

# Living with Lynch syndrome



March 2018

Lynch syndrome Awareness Day 22 March 2018

Don't let another family be Blindsided by Lynch syndrome



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Mission Statement

Our 2017 consumer report on Lynch syndrome in Australia, *Misdiagnosed, Misunderstood and Missing Out*, made 14 recommendations for urgent change on behalf of the thousands of Australians living with Lynch syndrome.

The first recommendation was to identify the missing 95% of people with Lynch syndrome who don't even know they are at risk, through a simple test of all bowel, endometrial and ovarian cancers at the time of diagnosis.

Each year, over 1000 Australians probably suffer cancers caused by a Lynch syndrome gene mistake without knowing it. Unaware of their risk, they and their families often go on to have many more cancers, yet don't understand why.

Our March campaign is



designed to raise support for universal tumour testing for Lynch syndrome of all bowel, endometrial and ovarian cancers in both public and private hospitals. It's the surest way to identify and protect the thousands of undiagnosed Lynch syndrome families in Australia and prevent cancers in the future.

[#BlindsidedbyLS](#) will support and add momentum to existing recommendations for bowel tumour testing from Cancer Council Australia and to important research currently underway at Cancer Council New South Wales.

For many people, Lynch syndrome can be an isolating experience but [#BlindsidedbyLS](#), our March 2018 campaign, is a way for



everyone involved with Lynch syndrome to stand together and stop more Australian families being blindsided by Lynch syndrome. Just [add your voice](#) and encourage everyone you know to do the same. This is *your* chance to be part of the change.

Whether you have Lynch syndrome, support someone who does or are involved in the research, treatment or care of Australians living with Lynch syndrome, please support our March campaign to test all bowel, endometrial and ovarian cancers for Lynch syndrome today. Find out more and [add your voice](#).

*Misdiagnosed, misunderstood and missing out: Lynch syndrome Australia's untold health story* was launched on Lynch Syndrome Awareness Day in 2017 at Garvan Institute of Medical Research in Sydney. The report was based on your experiences shared with us in our world-first survey exploring what it's like to live with Lynch syndrome.

If you haven't had a chance to read the report, you can find it on our website at [Misdiagnosed, misunderstood and missing out](#).

Since the launch of the report earlier this year, Lynch Syndrome Australia has used your stories, your quotes and your data in the following advocacy work:

- Firstly, in a consultation conducted by the **Australian Commission for Safety and Quality in HealthCare** (the Commission) to develop a safety and quality model for colonoscopy.



- Then, as invited members of a Topic Working Group established by the Commission to develop a national standard for all colonoscopy clinical care, no

matter where you live or who performs your colonoscopy.

- In response to a **Medical Services Advisory Committee** (MSAC) submission on immunotherapy, specifically a proposal to make Keytruda/ Pembrolizumab (MK-3475) available to people with Mismatch Repair Deficient (dMMR) Stage IV Solid tumours other than colorectal cancer.
- In a paper and a presentation at the **International Society of Gastrointestinal Hereditary Tumours, Hereditary Colorectal Symposium** in Florence Italy. We are grateful to Professor Finlay Macrae for delivering this presentation on our behalf.



- In a report by Deloitte Access Economics on [The New Wave of Immunotherapy Cancer Medicines, the Untapped Potentials for Australians](#).

Deloitte  
Access Economics



The New Wave of Immunotherapy Cancer Medicines –  
The Untapped Potential for Australians

- In a submission coordinated by Monash University to a joint Parliamentary Committee inquiry into the life insurance industry.
- In a submission to the **Senate Inquiry into the value and affordability of private health insurance and out-of-pocket medical costs**. We are thrilled to say that some of the data we incorporated in our submission has been included in the [final report for this inquiry](#).
- In a submission to the **Draft Implementation Plan for the National Health Genomics Policy Framework**.
- In our role as co-investigators in a **National Health and Medical Research Council (NHMRC) funded research project** coordinated through the Cancer Council NSW on a collaborative cancer research scheme, **Hide and seek with hereditary cancer**, to improve detection of colorectal cancer patients with a high risk of Lynch syndrome.

**Donate and help us to continue this important work**



### Genetic testing and insurance

Researchers at Monash University approached Lynch Syndrome Australia for help after reading in our consumer report that many of you had problems obtaining life insurance. Over the past few months, we have been working with the team at the Public Health Genomics Program at Monash University to provide more information and case histories to inform their work in seeking changes to the current laws around insurance. A Federal Parliamentary Joint Committee is currently inquiring into the life insurance industry and we wanted to make sure that they get the most up-to-date information on the difficulties we often face.

Thank you to those who took part in our survey on insurance and genetic testing in September 2017. As a result of our work with Monash University there has been regional and national media coverage

shedding light on the issue.

ABC's *7.30 Report*, the *Sydney Morning Herald* and Channel Ten's *The Project* investigated the life insurance industry and how it uses genetic testing information to reject applicants with genetic predispositions like Lynch syndrome. Our grateful thanks to Lynch activists Edwina, Sue, Leanne who agreed to help and share their experiences, and to the team at Monash University for spearheading this campaign for change to bring us in line with other countries, where using genetic testing information to determine whether someone is insured, is not allowed.

Let's hope the Parliamentary inquiry underway makes the vital changes we need to see for Australians with Lynch syndrome and their families.



#### Should insurance companies have access to your genetic blueprint?

Researchers say life insurers that reject people who have had genetic testing sets a dangerous precedent, claiming it is impeding research and putting lives...

ABC.NET.AU



#### Edwina is not sick, but a genetic test a decade ago is denying her insurance

How healthy people are being denied life and travel insurance because genomic testing results show they are at risk of diseases they may never develop.

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View on 6:30PM Thu 13 Dec

Genetic health testing

Air Date: Wed 13 Dec 2017. Expires in 3 months.

More people are testing out genetic testing to find out if their family history could lead to health problems in the future... But the cost might be much more than you think.



## Capp3 - Cancer Prevention Program

Aspirin is widely used as a preventative measure by those with Lynch syndrome. Researchers in Melbourne are asking for volunteers to join a Stage 3 trial designed to determine the optimal dose of aspirin for those with Lynch syndrome. Please contact the team directly if you would like further information or would like to take part in the trial. At the moment the trial is based in Melbourne but other trial centres are opening throughout Australia.



More Information



## Have you been diagnosed with Lynch syndrome?

The Royal Melbourne Hospital are conducting a clinical trial to find out the best dose of aspirin to prevent cancer.

In 2011, the CaPP2 study showed that taking 600mg of aspirin daily reduced the number of cancers by more than half in people with Lynch syndrome. This occurred 4 years after starting the aspirin. Other studies have shown that lower doses of aspirin may also be effective for cancer prevention.

CaPP3 will provide volunteers with regular aspirin at three different doses.

**Are you:**  
**Over the age of 18?**  
**Able to swallow tablets?**  
**Willing to complete the CaPP3 consent process?**

If you answered yes to the above questions or would like more information about the study please contact the Australian CaPP3 team on (03) 9342 8995

Visit us at [www.capp3.org](http://www.capp3.org)



This has been approved by the Melbourne Health Human Research Ethics Committee (V1 dated 9Oct16)

## Gene Connect

### Talk to someone who has been there

Carrying a gene that increases your cancer risk often causes distress. Many people find it helpful to talk to someone 'who has been there before'.

Gene Connect is a free phone service where you can talk to a trained volunteer who has been through a similar experience. Taking part in the Gene Connect program, you will be able to:

- Discuss concerns and challenges

- Gain a better understanding of what to expect.

Gene Connect is suitable for you if you have:

- Just discovered your genetic risk, such as Lynch syndrome
- Have taken or are considering taking, preventative measures to reduce your cancer risk
- A cancer diagnosis

Conversations are confidential and you can arrange to speak over the phone at a time that suits you.

**This service is available to anyone with Lynch syndrome not just those living in Victoria.**

Email:

[cancer.connect@cancervic.org.au](mailto:cancer.connect@cancervic.org.au) or call 13 11 20 to find out more about this program.



## Making a difference; raising funds

Many of you have been raising awareness of Lynch syndrome and raising much-needed funds. We thank you for your efforts. Here are two examples of successful fundraising initiatives:

- Carla Watkins from Victoria held an open day at her beautiful Ripplebrook Gardens. It was a great day for all attending to see the

lovely gardens, Rainbirds Mobile Farm and displays. What a great way for raising awareness for Lynch syndrome and we were appreciative that all of the funds raised for the day were donated to Lynch Syndrome Australia. Thank you, Carla for your great efforts!

- Sheryn Maher of CraftMyWorld donated

10% of her sales from her online craft supply business for two weeks and held a raffle at her craft retreat. Money raised was donated to Lynch Syndrome Australia. Thank you Sheryn for your great initiative!

Both volunteers used the things they love in life to help the cause of people with Lynch syndrome. The team

here are Lynch Syndrome Australia are happy to work with volunteers to put together great ways to spread the word and raise money for education and advocacy. Just get in touch!



RIPPLEBROOK  
Gardens  
Open Day



CraftMyWorld



To  
HOST A FUNDRAISER  
Click here



## Help others: share your story!

A Lynch syndrome diagnosis can be isolating and sharing your story can provide comfort, hope and inspiration to others whose lives and families have been touched by Lynch syndrome. Your story can help Lynch

Syndrome Australia raise awareness which also helps in our efforts of support, research and advocacy. Help us to give courage to other families in Australia whose lives have been touched by hereditary cancers.



### Lynch Syndrome Australia

[www.lynchsyndrome.org.au](http://www.lynchsyndrome.org.au)  
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LynchSyndromeAustralia



LynchSyndromeAU

## Social Media

Our mission is simple: to serve Australians living with Lynch syndrome.

We offer practical support and the latest information

We educate and work with healthcare professionals

We tell the wider community about the challenges we face

We fight for more research, resources and recognition for everyone affected by Lynch syndrome

We are founded and governed by Lynch syndrome survivors and healthcare professionals who understand the condition and its challenges.

When diagnosed early and properly supported, people with Lynch syndrome have a much better chance of surviving and thriving. We are dedicated to empowering the families involved, improving care and demanding respect for everyone living with this lifelong risk.



**Lynch Syndrome**  
Australia

Many families. Many cancers. One common cause.

