

On our way to discovering more



We've made some great strides in the Forgotten Cancers Project this year.

We've had more than 1800 participants sign up in the past 12 months which will greatly help us learn more about the causes of less common cancers. More than 1000 controls have also taken part – thank you to those family members who are helping out with this research.

The increase in numbers is largely thanks to people spreading the word about this important project in their communities. Please keep doing what you're doing!

The DNA collection process has continued, with the overwhelming majority of participants returning the completed saliva kit promptly for processing.

While our aim is to look at all less common cancers, at the moment our researchers are focusing on bladder, brain, kidney, leukaemia,

multiple myeloma, Non-Hodgkin lymphoma, pancreatic and uterine cancers. We are aiming to recruit 300-400 participants for each by the end of 2017 in order to commence analyses.

We are already preparing the data for an analysis for kidney cancer, with multiple myeloma and follicular lymphoma likely to start towards the end of 2016.

Who's taking part?



2433 people diagnosed



1462 family members



40% men



60% women



Carrie Bickmore put the spotlight on brain cancer when her fantastic speech at this year's Logie Awards made #beaniesforcancer go viral. In the same week we hosted a Brain Cancer Forum on the latest in clinical trials research, how to manage seizures, and handling practical challenges like financial and legal issues.

Thank you for taking part and supporting the Forgotten Cancers Project – with your help we can work to increase what we know about these cancers.



Dr Fiona Bruinsma
Research Coordinator



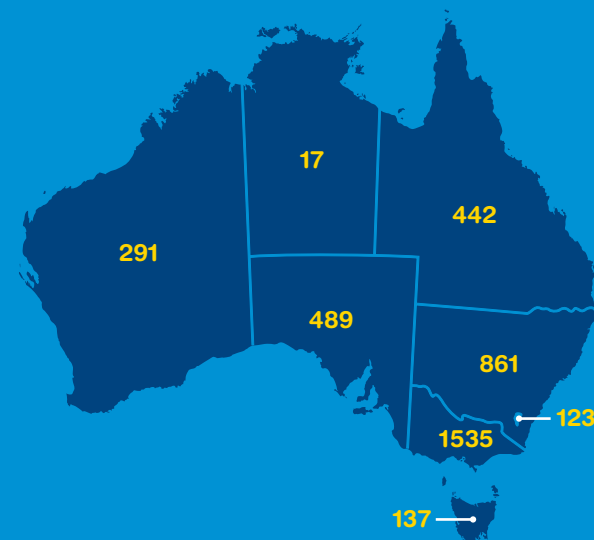
Where does my DNA sample go?

When you send your saliva and blood samples to us they are processed and stored at the Genetic Epidemiology Laboratory located at the University of Melbourne. Your samples are stored securely and only authorised staff can access them.

Within the next few years we will begin to examine small changes in the components of genes that may influence how a gene functions, as well as how lifestyle or environmental factors could influence gene expression. These analyses need to be carried out across large numbers of people to identify patterns for further investigation.

Australia-wide project

We now have **3895** Australians (both people diagnosed and family members – as shown in state by state breakdown below) taking part in the Forgotten Cancers Project but we still need more.



People 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.

Blood cancer leaves its mark on family



Non-Hodgkin lymphoma (NHL) has had a big impact on Geraldine Bull's family, with both she and her father diagnosed with the disease.

The Sydney resident was one of about 3500 Australians diagnosed with NHL each year. NHL is the sixth most common type of cancer in men, and the fifth most common type of cancer in women.

Geraldine initially found lumps in her neck and groin, with further scans revealing lymphoma in two other sites. She underwent antibody and oral chemotherapy before being given the all-clear.

"It was a tremendous relief when I was told the cancer was gone," Geraldine says.

Sadly a few years earlier, Geraldine's father died from a more aggressive form of NHL just 18 months after he was diagnosed.

It's this experience that spurred the retired social worker to take part in the Forgotten Cancers Project when she found out about it through an email from Cancer Council.

She has since filled in the questionnaires about her family cancer history, health and lifestyle, and provided a saliva sample.

"We don't know why some of these cancers develop so it's important to raise awareness of lesser known cancers to help people diagnosed with them," she said. "I know that while the research may not directly help me, it may help others in the future so that they don't have to go through what my family have."

Carers play vital role

Gwenyth Leighton is just one of the many family members across Victoria who has cared for a loved one with cancer.

It was after her brother underwent treatment for bladder cancer when Gwenyth decided to sign up to the Forgotten Cancer Project to help find out more about the causes of less common cancers.

"My brother dobbed me in and I agreed to do it." The siblings filled in the questionnaire together for the project. "It felt like we were doing something to help."

She hopes the Project can help reduce the risk of more of her family being touched by cancer. Her sister died of lung cancer and her father of an unknown primary, while her aunt and uncle have also had the disease.

"Why does it strike some and not others? I would like to know the answers," Gwenyth says.

"Hopefully my great, great grandchildren won't have to go through what my family and other families have gone through."

Gwenyth was able to take part as a comparison participant by providing her DNA sample and information about her lifestyle.

Groups show their support

With the assistance of community and support groups we have been able to spread the word about our project far and wide. Through their fantastic networks on social media, as well as electronic and print newsletters, a record number of participants have signed up to take part.

The more people who take part in the Forgotten Cancers Project, the more we may be able to find out.

If you're a member of a group and would like to help us promote the study, we'd love to hear from you. Contact us on **1800 068 289**.

We also have free posters, postcards, pens and brochures available, and links on www.forgottencancers.com.au to share on social media.



A friendly reminder...

Do you have a questionnaire to complete or a sample to send back?

The questionnaires are essential to the success of the research and collecting saliva samples enables us to investigate the genetics of cancer.

Need help? Call **1800 068 289**.

Have you moved?

If your contact details have changed, please let us know.



Want to offer support to others?

Would you like to help someone during their cancer experience? We are looking for Victorians who have 'been there', are two years post treatment and interested in becoming a Cancer Connect volunteer.

We are particularly keen to hear from people diagnosed with bladder, stomach, uterine, myeloma or acute myeloid leukaemia.

For more information contact Janine on **9514 6315**.

Out and about



The Forgotten Cancers Project has been supported by the Country Women's Association of Victoria, Tuxedo Junction and the Emeralds & Ivy Ball.



Country Women's Association of Victoria State Conference

The CWA generously donated \$30,000 to the Project at their State Conference in May. The money was raised through their Thanksgiving Fund, which supports a chosen medical research program each year.

Tuxedo Junction

Our charity ball raised \$175,000 for cancer research, including for the Forgotten Cancers Project thanks to the Margaret 'Mavis' O'Dea Research Award funded by Organisation Unlimited. Mick O'Dea spoke about his mother, Mavis' battle with the rare cancer, Neuroendocrine tumors (NETs).



Photo: Snappy Pics.



Cancer Council Australia's Emeralds & Ivy Ball

This year's Ball on October 9, hosted by Ronan Keating, will raise awareness and funds for the Forgotten Cancers Project.

Join our ABC Study

Our research team at Cancer Council Victoria has launched an exciting new project, the Australian Breakthrough Cancer Study. The team is seeking the help of 50,000 Australians between the ages of 40-74, who have never had cancer.

This prospective study will follow participants' health over time to further our understanding of cancer and other diseases. You can help by taking part or spreading the word.

To find out more visit www.abcstudy.com.au

Once a year
not enough?
Visit [www.forgotten
cancers.com.au/](http://www.forgotten
cancers.com.au/)
news to keep up-to-
date with the latest!

Thank you to
the Leukaemia
Foundation
for supporting
the Forgotten
Cancers Project

