



The Forgotten Cancers Project needs a total of 30,000 participants

15,000 cases



+

15,000 controls



## Family focussed research

The Forgotten Cancers Project is conducting research that aims to understand the roles of genes, lifestyle and early life environment in the causes of less commonly occurring cancer.

To do this, we are collecting a broad range of health and lifestyle information from people who have been diagnosed with one of these cancers. In addition, we collect the same types of information from one of their family members.

### Why do we invite family members to take part?

In scientific terms, we are conducting a case-control study. That is, we collect information from people who have been diagnosed with a disease (the cases) and compare it with information from people who are not affected by the disease (the controls). By doing this, we can try to identify any differences between the cases and the controls and see whether the differences might be associated with the development of cancer.

The Forgotten Cancers Project invites family members to act as controls because it has been shown that family controls can produce more reliable research findings. Further, the involvement of family members also allows us to explore the genetic basis of the cancers more fully. Family members play very important roles in our endeavours to understand the less common cancers.

## It's not too late

If you haven't been able to finish your questionnaires, or send us your saliva sample, it's not too late to do it now.

### Complete questionnaires

The information you give us in the questionnaires is essential to the success of the research. Need some help? Ring **1800 068 289**

### Return saliva sample

The saliva sample is important as it allows us to investigate the genetics of cancer.

Need another saliva kit, or need some help? Ring **1800 068 289**



People from across Australia are joining the Forgotten Cancers Project in increasing numbers.

A total of 1,614 people have registered, but more are needed.

Those who have been diagnosed with a less common cancer, and were 18 years or older at the time of diagnosis, can register to be part of this research.

## Helping to build the Project

Breakthroughs can come about by a single person having a really good idea, but this is rare. Medical breakthroughs these days are hard earned and usually come from the involvement of thousands in well designed research. The Forgotten Cancers Project is well underway, but is still in its building phase, and needs to hear from many more Australians who been diagnosed with a less common cancer.

More than 40,000 Australians will be diagnosed with a less common cancer this year and many of these people could welcome the opportunity to contribute to cancer research - if only they knew about the Forgotten Cancers Project.

So everyone has been busy getting out and about letting people know about the Project.

Team members have been in the community - spreading the word. Dr Fiona Bruinsma, Research Coordinator, has been giving radio and newspaper interviews. Fiona has also spoken at the Country Women's Association state conference and Juliet Anderson, Project Manager, has spoken to the CWA Pakenham branch. Juliet has also been joined by Lisa Hochberg and Belinda Barker talking to people about the Project at Cancer Council *Relay for Life* events in Mornington, Casey, Diamond Valley and Timboon, and at community health forums.

"It would be wonderful if those participating in the Forgotten Cancers Project could also help spread the word. We want to make sure that all who have been diagnosed with a rare cancer have a chance to take part," said Dr Bruinsma.



### Forgotten Cancers Project team

Juliet Anderson, Lisa Hochberg, Dr Fiona Bruinsma, Belinda Barker

## Country women supporting cancer research

Each year, the Country Women's Association of Victoria selects a worthy project as the focus of their fundraising activities. We are very grateful that in 2014, the Forgotten Cancers Project has been selected as the recipient of the CWA Thanksgiving Fund.



In July, the Birregurra Branch of the CWA hosted the 2014 Thanksgiving Dinner for the benefit of the Project. Heartfelt thanks go to the CWA members for their support.

How can you help? See next page



## Project participants spreading the word

Forgotten Cancers Project participant, **Allison McMaster**, has put her support into spreading the word about the Project.

Allison, who has been diagnosed with a rare cancer, has been sharing her story with the community to encourage others to take part.

The more people who take part, the stronger the research will be. So please help spread the word and give others the opportunity to hear about the Forgotten Cancers Project.

**Brave local raises awareness for Forgotten Cancers Project** By Sonia Clark

This time last year Mooloolah local Allison McMaster was jogging along Connection Road preparing for the Caloundra Foreshore Fun Run.

The personal trainer, wife and mother was a fit and healthy 47-year-old who was about to qualify as an enrolled nurse. Her work prospects were good, she and her husband of 18 years were building their dream home and life was busy and full. Returning home that day she discovered blood in her urine and her life as she knew it was turned upside down.

The first doctor diagnosed a Urinary Tract Infection (UTI), however she pushed for a second opinion that revealed a tumour. In August last year, Allison had her kidney removed with an 8cm tumour. She was diagnosed with Stage 2 CDC (Collecting duct carcinoma) a rare and aggressive type of cancer and commenced chemotherapy from October until January. Allison was then given the all clear but her relief was cut short when she discovered a lump in her groin in March of this year.

Allison McMaster keen to encourage others into the Forgotten Cancers Project

Devastatingly, a biopsy revealed stage 4 cancer and the prognosis of this rare type of cancer is poor. Allison has started radiation therapy, however last month, she was told she has between three - 12 months to live.

During this harrowing journey, Allison found information about her cancer very hard to find. Research into it has been limited and even doctors knew very little.

During this time, she came across the Forgotten Cancers Project which is an initiative that seeks to study and understand the causes of less common cancers. Although Allison's time may be limited, she is committed to raising awareness about this project.

The project seeks volunteers who are aged over 18 and have been diagnosed with a less common form of cancer to answer questionnaires and provide saliva samples. With the permission of participants, relatives are also invited to take part in the project to provide comparison information.

Along with trying to remain positive and healthy, Allison is determined to bravely fight on - she has set family milestones to look towards to inspire her positive outlook; such as her 20th wedding anniversary and her son Mathew's 18th birthday (he is currently 14).

This year Allison will walk along side a team of locals ladies in the Caloundra Foreshore event on June 22 proudly wearing the Forgotten Cancers t-shirts. As Allison says, "I would like to be remembered not forgotten." For more information see [www.forgottencancers.com.au](http://www.forgottencancers.com.au)

Article in *Glasshouse Country News*, 21 May 2014

## You can help

You can help the Forgotten Cancers Project by spreading the word, so that all those diagnosed with a less common cancer get the opportunity to take part.

We have a range of free promotional materials you can use to let your community know about the Forgotten Cancers Project. Please contact us to order materials or discuss ways that you can help promote the Project.

**Posters**  
**Bookmarks**  
**Postcards**  
**Fridge magnets**  
**Stickers**

**THE FORGOTTEN CANCERS PROJECT**  
Focussing on the causes of less common cancers

**What is the Project about?**  
Through intensive research, significant progress has been made in understanding, preventing and treating the most commonly diagnosed cancers, however less common cancers remain under researched.

**Are you eligible to participate?**  
✓ Have you been diagnosed with a less common cancer?  
✓ Were you 18 or older at the time of diagnosis?

**Get Involved**  
To participate or find out how you can be involved visit [www.forgottencancers.com.au](http://www.forgottencancers.com.au)

**Thank you for supporting THE FORGOTTEN CANCERS PROJECT**  
[www.forgottencancers.com.au](http://www.forgottencancers.com.au)  
1800 068 289

**THE FORGOTTEN CANCERS PROJECT**  
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**Less Common Cancers**

• Non-Hodgkin lymphoma	• Stomach	• Small intestine
• Leukemia	• Gallbladder	• Multiple myeloma
• Kidney	• Brain	• Oesophagus
• Thyroid	• Bone	• Uterus (endometrium)
• Bladder	• Liver	• Other rare cancers
	• Pancreas	

[forgottencancers@cancervic.org.au](mailto:forgottencancers@cancervic.org.au)  
[www.forgottencancers.com.au](http://www.forgottencancers.com.au)  
1800 068 289

**Cancer Council Victoria**



- Visit [forgottencancers.com.au](http://forgottencancers.com.au) and share on Facebook or Twitter
- Put up a poster at your local GP and leave some postcards or magnets
- Leave a stack of bookmarks at the library
- Give bookmarks, magnets or postcards to family and friends



Talk about how you can help

1800 068 289

Order promotional materials

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## Have you moved ?

If your contact details have changed, please phone or email your new details to us.

1800 068 289

[forgottencancers@cancervic.org.au](mailto:forgottencancers@cancervic.org.au)

Checkout the new look website  
[www.forgottencancers.com.au](http://www.forgottencancers.com.au)