

## Project update



With recruitment now complete, the Forgotten Cancers Project is moving to the next stage; data analysis and research.

On behalf of the team at the Forgotten Cancers Project we would like to thank everyone who has participated in the Project, as well as to our generous supporters and donors. Without you this research would not be possible. We look forward to keeping you up-to-date with the many ways in which the data generated from this project is contributing to the improved prevention and treatment of less common cancers.



**Dr Fiona Bruinsma**  
Research Coordinator

### Other changes

You may have noticed the Forgotten Cancers Project website has recently undergone a makeover!

The launch of the updated website coincides with and reflects the Project's transition from the recruitment stage to data analysis and research. As a participant you will still find study updates, information about less common cancers, and related news and case studies, however the registration and login pages will soon no longer be available.

Within the next few months, researchers who wish to collaborate with or access data from the Project will be able to apply through the website. A publications page will also be available for those interested in reading the research generated by the Project.

To find out more please head to our website:  
[www.forgottencancers.com.au](http://www.forgottencancers.com.au)

### Research collaborations

We have begun accepting requests from external researchers for collaborations and data access. The Forgotten Cancers Project has recently begun working with the National Cancer Institute (NCI), a leading cancer control institute based in Washington (USA). Through the NCI, groups of scientists, or consortiums, are working toward coordinated, interdisciplinary collaboration that is designed to help quicken the pace of research. The Forgotten Cancers Project has already provided data to two consortiums, the Pancreatic Cancer Case Control Consortium (PANC4)

and the International Lymphoma Epidemiology Consortium (InterLymph).

The Pancreatic Cancer Case Control Consortium is currently looking into the inflammatory potential of diet and how it may interact with related genes in the development of pancreatic cancer.

The International Lymphoma Epidemiology Consortium is also conducting genetic analysis but with a focus on lymphomas. The Forgotten Cancers Project is contributing biospecimens on non-Hodgkin lymphoma and myeloma toward this research.

# Personal stories from the Forgotten



I am way past menopause, so when I had a show of blood one Sunday, I went to the doctor the next day.

He gave me a referral to the hospital and as I was only a public patient, it was several weeks before I had an outpatient's appointment.

I was told that it was unlikely to be cancer as I was not overweight, had never smoked and was not a diabetic. However, the scan found that the lining of my womb was 18 ml thick instead of 4 ml, and the next procedure found that indeed I did have a tumour. The tumour was Grade 3 and aggressive, and the doctors said that they would need to operate on me as soon as possible. I had already made arrangements to visit friends in Perth, so they told me I would be operated on as soon as I returned. That proved to be the case, and three months after my initial bleed I had a complete hysterectomy. I was told that I was very unusual in that I had gone to the doctor's the day after my only symptom – most women would say "If it happens again I will go to the doctor." They might not have another bleed for two years, by which time it could be too late to save their lives.

Other than that one day of bleeding, I had no symptoms at all – no discomfort or pain, and because the cancer had not had time to penetrate beyond the lining of the womb, I had no need for either chemo or radiation or for any sort of medication.

I have been in remission now for three years, and don't really expect the cancer to return.

**Hazel Hillier**



In 1954 my father died as a result of the secondaries from an excised laryngeal cancer – brought about by heavy smoking.

I was 22 at the time and a smoker as well. Sadly my father's 'example' had a minimal effect on me – I still carried on smoking for another 20 years or so.

I was finally able to give up smoking in my late 40s. After turning 75 I was offered the chance for a full health review – sponsored by the Government of the day – and during this exercise the urinalysis showed traces of 'albumin' and blood.

**I regard that day as my Lucky Day.**

I was sent for an investigation where it was discovered that there were multiple growths in my urinary bladder. The look on the operator's face immediately told me that something was not quite right.

I was sent for a rigid cystoscopy investigation and woke up in a ward with a 'full irrigation attached'. What a surprise!

When the surgeon saw what was inside he felt that no time should be wasted and removed as much of the invading tissue as he was able at the time.

I was referred for a series of B.C.G. infusions with a follow-up cystoscopy for inspection.



# n Cancers Project

Again – I woke up in a ward with irrigation attached. A further course of B.C.G. was carried out, followed by another cystoscopy.

A urostomy was discussed but the surgeon was reluctant to perform this on someone my age (by this time 80) so we persisted with my treatment.

My last inspection, five and a half months ago, was clear and I’m due in a couple of weeks for the next flexible cystoscopy. We hope this will also give a clear result.

I have been told that smoking is a cause of cancer in the bladder. The first question that the surgeon asked me was “Do you smoke?” and when I said “No” he immediately asked “Have you been a smoker?” When I said I had, he told me that it was probably the cause. One of my sons and a daughter-in-law are smokers and I have not been able to persuade them to give it up and to get a check-up.

John Collingwood

**If you would like to submit your story to the Forgotten Cancers Team please email us at [forgottencancers@cancervic.org.au](mailto:forgottencancers@cancervic.org.au)**



## Who’s taking part?



**Total: 4331**



2676 People diagnosed



1655 family members



40% men



60% women

## ABC Study – half way there!



Do you know someone who is an Australian resident aged 40–74 years and has never been diagnosed with cancer?

If you do, please encourage them to participate! We are particularly interested in individuals with a family history of cancer – particularly men!

The Australian Breakthrough Cancer Study is researching the role that our genes, lifestyle and environment play in the development of cancer and other diseases. It is aiming for breakthroughs that will enable more individualised prevention and screening to occur. Currently, most public

health interventions are based on a one size fits all approach, rather than on personalised risk estimation.

We are just over the half way mark with about 26,000 people taking part so far. Please help us by registering to participate or spreading the word. You can find out more by visiting our website ([www.abcstudy.com.au](http://www.abcstudy.com.au)) or giving us a call on **1800 688 419**.



**New contact details?**



**If your contact details are about to change, please let us know.**

**Do you have a saliva sample or questionnaire yet to complete?**

**Recruitment is closing soon, so please hurry!**