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THE WALNUT

June 2023

Newsletter of the Prostate Cancer Support Group–ACT Region

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https://pcsg-act.org.au

From the President

Hi All,

I hope everyone is well and have their heating sorted ready for winter. This is definitely not my favourite time of year in Canberra!

Since my last report I have attended the post budget breakfast held at the Hyatt Hotel. Yes, I know a tough way to start the day but I guess being the group leader has to have some perks, right!😛.

I was asked by PCFA to join Sally Sara, PCFA's Director, Nursing Programs, and Russell Briggs, one of PCFA's prostate cancer nurses, to represent PCFA at this event.

It was an informative event, at which a number of new health initiatives were unveiled. A very interesting commitment made by the Minister for Health, the Hon Mark Butler MP, was that, where funds are allocated to projects that for whatever reason do not proceed, they can then be reallocated to other either new or existing projects that require ongoing funding. As you can imagine there were a number of people keen to speak with the Minister offering help to spend these funds!

A second event I attended was the ACT Master's Hockey fundraising night in April. Given that men need to be over the age of 35 to play in this league, it puts their members well and truly in our target demographic for early detection of prostate cancer.

This is now the second year I have attended this ACT Masters Hockey event and the third year we have been the recipient of a donation from it.

I mentioned at our recent executive committee

With Sally Sara and Russell Briggs (R) at the post-Budget breakfast

ACT Masters President, Leo Clarke, presenting me with a cheque for our Group from their annual fund raising event

meeting that during my term as leader of the group I have put considerable emphasis in developing these sorts of relationships to assist with ongoing fundraising for our group. The result of this year's event was that we were presented with a cheque for $1,000 last Wednesday night from Leo Clarke who is the president of the league.

We have already begun discussions on how to make next year's event even better as there will be a combining of the men's and women's masters leagues.

Finally, I would like to let you know that, as part of our contribution to Men's Health Week, the Group is sponsoring radio advertisements on Mix 106.3 this month to raise awareness of the need for appropriate monitoring of PSA levels to assist in the early detection of prostate cancer.

Thank you all for the support of our group and please remember we are always open to ideas on either how to improve how we do things or the types of speakers you would like to see at our meetings.

Take care and stay safe and well.

Greg McRoberts
President

A new network group for men working with or after cancer

The Cancer Council has announced that it has established a dedicated Network Group aimed at supporting men in balancing work/careers while dealing with cancer.

The group will be led by Daniel Quilty, a survivor of lymphoma who successfully overcame his own work-related challenges as a secondary school teacher. The Cancer Council invites you, your family members, friends, colleagues, or anyone you know who is managing work while living with cancer to join us.

The network will convene virtually once a month on the 2nd Friday, from 4pm to 5pm. Participation is completely FREE, and you'll benefit being connected with a group of people who understand your experiences first-hand.

To join, register via email as follows: enquiries@liveworkcancer.com.

The Cancer Council looks forward to welcoming you on **9th June, 4pm – 5pm**!

We need your help!

Your help is needed to secure the future of our Group.

We are a self-help group and all of our committee members are volunteers. We are people like you who have had a diagnosis of prostate cancer and want to help others who receive the same diagnosis.

We need members who are prepared to join our committee and so help to ensure the Group's long-term viability. This is not a particularly onerous task.

If you are willing to help, please contact our secretary, John McWilliam, at: secretary@pcsg-act.org.au.

Coming meetings

Monthly Group Meeting, 6:30pm for 7 pm, Wednesday 21 June

This meeting will be held at our usual location at the Pearce Community Centre, Building 2, Collett Street, Pearce.

The speaker for this meeting will be Dr Irmina Nahon. Dr Nahon has more than 17 years experience assessing and treating pelvic floor dysfunction. She has a PhD in the assessment and management of male urinary dysfunction.

Dr Nahon is very passionate about continence promotion, as well as research into the assessment and management of incontinence and pelvic pain.

Coffee morning, 10:00 am Tuesday 13 June 2023

Our next coffee morning is at the Canberra Southern Cross Club, Jamison.

'Christmas in July', 6:30 pm Tuesday 18 July

Instead of our usual Group meeting on Wednesday 19 July, we we will be having a 'Christmas in July' function in the Community Room on the ground floor of the Canberra Southern Cross Club, Woden. This will be held on Tuesday 18 July, not our usual Wednesday.

This will be an opportunity to catch up with other members in a relaxed social environment.

Please put this event into your diary. Acceptances (for numbers) will be invited nearer the time.

May Group Meeting

There were 13 at our May meeting (including one on Zoom).

Our speaker was Michael Irvine from Southside Physio. Michael mainly spoke about recent research findings on approaches to treating erectile dysfunction. He provided a handout that summarises these findings and the other matters covered in his talk. This is reproduced at page 3.

Some of the key points that Michael made were:

- Even with nerve sparing, it will take around 18-24 months for the nerves to completely heal from radical prostatectomy surgery.
- Pelvic floor training is not just important for regaining continence. It is also an important part of regaining erectile function.
- The use of a vacuum erection device is normally recommended to start 4-6 weeks post-operatively to help regain and maintain penile length and function. This is to avoid potential damage after surgery. However, there is some recent evidence that this can start earlier without these risks.
- It is important to get support before surgery from someone like *Men's Health Downunder* or him to provide the best chance or regaining erectile function following surgery.

Following Michael's presentation, Don Bradfield encouraged everyone to ask for copies of any reports on medical tests that they have. He said that, following tests he had recently taken, he had been provided with an oral report that focused only on his prostate issues. However, after much effort, he was finally able to receive the written reports, only to discover that they also reported on several non-prostate related conditions. Some medical practitioners may be reluctant to provide the written reports, by patients are entitled to be given copies of them.

Don also encouraged patients to monitor what information is being uploaded to their My Health Records (through the MyGov website).

Southside Physio

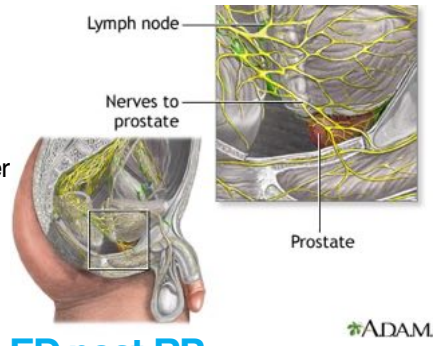
Erectile Dysfunction (ED) post Prostate Cancer Treatment

After radical prostatectomy (RP):

- Damage to the neurovascular bundle around the prostate (leads to dorsal penile nerve)
- nerve sparing: heals on average 18-24 months
- non-nerve sparing: nerve bundle completely removed
- ~85% still ED 2 years post-op (50% don't start rehab, further 50-80% don't finish rehab)

After radiotherapy:

- Arterial and neural damage
- ~50% EDD within 5 years (not right after radiation)



Primary Treatment/Rehab for ED post-RP

Start pre-operatively if already losing erectile function (EF) (rigidity, erectile time, sleep related erections)

ED20-40% in 60s (start losing sleep related erections [SREs]), >50% in 70+ age

1. Cardiovascular health
   - Rapid decline in EF can predict coronary artery disease (CAD). Get CV assessment
   - ED and CAD both linked with hypertension, obesity, smoking, reduced physical exercise
   - Weight loss, diet and regular exercise (180 min/wk mod): mod to mild ED, independent of PDE5i
2. Pelvic floor muscle training (PFMT)
   - Main role: bulbocavernosus muscle contracts/expands to block penile veins
   - Daily PFMT 6 months – 40% regained normal EF, 34.5% improved EF
   - Post-RP: at 15 months post-op, PFMT significantly better EF and climacturia
   - PFMT pre-op vs post-op: main benefit is earlier continence, so earlier focus on EF rehab
3. PDE5i medication (tadalafil, sildenafil, vardenafil)
   - Normal EF: nitric oxide vasodilates vessels, and relaxes corpus cavernosum to fill with blood
   - PDE5: enzyme that inhibits above process, mainly after orgasm (some always present)
   - Tadalafil (max 0.75-6hrs, HL 17.5hrs), sildenafil/vardenafil (max 0.5-2 hrs, HL 4hrs) (69% success rate)
   - RP: daily 36 wks: 4% vs 27% normal EF. daily 52 wk w SRE: 28% vs 47%, + on demand: 66% vs 86%
   - Radiotherapy: 2 years 56% vs 81.6% EF
4. Vacuum erection device (VED)
   - Maintain/regain penile length initially (start 4-6 wks post-op)
   - Much higher EF scores 3, 6 and 9 months post-op, with PDE5i (even if delayed VED start)
5. Psychology/counselling (besides just depression and anxiety)
   - 18 months post-op: higher all domains erectile function
   - Highest couple satisfaction, lowest discontinuation rehab rates

Other ED Treatment Options

1. Shockwave therapy (no research for radiotherapy yet)
   - Very recent evidence, 8 weeks weekly much higher EF scores
2. Intracavernosal Injection therapy
   - Trimix up to 90% success rate, work within 10 mins, not need stimulus
   - Injection in association with PDE5i med, not sig better than PDE5i alone (success), higher erection satisfaction
3. Penile prosthesis
   - Last option, high success srate, replaces penile muscles

Contact us for any further information, references or questions:
michaeli@sspg.com.au | www.southsidephysio.com.au | wod@sspg.com.au
Woden Ph: 02 6282 5010

PCFA News

PCFA's Life Force Program

Our Group provides presentations to workplaces and other organisations on prostate health.

PCFA's Life Force Program also aims to raise awareness of prostate cancer in workplaces and communities across Australia and encourage more men to take action to improve their health outcomes.

Under the program, PCFA will organise a presentation by a trained PCFA representative for a workplace team, giving access to information, materials, and support to help save lives.

The Group will explore being associated with the Program.

Click here for more information on the Life Force Program or contact our Group's secretary, John McWilliam (secretary@pcsg-act.org.au) and we will arrange a presentation for your workplace.

Riding the PSA wave: What to do when your PSA starts rising after treatment

Why do PSA levels rise again, even when men have had their prostate removed? Does the speed at which a man's PSA level rises mean anything? How can men manage PSA anxiety before each test? These are common questions asked by callers to PCFA's Telenursing Service. In this article, PCFA provides a clear understanding of what it means to be watching your PSA level after your initial treatment.

Read the article

New medicine listed

Life-extending medicine Erlyand was listed on the PBS from June 1 for men with metastatic hormone-sensitive prostate cancer. Erlyand is an anticancer medicine that contains the active substance apalutamide.

Around 3,000 men in our community, and their families, will benefit from this outcome. PCFA thanks all those of you who supported our advocacy on this in 2022, when the application was put forward to Australia's Pharmaceutical Benefits Advisory Committee.

Without subsidisation, Erlyand would cost these men and their families about $45,000 a year for 12 or 13 scripts.

The life-extending medicine works by blocking the action of testosterone in prostate cancer cells, preventing the hormone androgen (which plays a role in prostate cancer growth) from binding to the androgen receptor.

The therapy is taken as a tablet once a day, with or without food. It can delay the appearance of metastases (sites of tumour cell growth) and can extend survival time by 14 months for men with metastatic disease.

Importantly, clinical trials found that men who received the drug were less likely to die than those taking hormone therapy alone and were less likely to see their cancer progress to becoming treatment resistant.

NOTE:

There was a previous (and still current) indication for apalutamide. This was for CASTRATION RESISTANT NON METASTATIC prostate cancer (this refers to refers to the response of the patient to ADT and not the strict surgical definition) with a doubling time less than 10 months and the patient must be on ADT.

The NEW indication for apalutamide is for METASTATIC CASTRATE SENSITIVE prostate cancer. The patient must be on ADT and must commence apalutamide within 6 months of commencing ADT.

In both cases:

- *the patient must not receive PBS-subsidised treatment with this drug if progressive disease develops while on this drug, AND*
- *the patient must only receive subsidy for one novel hormonal drug per lifetime for prostate cancer (regardless of whether a drug was subsidised under a metastatic/ non-metastatic indication); OR*
- *the patient must only receive subsidy for a subsequent novel hormonal drug where there has been a severe intolerance to another novel hormonal drug leading to permanent treatment cessation.*

The Perfect Match for Men's Health Week

One Australian man is diagnosed with prostate cancer every 22 minutes. To help support research into the prevention and treatment of prostate cancer, PCFA is asking individuals and teams to raise funds by tackling 22 kms in one week, i.e. the same time as each Australian man is diagnosed with prostate cancer, as part of Men's Health Week beginning on 12 June.

As a bonus, all donations to the campaign are being doubled by iconic Australian brands Tyrepower and Hire A Hubby.

PCFA CEO, Anne Savage, said that:

"We'd love to see people supporting our joint campaign for Men's Health Week, by getting involved or making a donation if you can.

"Whether you're an individual or a business, every bit of support makes a difference.

"Our hope is to raise at least $500,000 for new research, but we can't do it without community support.

"With 1 in 5 local men likely to be diagnosed in their lifetime, we'd love to see locals doubling their dollars for prostate cancer research."

If you are prepared to help make up a Group team for this event, please contact John McWilliam on secretary@pcsg-act.org.au as soon as possible.

Articles and Reports of Interest

The following articles which have appeared recently on web sites or other sources may be of interest to members. Any opinions or conclusions expressed are those of the authors. See Disclaimer below.

Recruiting for the ANZADAPT trial

Cancer constantly evolves. This evolution may even be accelerated by treatments such as radiation, chemotherapy, targeted or hormonal therapy.

One therapeutic strategy to mitigate this evolutionary change is called 'adaptive therapy'. Adaptive therapy can be considered when using an effective but non-curative treatment. Treatment is used sparingly, for just long enough to control the cancer and maintain quality of life, but paused as soon as control is achieved.

Adapting' the treatment to each patient aims to increase the duration of benefit, by using treatment-sensitive cancer cells to compete with, and control, treatment-resistant cancer cells. By changing the goal of therapy from 'achieve the deepest/ quickest short-term biochemical/ radiological response' to 'delay inevitable treatment resistance ANZUP hopes to prolong each patient's life and quality-of-life as much as possible.

Mathematical models suggest substantial benefits may be possible. In a pilot clinical trial of adaptive abiraterone in castrate-resistant prostate cancer in the US, patient survival almost doubled [3] compared to contemporaneous and historical controls (time to progression 33.5 months vs 14.3 months in a contemporaneous cohort and ~11 months in COU-AA-302; median overall survival 58.5 months versus 31.3 months in a contemporaneous cohort and 34.7 months in COU-AA-302).

These provocative findings must be tested in a prospective randomised clinical trial. ANZUP hopes that the ANZadapt trial will provide the evidence to change practice and improve survival in men with metastatic castration-resistant prostate cancer.

84 patients with asymptomatic or minimally symptomatic metastatic castration-resistant prostate cancer in whom treatment with AA or ENZ is indicated are being recruited for the trial.

Unfortunately, there are no participating centres in the Canberra Region. Participating centres in NSW are: Calvary Mater Newcastle; GenesisCare Northern Cancer Institute St Leonards; and Border Oncology Research Institute.

Read more.

Breakthrough prostate cancer treatment trialled at Nepean Hospital

The next generation of prostate cancer treatment has arrived with a new robotic laser therapy system revolutionising the way surgery is performed. The new technology is improving patient outcomes for men and ensuring a better quality of life post procedure.

Currently trialled at Nepean Hospital is a needle guided laser ablation treatment that targets the prostate cancer without having to remove the whole prostate gland or affecting the function of prostate gland itself.

Nepean Hospital Urologist, Associate Professor Celi Varol, the mastermind behind the new Australian technology, has spent close to a decade perfecting its design, manufacture, and trial.

The procedure works by placing a needle into the prostate gland that has a laser system on the end which heats up the cancerous cells to destroy the most diseased part of the prostate.

While Prof Varol emphasises the breakthrough laser procedure is still in clinical trials and may not be appropriate for all patients, it does offer hope for many men facing prostate cancer in the future. Rather than lose their prostate entirely and risk significant and lifelong nerve damage, the focal laser therapy treatment could not only allow patients to survive the cancer but also maintain full function.

Read the full article on the NSW Government website.

New treatment approach for prostate cancer could stop resistance in its tracks

For the first time, researchers have discovered that prostate cancer can be killed by targeting a single enzyme, called PI5P4Kα. The findings, published recently in *Science Advances*, could help address the growing threat of treatment resistance in prostate cancer and could also lead to improved treatments for other cancers, such as those affecting the breast, skin, and pancreas.

The prostate gland requires male sex hormones, known as androgens, to grow. Prostate cancer hijacks the androgen signaling machinery of the prostate in order to grow rapidly, which is why treatments that disrupt these pathways are effective.

The researchers say that it is remarkable that they've found an enzyme that can be targeted against prostate cancer even in cases where treatments that lower hormones are ineffective or where resistance has developed. This could give us a whole new weapon against prostate cancer and other cancers that rely on this enzyme, they say.

There is no drug for this as yet, but clinical trials are expected in an effort to find a suitable drug.

Read the article.

Prostate cancer: New combination therapy could reduce progression risk

MedicalNewsToday (24 March 2023) has reported on the results of a multinational, phase 3 clinical trial – TALAPRO-2 – that tested whether the combination of two medicines, talazoparib and enzalutamide, may improve clinical outcomes in adult men with metastatic castration-resistant prostate cancer.

Enzalutamide is a type of hormone therapy that is approved to treat men with prostate cancer. It works by blocking testosterone, without which the prostate cancer cells cannot grow, even if they have spread to other parts of the body.

Talazoparib belongs to a class of cancer drugs known as poly-ADP ribose polymerase (PARP) inhibitors. PARP is an enzyme (protein) found in cells, which helps damaged cells repair themselves. PARP inhibitors are used in cancer treatment to block the repair function of PARP in cancer cells, causing the cells to die.The trial found that the treatment with talazoparib and enzalutamide resulted in a 37% reduced risk of cancer progression or death, compared to treatment with placebo and enzalutamide.

Read the article.

NOTE: Talazoparib is currently not available under the PBS for the treatment of prostate cancer, just breast cancer. Enzalutamide is available for the treatment of castrate-resistant metastatic cancer. It is in the same family as apalutamide (see pages 5 and 6 for further information about apalutamide).

Borrowing Items from the Library

You can borrow items from the Group's library. There is a wide range of materials, from books to videos. Those who are interested in borrowing items from the library or finding out more about our collection can contact U.N. Bhati, email:
librarian@pcsg-act.org.au

Personal Support

For general information, please call SHOUT (Self Help Organisations United Together) during normal office hours on (02) 6290 1984, and their staff will arrange for someone to contact you.

If you would like immediate advice, support or assistance, please contact one of the following two people:

President: Greg McRoberts, president@pcsg-act.org.au 0413 480 864
Secretary: John McWilliam,secretary@pcsg-act.org.au 0416 008 299

Appreciation

Thanks to all those supporting the Group's fund raising activities, in particular, Harness Racing ACT, the Canberra Southern Cross Club, ACT Masters Hockey, Chartertech ACT, Paddywack Promotional Products and SAC Tyrepower, Belconnen.

From the editor

If you are aware of news, products, publications, web sites, services or events that may be of interest to members of the group, we would like to be informed of them. If you have received this newsletter indirectly and would like to be emailed a copy direct, or if you would like to add any of your friends or carers to our distribution list, or if you no longer wish to receive copies of the newsletter, please send an email to:
secretary@pcsg-act.org.au

Disclaimer

From time to time in our newsletters we provide information about developments in the diagnosis and treatment of prostate cancer, research articles, documents, audiovisual products, presentations and other interesting materials. However, the group does not have the medical expertise required to make an informed evaluation of the conclusions and recommendations presented in such materials, and we have not verified such conclusions and recommendations through appropriately qualified medical professionals. The information presented in this newsletter must not be interpreted as being endorsed or recommended by the group.

Any recommendations made in such materials may not be applicable in your case. Before implementing any recommendations made in the materials that are reported, it is essential that you obtain advice from appropriately qualified medical professionals. The view of the group is that no two prostate cancer cases are alike and that no single treatment option is better than any other in all cases. While the information in this newsletter should be of interest, there is no substitute for getting informed medical advice from your own GP, specialists and other medical professionals.