

# Newsletter

Please accept my apologies, yet again, for the rudimentary nature of this newsletter. As you will be aware, Toby Heriz-Smith, agreed to take on the role of editor in October of last year but unfortunately his health has deteriorated to such an extent that he has been unable to keep up with his many commitments. At the time of writing, he is recovering from surgery in the RD&E but hopes to be home soon and “back in the saddle”. We wish him a speedy recovery. In the meantime and despite his personal difficulties, Toby has managed to influence the approval of up-front Docetaxel treatment and the benefits it provides to men with advanced prostate cancer. This follows some prolonged and occasionally heated negotiations he has had with Prostate Cancer UK. Toby is to be commended for sticking to his guns and pushing the powers that be to approve the drug in January of this year, despite the many bureaucratic hurdles that were thrown in his way.

This unfortunate situation does highlight the need for a deputy newsletter editor who can step in on a temporary or permanent basis to carry out the necessary work. The newsletter is one of the key elements of our organisation and without it we will lose the regular contact and exchange of information between our widely spread local groups.

If you can help, now or in the future, please get in touch.

It's vital that we keep it going, so don't delay!

Tony Lowe

## Association Meeting at the ISCA Centre on 21<sup>st</sup> January

Our speakers for this meeting were Tam Jackson, Specialist Nurse for Organ Donation and Claire Turner, Uro-Oncology Nurse Specialist at RD&E. Claire was there to talk specifically about Health & Wellbeing Clinics for newly diagnosed prostate cancer patients (see below). Unfortunately, I was unable to attend due to illness and I've not received a written report of the event to include in this newsletter. Consequently, for those of you like myself who were unable to attend, there is little more that I can tell you at this stage. Hopefully, we can include a more informative report in the next full edition of the newsletter.

## **Health & Wellbeing Days**

The first Health and Wellbeing prostate specific event was held on the 28<sup>th</sup> January at the RD&E. This initial session was intended as a pilot for patients who were heading towards radical prostate cancer surgery, so the event was focussed on this type of treatment. The intention is to roll out this type of event to further prostate cancer patients once the pilot has ironed out any teething troubles.

The sessions will be made mandatory prior to surgery and will include subjects such as healthy diet (pre and post surgery), exercise and its importance during cancer, urinary leakage and pelvic floor exercises, family support, impact on sexual relationships and erectile dysfunction. They also plan to have tables in the room with information and some “props” – such as catheters, diet sheets etc, for patients to look at.

Apparently, RD&E have done a survey of 50 patients and the results of this were very much in favour of this type of “more in depth” information sessions pre- treatment. It is hoped that these type of events will give significant benefit to patients.

NEDPSA was invited to send two representatives to this meeting to provide some real-life experience of what it’s like to have prostate surgery and cope with the after effects. Alan Bosley and Peter Harvey from the North Devon group were first into the “den”. They reported a very successful meeting and were able to provide lots of reassurance, encouragement and positive tips to those who attended. This is an excellent example of how NEDPSA members can help newly diagnosed patients in a very positive manner and could well form an important part of the Association’s activities in the future.

## **Local Group News**

### **Budleigh Salterton & Exmouth Group**

22 of us met together at the Manor Hotel, Exmouth on 3<sup>rd</sup> December for our Christmas Lunch. The meal was first rate and the whole occasion was enjoyed by everyone. Welcoming all to the lunch, David Warner thanked members for their support throughout the past year, which had been a busy one for us all. We’d had 3 well-attended meetings during the year and also carried out a successful collection at Tesco in April. As always, we remain very grateful to the consultants and medical staff at RD&E for their readiness to come and speak to us.

David thanked Linda Hicks for her donations to NEDPSA funds of £185, which she had raised from selling pet portraits in graphite. Linda confirmed that she is still willing to accept further orders.

Our first meeting in the New Year will be on Thursday March 17<sup>th</sup>, when we shall have a visit from Dr Denise Sheehan, Consultant Clinical Oncologist at RD&E.

David Warner  
01395 445614

## **Barnstaple & Torrridge**

As is now customary, our Christmas Lunch on 3<sup>rd</sup> December was a combined affair for both Barnstaple and Torrridge groups. This year we enjoyed another excellent meal in the impressive surroundings of The Commodore Hotel at Instow, which was much enjoyed by all who attended. Our thanks go to Ron Cave for organising the event. At this stage, there are no future events planned for the Barnstaple & Torrridge groups.

Tony Lowe  
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## **CONTACTS**

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### **Newsletter Editor**

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## **DATES FOR YOUR DIARY**

**Thursday 17th March, – Budleigh Salterton & Exmouth Group** – 10.00 at the Manor Hotel, Exmouth when our speaker will be Dr Denise Sheehan. Contact David Warner on 01395 445614 for further details

**Wednesday 30th March, – Tiverton, Cullompton & Honiton Group** – Lunch, 12.30 at the Ruffwell Inn, Rewe. Contact Sylvia Trow on 01392 841603 for further details.

**Thursday 21st April – Annual general Meeting** at the ISCA Centre, Exeter starting at 10.00am. Our speaker will be Daniel Lavery from Devon Freewheelers National Blood & Organ Transfer Services.