

Issue 16 : February 2016

In this edition.....

Welcome from Brian

Survey Results

Good Practice Award

Gleason Score changing?

Future Events

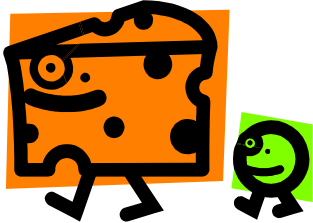
AGM Report

PSA Testing

Next Quiz night

STAMPEDE Trial results

Welcome from Brian



Here we are again, another year ahead and our group is as strong as ever. That's down to the continued support of our members, helping each other and helping with those who are newly diagnosed. As I said at our AGM (you can read below) I believe we are punching above our weight for what we do as a relatively small group. Onwards and upwards!

AGM Report

For those of you who could not attend the AGM on 1st February, here is a summary of the Chairman's report and other proceedings.

We are continuing to pursue our aims of raising awareness locally and to offer comfort and support to newly diagnosed patients. We should be proud of our efforts on both fronts, and we know how new patients welcome the opportunity to talk to our members, who have helped several this past year. We also made some home visits.



In terms of awareness, we had the most successful week yet at Hale Leys, and we also had our usual stand at Thame Show. At an evening talk from Professor Peter Hoskin we heard about recent advances in treatment and this proved to be illuminating for all that attended.

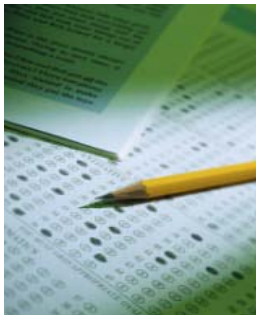
On the social front we had a summer BBQ with the Milton Keynes group at Thame, and we hope to continue this in 2016. Two successful quiz nights were held, with the Chairman's team winning on both occasions! Our summer musical concert was the highlight of the year, raising some £5000 for our group, and our thanks go to Berkhamsted Rotary for choosing us as their charity. We made a donation to Ken Bruce's chosen charity for his help at the concert. Another £500 was raised from the "community token" scheme at Waitrose. A visit to the Medical Detection Dogs at Gt. Horwood was well received, and we made a donation of £250 to the cause.

Overall, we feel we are punching above our weight and we are pleased to learn we have been awarded a "Good Practice Award" from PCUK . This is down to all our members who make the group what it is. Thanks must go to our John Brown as our Hon. Treasurer, Roger as our Hon. Secretary, and our fellow trustees, David and Bruce, for their tireless endeavours. We were also pleased to see Roger elected as National Chairman of Tackle. Special thanks were also extended to David Rogers for his work in setting up our new web site, and to John Hazell, who is acting as our link man with the MK group.

As far as election of offices was concerned, Brian agreed to serve as Chairman for one more year. **This will be his last**, so we will be looking for fresh talent to take over. Roger was re-elected as Hon. Secretary but made a plea – if there is a member's wife or partner that would be willing to step up to take the role, with Roger's help, they would be warmly welcomed. **Offers to Roger please.**

John Brown was re-elected as Hon. Treasurer and David Barrow and Bruce Cameron agreed to continue as other members of the committee. If anyone else would like to join this small select band of brothers, we could do with one or two more committee members, please let Roger know. Wives or partners may also be a committee member!

Survey Results



As we reported in the last newsletter a short survey went out to members asking them to confirm the details we held for communication purposes and also about how we should spend the money we now have as a result of last year's concert. I'm pleased to say we had a response from most members and there were only six in total who felt they no longer wished to remain as members, but wished us well all the same. Encouragingly, some 22 members said they were willing to do more to help the group so we shall be following that offer up! Twelve of these said they would value further training in being able to help others with counselling and advice and we will be following this up also at a future meeting.

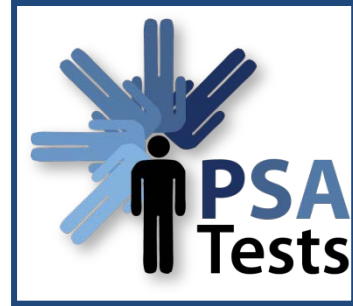
On the question of what we should spend our newly acquired funds on, the votes for each of the five suggestions we made were roughly equal as follows: PSA Testing 26 votes, Medical Detection Dogs 27 votes, Joe Kearney's ED clinic 23 votes, Counselling Services 28 votes, Local Awareness Campaign 22 votes. Where some members ranked their preferences it showed PSA testing as a clear first or second preference. See the separate item on PSA testing.

Further comments/suggestions included having more meetings with partners, more speakers and more social events. Varying the meeting format, visiting other groups, organising a pub supper and a summer BBQ were other suggestions. We will be considering how we can adjust our programme to take into account these suggestions, as well as preferences for spending our funds.

Our thanks to Esther Davidson for helping with compiling the survey results.

PSA Testing

With PSA testing being the first choice in the member's survey we are holding two testing sessions in April. One will be at The Masonic Hall in Aylesbury on **Saturday 23rd April**, and the second on **Saturday 30th April** at the Civic Centre Berkhamsted. Both of these sessions will be hosted by the Graham Fulford Charitable Trust, which operates in conjunction with our national charity, Tackle. A simple blood test is offered to any man who wishes to have a PSA test. This has proved very successful elsewhere, and other local prostate cancer support groups regularly offer these sessions. Everyone who has a test receives the result from a clinician a few days later, and any follow-up required is discussed. Details will be coming out shortly but if you know of anyone who you think might benefit from having a free PSA test please let Brian know.



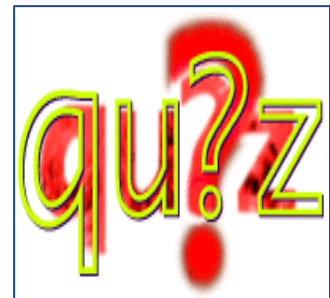
Good Practice Award



As you know we were being considered for a Good Practice Award by Prostate Cancer UK and we are pleased to report we have been successful! This is down to you as members, ensuring we continue to thrive and support others who are diagnosed. We had to comply with a couple of conditions – namely developing a home visit policy and validating our membership list. These have been done and we are just awaiting the certificate. We are one of just four groups in the country to have received this award. Our thanks to Roger for putting us forward for this award. .

Next Quiz Night

Following from our regular and successful quiz evenings, the next one will be on **Tuesday 22nd March** at the Chandos Arms, Western Turville. The evening will start at 7pm and the cost is £10 to include a fish and chip supper. These are always very popular evenings so please let Roger know as soon as possible if you wasn't to enter a team. Let's try and stop Brian's team from walking away with the prizes!



Gleason Score changing?

Here is an interesting article from the USA to keep you up to date with developments. There is talk of the well known "Gleason" score changing.

The 50-year old Gleason scoring system for prostate cancer pathology is changing! Finally! The new system is being referred to as some version of either “ISUP grading”, or “prognostic Gleason grading,” or “Epstein grading.” One of the primary reasons for the change—which has already been agreed-to via worldwide consensus—is to help simplify the system and reduce the recent epidemic of overtreatment of men clinically diagnosed with low-risk prostate cancer...an effort we can all loudly applaud!

There has been a widely recognized “counselling problem” with the current system...mostly with the Gleason 6 (3+3). Being diagnosed with a “6” out of “10” sounds more ominous than “low” grade or “grade 1,” which might better reflect the natural history of these tumours. A fear amongst PC care thought leaders is that the *current* Gleason labelling scheme reactively leads low-risk men to a *slippery slope* resulting in overtreatment of the disease. Historically, the majority of patients with even low-risk PC received radical treatment, although the use of Active Surveillance (AS) is increasing globally. In many regions, >40% of men with low-risk disease now receive initial AS (July 2015 report) and these numbers continue to grow.

Several re-naming approaches have been recently proposed and discussed. Noting that the term “cancer” should be reserved for a disease that might actually kill a patient, some experts have proposed not labelling low-risk PC with the emotionally-laden term “cancer.” Others proposed using the term “pre-cancer.” Dr. Jon Epstein developed, validated and recommended the new approach which was approved at the 2014 ISUP Consensus Conference. The new system has only 5 “grade” levels. The different grade levels are based on observed histological definitions...and I won’t bother to copy/paste them here because one really does have to be a pathologist to fully appreciate the differences. However, it is fair to say that these close similarities exist:

- Epstein grade 1 is similar to any Gleason score of 6 or less
- Epstein grade 2 is similar to any Gleason score of 3+4=7
- Epstein grade 3 is similar to any Gleason score of 4+3=7
- Epstein grade 4 is similar to any Gleason score of 4+4=8
- Epstein grade 5 is similar to any Gleason score of 9 or 10

The new grade group 1 will help define the indolent nature of the cancer and confirm an initial strategy of AS in the appropriate patient. There will also be some men with grade group 2 tumours who are also candidates for AS (or a less morbid radiotherapy) depending on individual factors such as age, co-morbidity and extent of cancer. Furthermore, in the new system grade group 2 is now clearly distinguished from grade group 3 as opposed to the frequent “misuse” of an aggregated “Gleason 7” score. Studies show that the 3+4 cases—despite the presence of high-grade tumor—have significantly better prognosis than the 4+3 cases, yet these were often incorrectly grouped together or closely associated.

In Dr. Epstein’s own words, one of the key benefits of the new system is *“having a grade group 1 out of 5, as opposed to a Gleason score 6 out of 10, to permit a more rational and less emotional decision making, and help reduce the overtreatment of indolent prostate cancer.”*

STAMPEDE Trial Results

Many of you will be familiar with the long running STAMPEDE trial led by Professor Nick James of Warwick/Birmingham universities. He is a member of Tackle's Clinical Advisory Board. The trial has recently reported, with very positive results from taking docetaxal (a chemotherapy drug) at the same time as starting long-term hormone therapy. If you are interested, it is worth watching a video which you can find at :



www.vimeo.com/mrcctu/stampederesultsforpatients

Future events



Make a note in your diary now of key dates in 2016

- Tue Mar 22 – Quiz at Chandos Arms, Western Turville
- Mon April 4 - Lunch meeting Thame Football Club
- Sat Apr 23 – PSA Testing Aylesbury Masonic Hall
- Sat 30 April - PSA Testing Berkhamsted Civic Centre
- Wed June 22– Stand at Macmillan cancer day The Gateway Aylesbury
- Fri 8 July - BBQ Thame Football Club
- Mon 12 Sep – Lunch meeting Thame Football Club
- Thur Sep 15 – Stand at Oxfordshire & Thame Show
- Tue 4 Oct - Evening speaker at Stoke Mandeville
- Tue 1 Nov - Quiz at the Chandos Arms, Western Turville
- Mon 5 Dec - Lunch meeting Thame Football Club

Brian

Roger