



## Improving the Future of Prostate Cancer



Prof Kim Moretti says the database is helping to improve the outcomes of patients with prostate cancer.

Around 1 in 4 men will develop prostate cancer by the age of 85.

With this frightening statistic in mind, it's important for health professionals to facilitate the collection of data in order to monitor, analyse and ultimately improve outcomes for prostate cancer patients.

A South Australian online database is playing a key role in this by helping to better understand the progression, treatment and management of prostate cancer to help clinical decision making.

The South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC), established in 1998, is an ongoing collaborative venture of Flinders University, Repatriation General Hospital, Royal Adelaide Hospital, The Queen Elizabeth Hospital (TQEH), the University of Adelaide, the University of South Australia and Flinders University.

Australian Prostate Cancer (APC) is committed to assisting in the elimination of prostate cancer as a health burden in our community and has recently provided SA-PCCOC with a grant to help improve their processes.

Associate Professor Kim Moretti, Chair of SA-PCCOC and Head of Urology at TQEH said the grant will allow them to automate aspects of the data collection, improve the efficiency of the entry of TQEH data and assist with the data entry of prostate related patient outcomes.

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## "Early Detection Will Save Your Life"

At 46-years-old Mark Hore was living a carefree life in country New South Wales. Until he was diagnosed with prostate cancer...

### *The beginning...*

In 2012 my sinuses were playing up, I used to have trouble all the time. So I made an appointment with my doctor to get them looked at. While I was there I realised that I hadn't had a men's health check in about 18 months, so I made another appointment for a few days later.

I remember it was a Monday and I was at work when my mobile rang. It was the doctors surgery. The woman on the phone told me that the doctor had picked up something in my blood test. My heart fell into my stomach. I thought the worst. I never thought it could be prostate cancer – I didn't even know what prostate cancer was. A PSA test - what was that?! The guys at work were reassuring me that it was probably just my cholesterol or something trivial...

### *The diagnosis...*

My mum came with me, and when we were waiting I realised she had rosary beads in her hand. My father had died 20 years before, at only 55 from a brain tumour – it was pretty tough. I had always told myself that at least I'll live past 55...sitting there I wasn't so sure.

When the doctor said that my PSA levels were elevated, to be honest I didn't really know what he was talking about. I was then referred to a urologist. The urologist thought it was just an infection so I got some antibiotics and after the four week course I had another blood test. The PSA levels hadn't changed.

Another four weeks passed and I was booked in for a biopsy – I was very nervous. A few days later I was told I had prostate cancer.

I was numb – I didn't know what had happened. I didn't feel anything. To add to everything, two days after I was diagnosed I got retrenched.



Mark hopes sharing his story will encourage other men to take prostate cancer more seriously.

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"We've now got over 9,400 patients on the database with all the major public hospitals plus some private practices providing data," he said.

"This is an observational study - so we observe the treatments in the state, analyse them and feed outcomes back to clinicians, to ultimately improve the health and management of prostate cancer in South Australia.

"Over the current period of data gathering we have certainly seen an improvement of the standard of care," he said.

Now in its 15th year of operation, SA-PCCOC is regarded as one of the most sophisticated and productive clinical prostate cancer databases in the southern hemisphere containing a huge wealth of information that has produced research of a national and international quality.

In addition to pathology and treatment outcomes, the database also collects patient reported outcomes to assess the quality of life after treatment.

"The patients get a series of forms firstly upon diagnosis, and then six months, twelve months, two years and five years afterwards to assess how they are performing," A/Prof Moretti said.

"This includes various personal problems such as incontinence, bowel problems and anxiety, so it is from the patient perspective as opposed to just collecting pathology and treatment data."

While the database captures about 90 per cent of all state public hospital data the collection for private patient data is around 35-40 per cent.

"The improved electronic data collection, largely thanks to this grant from APC, will make gathering this private patient data as easy as possible and improve the quality of our database analysis," said A/Prof Moretti.

"This grant has really given us a much needed boost to achieve the aims and objectives of SA-PCCOC and help improve the outcomes of patients with prostate cancer now and in the future."

## Personal Experience Inspires Support

For more than 20 years, John lived with increasing symptoms of prostate cancer.

"I had a lot of unpleasant symptoms that were gradually getting worse as the years went by," explained the 66-year-old from Adelaide, SA.

But it wasn't until April 2014 when John reached the point of intolerable discomfort and exhaustion, that he visited his GP.

Testing revealed that John had a PSA level of 148 – which is extremely elevated. Further tests showed that John had a large cancerous prostate tumour – it was advanced and aggressive.

"My specialist advised me I wouldn't be a good candidate for surgery, so I started on Androgen Deprivation Therapy (ADT) immediately."

Once he commenced treatment, John said his symptoms reduced dramatically.

In hindsight, John recommends that other men who may be experiencing prostate cancer symptoms seek help.

"I hadn't been sharing my concerns with my wife or with anybody. I had been keeping it to myself which I think made it much worse."

John believes there is truth in the saying – 'when you tell people about your problems, you reduce them'.

"I kept things bottled up for years and let myself get to an extremely depressive mental state before I took action. I wouldn't want others to go through that," he said.

After three months of ADT John's PSA reading dropped from 148 to 1.8. While this was a positive result, ADT only bides time, so John went through an eight week course of radiation therapy which gives hope of a long term cure.

**"I'm not sure how much time I've got, but I'm grateful for whatever I get."**

"Earlier in the year I would go to my daughter's place and my wife would be playing with my two gorgeous grandchildren, and all I wanted to do was lay back in a big comfy chair and go to sleep.

"Now I'm up and kicking the footy around with them. It's quite amazing how different I feel now I'm having treatment.

"Now I know about the problem and I'm doing everything I can to fix it. One way to do this is regularly supporting prostate cancer research to help find a cure."

**Read more of John's story at [www.ausprostatecancer.com.au](http://www.ausprostatecancer.com.au).**

**If you would like to share your story about prostate cancer then please contact us via email: [contactus@ausprostatecancer.com.au](mailto:contactus@ausprostatecancer.com.au) or phone: (08) 8243 1101.**

### How to keep your prostate healthy!

1. Eat lots of fresh fruit and vegetables

2. Exercise regularly

3. Quit smoking



## "Early Detection Will Save Your Life"

Mark's Story

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Mark (right) with his friend Loughin who participated in a race with him, helping him become a stronger person.

### The surgery...

On November 17th, 2012 I had surgery. I was pretty brave during most of the lead up, but I did lose it a few times and I still get emotional about it now.

After the surgery I was in hospital for five days and then stayed in a motel with my mum for another ten. Those three weeks made me a stronger person. I've come such a long way...

### My goals...

After my surgery I wasn't allowed to ride my bike initially, but I set a goal of riding 175km in an upcoming event. Slowly I built up my strength and managed to do the ride. It took almost seven hours and I remember finishing and crying – it was awesome. Then I thought, what's next? I saw a 'learn to run 5kms'. I signed up. I wanted to get back to the old Mark.

So over eight weeks I learnt to run 5kms. It was good and something other than bike riding. Then I did the 'learn to

run 10kms', with a goal to run the Melbourne Marathon 10km race. I finished that race in the MCG and cried once more. I was so emotional – I thought 'this is amazing'.

I noticed that a few months later a half marathon was coming up. So I signed up and trained all through the summer and then completed the Canberra Running Festival Half Marathon in April and went on to run another three! Running has been the best medicine for me – it clears your head.

### Now...

Prostate cancer has changed my life for the better. I just have so much that I want to do now. I'm now incredibly driven and I work in a hospital as an orderly! I look back two years ago and I know I've come a bloody long way.

I've had mates tell me that they've been checked, luckily they have all been fine but all it takes is for one person to say that an early diagnosis has saved their life.

That's the biggest issue – men just don't know about prostate cancer. I had no symptoms, everything was fine. I like to think that I'm making a small impact on everyone just getting them to think about things more seriously – even my doctor has said that he is more thorough with his patients because of me. I am so driven to get out there and get rid of it.

Prostate cancer is not a death sentence if you catch it early – my uncle said that to me and that's one thing I've always remembered. Early detection will save your life. It certainly saved mine.

## Researcher Profile: Eric Smith



Dr Eric Smith hopes to decrease the burden of prostate cancer.

One of Australian Prostate Cancer's researchers is Dr Eric Smith. We sat down with him recently to find out a bit more about his research and what motivates him to find a cure for a disease which affects 1 in 4 Australian men.

Dr Smith is looking at the use of fibroblasts (which occur in our body) and their effect on cancer cells, some fight the cancer, while others cause it to grow.

### How will your research help?

Our research is focused on the interactions between the cancer cells and the normal cells of the prostate. Some of these normal cells support and encourage the growth of the cancer cells whilst others have the potential to kill or restrict the growth of cancer cells. If we can better understand the interactions between the different types of cells, then we may be able to develop new treatments for prostate cancer.

### What do you hope your research will do for the community?

Prostate cancer is the most common cancer in Australian men (excluding non-melanoma skin cancer), accounting for one third of all new cases diagnosed in men. With our research we hope to decrease the burden of prostate cancer and other solid cancers.

### What motivates you to continue your research?

Despite recent advances in the diagnosis and treatment of prostate cancer, it continues to affect the lives of so many people, both the men with the disease and their family and friends.





Following his father's diagnosis, Rhys is now much more mindful of the disease.

## Rhys Inspired to Run for a Cause

Eight years ago Rhys' father was diagnosed with prostate cancer.

"My parents are living in Wales, so dropping by for a visit is not something that can be done easily," Rhys said.

The diagnosis happened at the same time that Rhys and his partner were expecting the birth of their son, however they hadn't yet shared their news due to it still being at such an early stage.

"When Dad gave me the news it was a shock, but I decided to let him know our news to put a smile on his face and give him that goal of meeting his new grandson!"

Rhys' parents came and visited their new grandson for a few weeks soon after he was born.

"During the diagnosis it was so important to keep positive and have goals to achieve," he said.

Late last year Rhys decided to run his first half-marathon as part of the Mornington Running Festival in Victoria supporting Australian Prostate Cancer. He raised more than \$590.

Aiming for a time of 1hr and 50 mins, Rhys exceeded his expectations and thanks to a final uphill sprint, finished in 1hr and 44 mins.

"The run went well. I was really happy with my time as I had exceeded my expectations."

Thankfully, Rhys' father has been in the clear from prostate cancer for seven years.

His diagnosis has also made Rhys much more mindful of the disease.

"I am a lot more aware of the risks involved and will be undergoing regular checks now that I'm approaching the big four-oh!"

## 100 Holes for Prostate Cancer

APC would like to say a big thank you to Victorian Jay Claringbold and his friends for completing their '100 holes of golf in a day' challenge to raise money for prostate cancer research.

In its second year, the group have raised more than \$3,000!

"We wanted an event that was different, challenging and fun!" explained Jay.

The event is dedicated to the father of a friend who passed away from prostate cancer.

"My own father is in his late 60s and a lot of his friends are dealing with prostate cancer and related issues. As men it's something that is part of our lives and we need to be conscious of it."

For those who don't know, 100 holes of golf is more than five times a usual round (18 holes). The gang teed off just before 5:30am and finished at 7:30pm, 14 hours

after they first started playing...

"It was gruelling. We walked about 40kms and each player carried a full set of clubs. That said, it was a really fun day!"

"And thank you to the Mansfield Golf Club who have supported us each year," Jay said.

We'd like to say a huge thank you to Jay, Jeremy, Ed, Tim, Steven, Adam, Richard and Steve - you definitely earned that beer!



Jay and his teammates dedicated the event to a friend's father who passed away from prostate cancer.

**If you would like to support world-class prostate cancer research like Rhys and Jay, then please email [events@ausprostatecancer.com.au](mailto:events@ausprostatecancer.com.au) or call us on (08) 8243 1101.**

## Host a Dinner to Fight Cancer

During the time you have friends over for dinner, 40 Australians will be diagnosed with cancer. You can help change this by hosting a Longest Table.

APC is proud to this year be one of the beneficiaries of The Longest Table; a fun and simple event where you host a dinner with your friends. Your dinner can be as laid back or as elaborate as you like, whether it's a pizza or burger night or even an eight-course meal.

The official date is Saturday, 20th of June, but you can hold your dinner at any time that suits you. Visit [www.thelongesttable.com.au](http://www.thelongesttable.com.au) now to find out more and register your interest.



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