

Why are we doing this study?

The most recent national statistics show that almost 3,000 Australians are diagnosed with kidney (renal) cancer annually. The CONFIRM Kidney Study, which is run by the Cancer Council Victoria, is investigating the causes of kidney cancer, and aims to improve prevention and treatment of the disease. CONFIRM (also known as the Consortium for the Investigation of Renal Malignancies) is a research partnership including hospitals, universities and research institutions in Australia. There is also a Queensland arm of the study, the CARE Study (Collaborative Australian Renal carcinoma Epidemiology).

The CONFIRM and CARE studies are looking at the roles of genes, lifestyle and environment in the development kidney cancer.

The studies are investigating whether lifestyle choices, such as diet or exercise, or environmental exposures, such as exposure to sunlight or chemicals, can effect the risk of developing kidney cancer or recovery from the disease.

Further, while we know that the disease has an inherited component, as people who have a family member with kidney cancer are at greater risk of developing the disease, there is much more we need to know about the ways in which genes affect its development.

The studies are funded by the National Health and Research Council of Australia.

The studies are led by Associate Professor Gianluca Severi, Deputy Director of the Cancer Epidemiology Centre at Cancer Council Victoria, and involve researchers at the Queensland Institute of Medical Research, University of Melbourne, Royal Melbourne Hospital and Cancer Council Victoria.

The information collected by the study will also contribute to other studies world wide.

Thank you to all taking part

For a research study to be successful, it is necessary for a lot of people to generously give their time and energies. The CONFIRM and CARE Kidney Studies are extremely grateful to those who are taking part.

The study teams wish to thank the 1413 people who have taken part in the study so far, including 813 participants who are affected by kidney cancer, and 520 of their family members.



Associate Professor Gianluca Severi
Cancer Council Victoria

All have generously provided the information that is essential for the success of this research.

It is only through your efforts, and those of your fellow participants, that progress can be made towards understanding this disease.



**CONFIRM
Kidney Study**

CONFIRM Kidney Study team

The CONFIRM Kidney Study team is led by Associate Professor Gianluca Severi, who is assisted by Study Manager Jennifer Walsh, Senior Project Officer Roxanne Kritharidis, and Project Officers Lydia Vanikiotis and Lena Elkman.



Roxanne, Jennifer, Lena and Lydia

The team members bring a wide range of health and project management skills to the CONFIRM Study.

“We all value the opportunity to be involved in such important research,” said CONFIRM Study Manager, Jennifer Walsh.

If you have any questions, or need assistance with the study, please contact the team.

Contact us on:

1800 172 352

confirm@cancervic.org.au

Questionnaires

Do you still have questionnaires to complete?

The information you give us in the questionnaires is very important for the success of the research, so returning completed questionnaires is greatly appreciated.

If you need any information, or require assistance completing the questionnaires, please call Jennifer Walsh on **1800 172 352**. She will be happy to help you.

Misplaced your questionnaires?

Contact us and we will send you replacement copies.

Need another reply-paid envelope?

Contact us and we will send you one.



Our study partners

While our most important study partners are the people who agree to take part in the study, there are also a number of partner organisations who are essential for the study's success.

These organisations put the study team in touch with those affected by kidney cancer, or those at a greater risk of developing kidney cancer. This gives us the opportunity to invite these people become involved.

These organisations contribute a considerable amount of time and resources to support the study. It is an indication of the importance of this research that so many organisations have become partners in the study.

The CONFIRM Kidney Study team wishes to acknowledge their involvement.

Those taking part are:

- Victorian Cancer Registry
- Victorian Familial Cancer Register
- Familial Cancer Centre, Royal Melbourne Hospital
- Southern Health Familial Cancer Centre, Monash Medical Centre
- Austin Health, Heidelberg Repatriation Hospital
- Hunter Genetics, John Hunter Hospital
- Family Cancer Clinic, Cabrini Institute
- Familial Cancer Centre, Peter MacCallum Cancer Centre
- Hereditary Cancer Clinic, Prince of Wales Hospital

The following organisations will soon be taking part also:

- Familial Cancer Service, Westmead Hospital
- Cancer Genetics Department, Royal Prince Alfred Hospital
- Department of Clinical Genetics, Royal North Shore Hospital
- South Australian Clinical Genetics Service
- Genetics Services of Western Australia



Do you know someone who might be interested in taking part in the CONFIRM Kidney Study?

The success of the CONFIRM Kidney Study relies on getting information from as many people as possible. Ideally, it is hoped that 1,300 people with kidney cancer and 2,600 family members will eventually take part in the study.

CONFIRM Kidney Study would like to hear from Victorian residents, aged between 18 and 75 years, who have been diagnosed with kidney cancer (renal cell carcinoma), or have a strong family history of kidney cancer, with 2 or more close relatives (parent, sibling, child, uncle or aunt) having been diagnosed.

If you know someone who might be interested, please ask them to contact the CONFIRM Kidney Study Manager, Jennifer Walsh, on **1800 172 352** or email **confirm@cancervic.org.au**

Help us stay in touch

We would like to keep you posted on how the studies are progressing and new activities that are underway.

Please tear off this strip and send it to us when you move, change your name, telephone number or email address.

First name Mr/Ms/Mrs/Miss

Middle name

Last name

Phone

Email

NEW ADDRESS

Suburb

State

Postcode

OLD ADDRESS

Suburb

State

Postcode

Mail to:

CONFIRM Kidney Study
Cancer Epidemiology Centre
Reply Paid 83943
Carlton VIC 3053

OR email your details to:

confirm@cancervic.org.au

OR phone 1800 172 352

Remembering forgotten cancers

The Cancer Epidemiology Centre, Cancer Council Victoria, which runs the CONFIRM Kidney Study, recently launched another large-scale study which focuses on the causes of less commonly occurring cancers - The Forgotten Cancers Project.

Over the past 2 to 3 decades, extensive research has been conducted on common cancers such as breast cancer and prostate cancer. However, recent statistics show that over half of all cancer deaths in Victoria are from less common cancers, and these receive relatively little research attention.

The Cancer Epidemiology Centre's major new study to investigate these cancers that have been largely forgotten by the research community.

Around 30,000 people will be able to volunteer for The Forgotten Cancers Project. The aims of the study are to:

- understand the causes of less common and/or under-researched cancers;
- establish ways to detect these cancers earlier; and
- develop prevention campaigns to reduce people's risk.

Australians 18 years of age or older, who have been diagnosed with one or more rare cancers are invited to participate.

Some of these cancers are non-Hodgkin lymphoma, leukaemia, multiple myeloma, kidney, bladder, stomach, brain, liver, oesophagus, pancreas, uterus, thyroid, gallbladder, small intestine, bone cancer and other rare cancers.

Participants will be asked to complete a questionnaire about topics such as lifestyle factors, family history of cancer and medical history. They will also be asked to give DNA from either saliva or blood samples.

Cancer Epidemiology Centre Deputy Director, Associate Professor Gianluca Severi, encourages people who have been diagnosed with one or more of these cancers to participate.

If someone you know might be interested in participating in the Forgotten Cancers Project they can visit www.forgottencancers.com.au or call 1800 068 289 for more information.

Would you like us to email your next newsletter?

Just type into your email subject line: "e-news please"

Please include your name and address.

Send to: confirm@cancervic.org.au