Prostate Cancer Foundation of Australia

PROSTATE HEIDELBERG - CANCER SUPPORT GROUP

Affiliated with the Prostate Cancer Foundation of Australia

Newsletter No: 134 **Next Meeting: 10 September 2014**

MRI scans a 'game-changer' in prostate cancer testing?

Magnetic resonance imaging (MRI) is a scan used for a medical imaging procedure. An MRI uses a magnetic field and radio waves to take pictures of the body's interior.

The media has been full of reports that "MRI scans could be a 'game-changer' in prostate cancer testing" since a research article appeared in the July 2014 issue of the Journal of Urology.

Researchers found that if the MRI was clear, there was a 97% chance of not having a significant prostate cancer. If it was positive, there was an 88% chance of having a significant prostate cancer. It was suggested that this advance in imaging could avoid unnecessary biopsies in many prostate cancer patients. More targeted biopsies would also be possible using MRI-guided technologies to accurately sample the lesion.

At present there are only a limited number of MRI machines in Australia and the cost of using MRI scans to screen for prostate cancer is not covered by Medicare.

Before the Prostate Cancer Foundation of Australia (PCFA) makes a decision whether to advocate for MRI availability in the context of prostate cancer, it is looking at the evidence available for this technology in the diagnosis and management of prostate cancer and is discussing the issue with the Urological Society of Australia and New Zealand.

For more information, see: http://tinyurl.com/pgwurjl

Update on New Drugs and the PBS

The Pharmceutical Benefits Advisory Committee has recommended that Enzalutamide be listed on the PBS post chemo. The Committee rejected Abiraterone pre chemo on cost grounds. The drug company will need to lower its price as discussions continue. Abiraterone is already approved post chemo.

Our Next Meeting

Date: **Wednesday 10 September 2014**.
Time: **10:00 am to 12.30 pm,**
Place: Ivanhoe Uniting Church, Seddon Street, Ivanhoe (Melways 31 F8)
Free car parking available at rear.

- Meetings are open to anyone interested in getting support or information on a prostate cancer journey.
- Partners or carers are welcome to all meetings
- **There is no charge for attending**.

Contact Us

Email us: prostateHeidelberg@gmail.com
Phone: Max Shub 0413 777 342 or Paul Hobson 0405 086 869
Website: www.prostateheidelberg.info
See the last page of this newsletter for more information about the Group.

DISCLAIMER: Information in this newsletter is not intended to take the place of medical advice. You should obtain advice from your doctor relevant to your specific situation before acting or relying on anything in this newsletter. We have no liability whatsoever to you in connection with this newsletter.

ANZUP Community Engagement Forum

ANZUP is the Australian and New Zealand Urogenital and Prostate Cancer Trials Group.

ANZUP's mission is to conduct clinical trial research to improve the treatment of bladder, kidney, testicular and prostate cancer.

Prostate Heidelberg Committee members, Max Shub, Spiros Haldas and Paul Hobson, attended the recent Community Engagement Forum held by ANZUP. Max is a member of ANZUP's Consumer Advisory Panel.

An overview of ANZUP & its work

Professor Ian Davis, the Chairman of ANZUP, opened the forum with an overview of ANZUP and its work.

Professor Davis noted in the 20th century there were only 4 or 5 times in which there were major breakthroughs. Most progress came in small steps through clinical trials showing better ways to do things.

On the Internet you will find thousands of ideas about how to cure cancer. These ideas ranged from those with very good science behind them to black magic and fish-slapping theories. But in one sense they were all the same: until they were proven to work, they were unproven, and if they were unproven, no one can make claims about how effective they were. Doctors and researchers made no assumptions about these things because even the weirdest ideas have become part of mainstream medicine, after they have been properly tested.

Clinical trials of a treatment ask questions such as:

- Is it safe for humans to use?
- How often does it work?
- How does it stack up against existing treatments?

ANZUP's clinical trials are different from those conducted by industry.

Drug companies are looking to bring new drugs to the market that they can sell and make profits for their shareholders. ANZUP looks at the clinical needs of patients and does the trials that industry can't or won't do. Sometimes this can involve using drugs from more than one company; sometimes it can involve using drugs which are out of patent. Some clinical trials may not involve drugs at all.

Professor Davis gave an example of a clinical trial conducted by ANZUP for a drug commonly used in testicular cancer. The trial looked at whether one way of taking the drug was better than another. The trial found that it was better and this method of taking the drug has been adopted world wide as best practice.

Professor Davis stressed the importance of doing clinical trials in Australia. Our health systems were not the same as the US or Europe and it was important to know how a treatment could or should be used in the Australian setting. Australian research was recognised around the world as being of the highest quality and it was important to provide research opportunities within Australia for our leading researchers. Even if you looked at it in the most basic economic level every dollar invested in Australia in medical research returned about $6 to the economy and in terms of savings in health care costs

Each clinical trial carried out by ANZUP must be funded, either from grants or donations. Whilst there are many organisations seeking to raise funds for cancer relief, ANZUP is the only body which is actually doing research that will produce outcomes for patients.

Professor Davis said that there are a number of ways that people can get involved in research. One was by asking their doctors whether there were any clinical trials in which they could participate. Another was to advocate for more resources for research.

A patient's perspective

Ian Roos gave a patient's perspective of clinical trials.

Ian has been a prostate cancer survivor since 1998. His treatment was influenced by RADAR (Randomised Androgen Deprivation And Radiotherapy) trial. He participated in a small Phase 2 clinical trial of PDR brachytherapy as salvage therapy. He tried to be part of Phase 3 MDV 3100 trial and participated in the Phase 1 Avipep trial and Phase 1 TAK 700 trial

Ian said that we were indebted to the past. All our current best clinical practice has come out of clinical trials that were conducted in the past. All of these trials involved people who were willing to contribute to a better future and as a result there was improvement in cancer treatments.

We need Evidence Based Medicine and the evidence came from clinical trials. Ian showed a slide about the "7 Alternatives to Evidence Based Medicine."

There are four phases of clinical trials involving humans:

- Phase 1 Small numbers - could the intervention be given to humans?
- Phase 2 Larger numbers - was the intervention effective?
- Phase 3 Large numbers - was the intervention better than existing treatment?
- Phase 4 Post initial use studies

7 Alternatives to Evidence-based medicine*.

1. **Eminence based medicine**
   The more senior the doctor, the less importance he or she places on the need for anything as mundane as evidence. Experience, it seems, is worth any amount of evidence. These doctors have a touching faith in clinical experience, which has been defined as "making the same mistakes with increasing confidence over an impressive number of years."
2. **Vehemence based medicine**
   Instead of evidence, the loudest doctor decides what should be done.
3. **Eloquence based medicine**
   The year round suntan, carnation in the button hole, silk tie, Armani suit, and tongue should all be equally smooth. Smooth talking substitutes for evidence.
4. **Providence based medicine**
   If the caring doctor has no idea of what to do next, the decision may be best left in the hands of the Almighty. Too many specialists, unfortunately, are unable to resist giving God a hand with the decision making.
5. **Diffidence based medicine**
   The timid doctor may hesitate and do nothing. This, of course, may be better than doing something merely because it hurts the doctor's pride to do nothing.
6. **Nervousness based medicine**
   Fear of litigation is a powerful stimulus to overinvestigation and overtreatment.
7. **Confidence based medicine**
   This is restricted to surgeons in the operating theatre.

   * Originally from the British Medical Journal

Ian said that clinical trials involved a lot of hard work by many people: clinicians, researchers, nurses and trial coordinators. Most trials involved more than one institution and many were multinational.

Just coordinating a multi-institution trial, ensuring that all procedures were done in exactly the same way was a huge task. Multi-national trials were even more work. On top of that was the need to get ethics approval across all sites.

Trials usually took a long time to complete. They involved recruiting large numbers of patients and often following them up over a long period of time. In one of the trials Ian was on, patients were followed up for ten years to assess long term side effects.

There were a number of reasons why people go on clinical trials.

- Getting access to new treatments and drugs
- Getting better treatment, and
- Being altruistic, wanting to help others.

Going on a clinical trial may, but not necessarily, provide access to new drugs. If it was a randomised controlled trial, there had to be a control group that received the current best practice treatment. Where there was a control group, they were getting the best available treatment, and that may in fact be better than the new treatment, for that was usually what the trial was about.

Going on a clinical trial, you will be closely monitored, with a lot of tests being done along the way to ensure not only the outcomes but your general health as well.

People like giving and helping others: look at the results of national appeals held each year, or the response of ordinary Australians to emergencies such as bushfires or floods. People were willing to assist enough though they may not get any immediate benefit.

We also want the world to be better for our children and grandchildren. Ian said that, when he looked at his grandchildren, he hoped that their risk of getting cancer would be drastically reduced and the chances of cancer being readily cured would be significantly higher than it was now. Ian said that this would only happen if we did the laboratory and clinical research now.

Information about what clinical trials are available was now readily available online:

- www.australiancancertrials.gov.au
- www.anzctr.gov.au
- www.clinicaltrials.gov

The best way to find out about clinical trials was to ask your clinician: “Are there any clinical trials that might be suitable for me”.

ENZAMET and ENZARAD studies

Like Professor Davis, Professor Dickon Hayne, a member of ANZUP’s Scientific Advisory Committee, spoke about the importance of Evidence Based Medicine obtained through clinical trials in improving treatments for cancer patients and the importance of a flourishing medical research climate, not only for patients, but for the Australian economy.

Professor Hayne spoke about a number of ANZUP’s current clinical trials, including the ENZAMET and ENZARAD studies

ANZUP will be the international lead for two of the largest clinical trials involving Enzalutamide, one of the new hormone treatments for prostate cancer. Professor Hayne stressed how significant it was for Australian medical research that Australia was taking the lead in organising these trials.

The ENZAMET study is a randomised phase 3 trial of Enzalutamide in first line androgen deprivation therapy for metastatic prostate cancer. The study will involve about 1100 men with prostate cancer that has spread but has not yet been treated with hormones. One arm of the study will

receive a luteinising releasing hormone releasing hormone (eg Zoladex or Eligard) plus Enzalutamide whilst the control arm will receive a luteinising releasing hormone releasing hormone (eg Zoladex or Eligard) plus conventional Non-steroidal anti-androgen (bicalutamide, nilutamide, or flutamide).

The ENZARAD study is a randomised phase 3 trial of Enzalutamide in androgen deprivation therapy with radiation therapy for high risk, clinically localised, prostate cancer. The study will include about 800 men with prostate cancer that has not spread and that is planned for treatment with radiotherapy. The ENZARAD study will answer the question: will men with prostate cancer apparently confined to the prostate but at high risk of coming back elsewhere benefit, in terms of living longer, from adding Enzalutamide to radiotherapy plus ADT?

More information about ANZUP's current clinical trials can be found at www.anzup.org.au

Support and Quality of Life

Not all clinical trials are about new treatments or modifications of existing treatments. Some clinical trials relate to supportive care and quality of life issues. We need to know that those efforts we put into support, care and improving quality of life are backed up by good evidence.

Professor Suzanne Chambers spoke about the "Living Well with Prostate Cancer" trial that she is conducting.

There are approximately 22,000 Australian men alive today with advanced prostate cancer. Research into the impact of advanced prostate cancer shows that men report higher levels of psychological distress, poorer quality of life, and have an increased risk of suicide compared to men with localised disease.

This study is trialling a professionally led and telephone delivered mindfulness-based cognitive therapy (MBCT) group intervention for men with advanced prostate cancer. MBCT is designed to assist men with stress management and improve their psychological wellbeing. In this trial its effectiveness will be compared to an educational program consisting of the best available resources for men with advanced prostate cancer.

Information about this trial can be found at www.anzup.org.au

[I participated in this trial and was fortunate enough to be randomised to the mindfulness arm of this study. I found the mindfulness training to be very beneficial. The Olivia Newton-John Cancer and Wellness Centre has regular courses in mindfulness mediation. -Edit]

Guest Speakers October Meeting

Our focus on medical research will continue.

Dr Mitch Lawrence from Monash Institute of Medical Research and Dr Carmel Pezaro, medical oncologist will talk about tissue research and how the oncologist applies this

Reminder - World Cancer Congress Consumer Day

If you want to attend the Consumer Day on Saturday 6 December and haven't put your name down yet, please email prostateheidelberg@gmail.com **by not later than Wednesday 10 September**.

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Prostate Heidelberg provides information, education and support for those affected by prostate cancer. At the meetings, we

1. ***Show respect to members and speakers;***
2. ***Allow people to speak and we listen;***
3. ***Respect confidentiality;***
4. ***Allow new ideas to be shared.***

COMMITTEE:
Max Shub, Facilitator 0413 777 342
Paul Hobson Secretary 0405 086 869
Chris Ellis
Spiros Haldas
Patrick Woodlock

Annual subscription - $5 *from 1st January per individual, couple, or family.*

MEETING VENUE:
Uniting Church Meeting Room
Seddon St, Ivanhoe
(behind the Commonwealth Bank in Upper Heidelberg Rd).

CALENDAR 2014
Meetings: **10:00am -12:30pm**

Wed 10 September '14
Wed 8 October '14
Wed 12 November '14
Wed 10 December '14 (Christmas lunch)

CORRESPONDENCE

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Please contact Paul Hobson to redirect or cancel receipt of this Newsletter.

Financial summary
Year ending 30 June 2014

Expenses up, receipts down.

As at 30 June 2014, Prostate Heidelberg had $ 5535 (*30 June 2013, $7,240*) in its NAB bank account.

In 2013 the Department of Health Community Support Grants changed from being annual grants to biennial grants. In 2013 we received the same sized grant as previously but it covered a two year period. This has resulted in a decrease in our 2014 receipts, compared with previous years.

The Group's main expenses were venue hire and the purchase of library books. The holding of evening meetings resulted in a significant increase in venue hire.

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