http://www.nedpsa.org.uk)) and let us know what you think. If you have any suggestions for improvements or criticisms please let us know.

It is your website!