

Living with Lynch syndrome



July 2016



Little-known cancer gene story trends around the world

A story about Lynch syndrome, the most prevalent hereditary cancer predisposition, has now been read by almost half a million people worldwide, thanks to *The Conversation Australia* and *IFL Science*.

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Since its publication on Good Friday, The Conversation 'Explainer' article, co-authored by Lynch Syndrome Australia Board member and Macquarie University academic, Dr Sharron O'Neill, and Macquarie University translational health researcher, Dr Natalie Taylor, trended third all weekend on 'Most Read on the Web' of *The Washington Post*.

By Easter Monday evening, 451,925 views were recorded and a short film linked to the article had been viewed over 10,200 times. For days after its publication, the Lynch syndrome 'explainer' was still trending fourth most widely read on *The Conversation*, globally.

Dr O'Neill explained, "This article was developed in cooperation with Lynch Syndrome Australia to bring much-needed

attention to a condition that affects roughly 1:280 people, yet is virtually unknown. It was intended as a resource for people seeking a detailed explanation of this hereditary cancer syndrome. We weren't sure what level of interest there would be and were thrilled to see it was re-posted by one of the most popular science websites. With their help, it has reached far more people than we could have possibly imagined."

"Lynch syndrome is a common but incredibly under-diagnosed cancer susceptibility that can lead to many different cancers, in multiple family members, often from a young age. If a family has three blood relatives with

these cancers, over two generations, with at least one diagnosed before fifty years of age, then the potential for Lynch syndrome needs to be thoroughly investigated."

"At the moment, only around 5% of those with Lynch syndrome even know they are at risk. If you don't know, then you cannot take steps to protect yourself."

This article in *The Conversation* was part of a suite of activities supported by other cancer charities, cancer control agencies and academics interested in improving Lynch syndrome education and coincided with Lynch syndrome awareness 22nd March.



Sharron O'Neill
Researcher, International Governance and Performance (IGAP) Research Centre, Macquarie University. Director Lynch Syndrome Australia



Natalie Taylor
Senior Research Fellow in Behaviour Change and Implementation Science, Macquarie University

<https://theconversation.com/lynch-syndrome-explainer-a-common-cancer-risk-few-have-heard-of-56274>



Living with Lynch Syndrome returned to the Queensland capital, where it all began.

Living with Lynch Syndrome, Queensland

In 2013, our very first Living with Lynch Syndrome conference was held in Brisbane. In September 2015, LSA's 6th Living with Lynch Syndrome event, returned to the Queensland capital, where it all began, with twice as many delegates and an array of experts on hand to share their knowledge about Lynch syndrome. We would like to thank Dr Rachel Susman, Jan

Wakeling, Dr Mark Appleyard, Professor Andreas Obermair and Associate Prof Anusch Yazdani for donating their valuable time, especially on a weekend. And our thanks go out to the two brave advocates who shared their experience of living with Lynch syndrome. Everyone involved helped to make the day a great success.



Professor Andreas Obermair (pictured with LSA Director Eve Raets) was presented an LSA appreciation award in recognition of his valuable contributions to Lynch syndrome and LSA

Cooper Energy and Lynch Syndrome Australia Making a Difference

72% of Lynch syndrome survey respondents said that their family doctors need to be better informed and we are always looking for new ways to engage with GPs to help them understand the complexities of Lynch syndrome and to better identify affected families.

In October 2015, volunteers from our corporate partner, Cooper Energy, joined our very own Eve Raets on the streets of Adelaide, raising

awareness of Lynch syndrome with delegates attending the Rural Medicine Conference. Doctors, medical students and support staff were reminded to Join the Dots of Family Cancers and think about Lynch syndrome. Brochures and cookies proved to be an enticing combination and were distributed with enthusiasm by our volunteers.

A big thank you to the team at Cooper Energy for all of their support to date.



Introducing LSA's Scientific Advisory Committee

Lynch Syndrome Australia is grateful for the support and guidance provided by the following members of the Scientific Advisory Committee. These members represent experts across the many fields that are involved with the hereditary cancer condition and will serve a three year term on the committee.



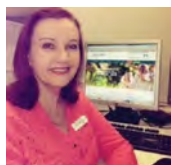
Dr Kathy Tucker - Geneticist

Director, Hereditary Cancer Clinic Service, Prince of Wales and St George Private Hospitals, NSW Health (South East Sydney Local Health District)



Professor Finlay Macrae - International Researcher

Professor, Department of Medicine, University of Melbourne Head, Colorectal medicine and genetics, Royal Melbourne Hospital, Chair, Hereditary Bowel Cancer Group, The Cancer Council of Victoria, Secretary, International Society of Gastrointestinal Hereditary Tumours (InSiGHT), Steering Committee member, US National Institutes of Health Colon Cancer Family Register, International vice chairman, CAPP organisation



Sian Greening - Genetic Counsellor

Genetic Counsellor – NSW Health (Illawarra and Shoalhaven Local Health District)



Professor Andreas Obermair - Gynaecological Oncologist

Professor of Gynaecological Oncology, University of Queensland, Gynaecological oncologist & cancer surgeon, Royal Brisbane Hospital, Brisbane Women's Hospital, Greenslopes Private Hospital.



Dr Diana Rubel - Dermatologist

Consultant dermatologist, Woden Dermatology, Canberra, Visiting medical officer, The Canberra Hospital, Clinical Senior Lecturer, Dermatology, Australian National University.



Dr Daniel Buchanan - Researcher

Senior Research Fellow – University of Melbourne



A/Prof David Hewett - Gastroenterologist

Gastroenterologist – MBBS(Hons Qld) MSc PhD FRACP, Academic Lead – Medical leadership program, The University of Queensland, Deputy Director (Endoscopy), Queen Elizabeth II Jubilee Hospital

Karen Eaton - Cancer Nurse

Registered Nurse with extensive experience in cancer and palliative care.

Breaking New Ground for Lynch Syndrome

Researchers and advocates broke new ground for Lynch syndrome at the 2015 Clinical Oncology Society of Australia annual scientific meeting, in Hobart in November. It is the most important cancer meeting in the country and involves doctors, nurses, allied health professionals and scientists working in cancer care. Thanks to the drive of Dr Natalie Taylor, Macquarie University, and her

illustrious colleagues from across Australia, a ninety-minute symposium, devoted to improving patient outcomes for people with Lynch syndrome, was the first of its kind to be held at this conference. LSA was invited to join this team of committed LS researchers to present the findings from our worldwide survey earlier last year. For those who took part in this survey, their experiences of living with Lynch syndrome

were delivered directly to leading national and international cancer practitioners.

The spotlight fell on Lynch syndrome at the symposium supported by Dr Kathy Tucker, Professor Nick Hawkins, Dr Mathew Sloane and Dr Natalie Taylor. These experts shared the latest developments in antibody screening, clinical management of Lynch syndrome families, how to change the behaviours of professionals in detecting and

managing LS and how to help people communicate a diagnosis with at-risk family members. LSA Director, Susan Morris, shared the conclusions from the survey in her presentation, "Lynch syndrome: The Greatest Story Never Told".

We will continue to push for the change we need to improve diagnosis, treatment and care.



Australia Day Honours

A member of LSA's Scientific Advisory Committee, Professor Finlay Macrae, received Australia Day Honours for distinguished service to medicine in the field of gastroenterology and genomic disorders as a clinician and academic

and to human health through the Human Variome Project. We would like to extend our congratulations to Professor Macrae for his achievements in this field and thank him for dedicating his life's work to medicine and to efforts to improve diagnosis and



How We Work

Everyone at LSA is a volunteer. We are five passionate women, all with full-time jobs. After a full day at work we then come home get our families sorted and then take on LSA putting more

hours in, working from our own homes after hours and on weekends. Fighting for a cause that has personally touched our lives. We are not a big corporation, we don't yet have a nationally

recognized ribbon day and donations are small. We do so much with so little that we have. With a little more funding, we

could do so much more. One off donations or regular giving, workplace giving, raising funds for fun runs/walks, trivia nights, etc.... the possibilities are endless!

Please donate: <http://www.lynchsyndrome.org.au/cause/lynch-syndrome-donation/>

Our Valuable Input Sought

LSA directors attended a workshop in Sydney conducted by the Australian Safety and Quality Commission in Healthcare. The purpose of the consultation was to look at standards for Colonoscopy services and credentialing of doctors who perform

colonoscopies. Who better to ask than those consumers with Lynch syndrome who have annual colonoscopies all their adult lives. They valued our opinions so much that they asked us to come back two more times!

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE



Cancer Counselling Professionals

LSA Director Sharron O'Neill presented at the Cancer Counselling Professionals conference for accredited counsellors who specialise in counselling cancer patients and their families. They hold a Biannual conference for

their members. The theme at this conference was "Cancer in The Family Tree" where they spoke about family history and inherited cancer genes.



Adelaide's Living with Lynch Syndrome Conference and Live Webinar

With the support of Cancer Council SA, LSA is improving our reach and broadcasting our Adelaide Living with Lynch Syndrome conference live on July 30, 2016. Webinar attendees will have the opportunity to access invaluable information

from leading clinicians as well as interact and ask questions via the live chat. We strongly encourage individuals and families living in South Australia attend the live conference to maximise the benefit of meeting others in similar circumstances and

building a strong local support network.

For more information:

<http://>

www.lynchsyntax.org.au/adelaide-living-with-lynch-conference-with-live-webinar-to-reach-all-australian-lynch



Awareness Day 2016

Awareness Day Campaign

Just in time for Lynch Syndrome Awareness Day we were able to launch our new comprehensive website thanks to Charlie Olsson & LSA Director Eve Raets for all their endless hard work. <http://www.lynchsyndrome.org.au/>

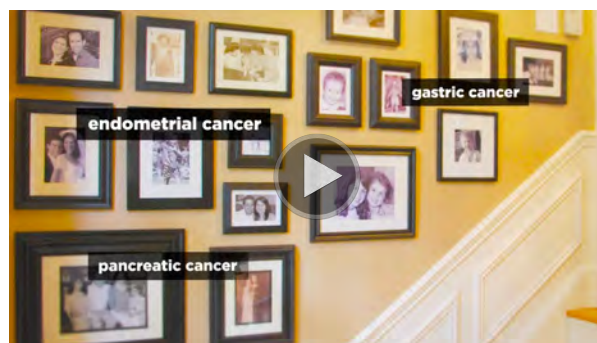


Because you deserve to know - Video

With the generous help of the PWC Creative Communications team we were able to create this awareness video. It took a long time to develop the video because there is such a complexity with Lynch syndrome, but we needed it to be easy to understand and had to get the message right. 95% of people with Lynch syndrome don't know that they have inherited a mistake in a gene that

protects against cancer. One way to find out if you might be at risk is to look at your family's cancer history.

So please, watch this video and share it with your friends, family and colleagues. Because everyone with Lynch syndrome deserves to know.



Video:

https://www.youtube.com/watch?v=_dARj1Y4R0w&feature=youtu.be

Awareness Day 2016

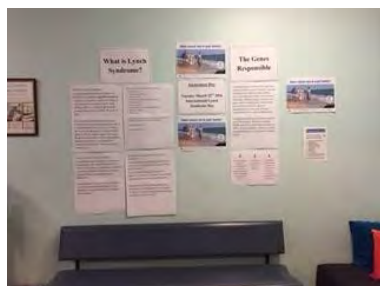
Sian Greening is a genetic counsellor on the LSA Scientific Advisory Committee. She comments quite a bit on our Facebook page and is an awesome supporter of Lynch Syndrome

Australia! Sian organised a cupcake stall at the Wollongong hospital for Lynch Syndrome Awareness Day. Thank you to the Hereditary Cancer Clinic - Illawarra and Shoalhaven and

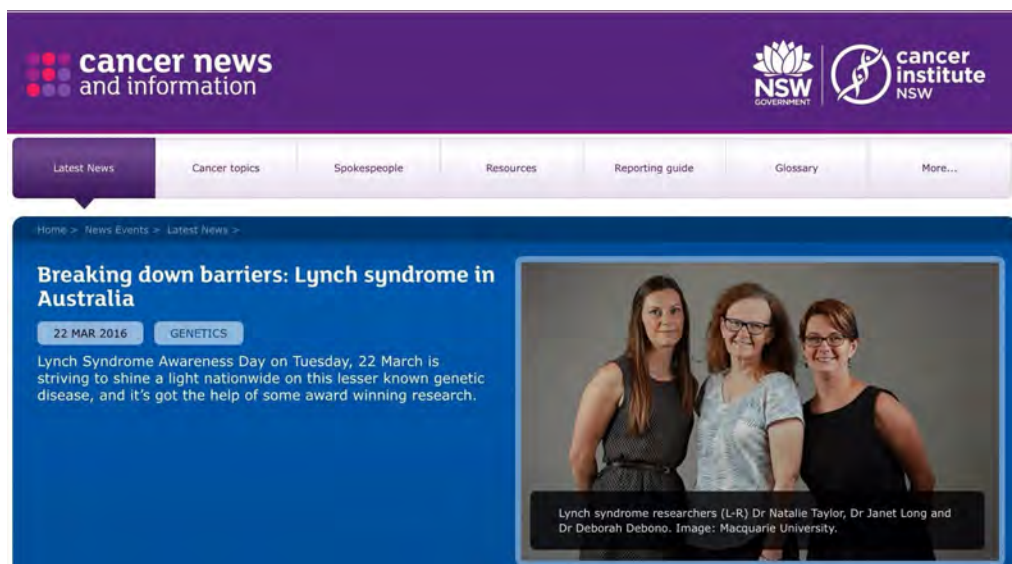
thank you to Sian Greening and team for raising awareness for Lynch syndrome!



The Murray GP clinic in SA put up a display to inform their patients (and doctors!) about this important day and how vital it is we know about and discuss family histories of cancer. Thank you Dr Laura Brownbill for raising awareness!



Raising awareness at Westfield Chermside Qld with Ellen & Sandra Stewart.



The screenshot shows a website header for 'cancer news and information' with logos for NSW Government and Cancer Institute NSW. Below the header is a navigation menu with options like 'Latest News', 'Cancer topics', 'Spokespeople', 'Resources', 'Reporting guide', 'Glossary', and 'More...'. The main content area features an article titled 'Breaking down barriers: Lynch syndrome in Australia' dated 22 MAR 2016 under the 'GENETICS' category. The article text reads: 'Lynch Syndrome Awareness Day on Tuesday, 22 March is striving to shine a light nationwide on this lesser known genetic disease, and it's got the help of some award winning research.' Below the text is a photograph of three women, identified as Lynch syndrome researchers Dr Natalie Taylor, Dr Janet Long, and Dr Deborah Debono. The image credit is 'Image: Macquarie University.'

It was great to have the support of NSW Cancer Institute for Lynch Syndrome Awareness Day! Of course, a big thank you to the researchers Dr Natalie Taylor, Dr Janet Long and Dr Deborah Debono.

For the full article: www.cancerinstitute.org.au/news-events/latest-news/lynch-syndrome

Your Story

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.

Share your story

<http://www.lynchsyndrome.org.au/stories/share-your-story/>



Rowan's Story

Rowan's wife just wasn't convinced. In fact, that May day in 2013, India was pretty sure that he was faking the pain in his stomach to avoid a social engagement later that day. But the Melbourne banker was not

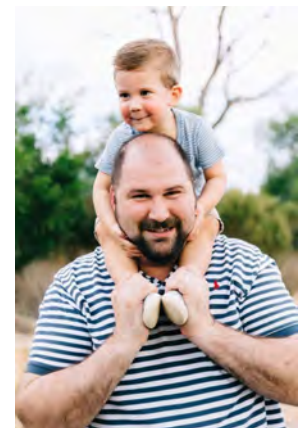
pretending, and within a week, the then 31 year-old had been admitted to hospital with acute appendicitis.

"Luckily, my surgeon was wary and a scan later revealed a hamburger-shaped growth in his

bowel. This was rather alarming, given the surgeon said the colon should look more like a sausage!"

To read the rest of this story and more like it follow this link:

<http://www.lynchsyndrome.org.au/stories/your-stories/>



Facebook Community and Peer to Peer Support coming soon!

A Lynch syndrome diagnosis can be one of the most devastating realisations in your life. It triggers strong emotions. Feelings of disbelief, shock, anger, sadness or fear are common while others may roll up their sleeves and say "OK, what do I need to do now?" Others go on a crusade to notify their family members...bringing it

up at every opportunity, every family gathering. For others, they don't want to know about it. There is no right or wrong way to react. Everyone is different.

We are creating a private support group on Facebook where you can go to share your feelings and challenges and find strength in knowing that there are others

experiencing the same feelings as you are.

This group is not a substitute for independent professional medical advice or counseling, just a place to go and know that you are not alone.

We will be officially launching our online community 30 July at the Adelaide Living with Lynch Syndrome live conference and webinar

If you are on Facebook, if you have Lynch syndrome and you are interested in joining our online support community please send us a private message on our Facebook page or email us at: info@lynchsyndrome.org.au and we can send you a short registration form to join our online community.



Lynch Syndrome Australia

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LynchSyndromeAustralia



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LynchSyndromeAU

DID YOU KNOW?

Mutations matter! Your Lynch syndrome cancer risk depends on lots of things, including which particular gene fault you have inherited. If you don't know, then contact your genetic counsellor or doctor and find out.

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Do you have Lynch syndrome and have thought about donating blood? There is no reason why healthy Lynch syndrome (LS) patients couldn't donate blood (the person receiving the blood will not get LS) provided they do not have cancer and can meet the other Australian Red Cross eligibility criteria. However if a LS person has had cancer then they need to be cancer free for 5 years. On a case by case basis the Red Cross need to take into account cancer history when considering the suitability of donors (and LS patients are more likely to have a history of cancer than the general population).

Organ donation is different.

LS people cannot be an organ donor unless the circumstances were truly truly extraordinary. For more information: <http://www.donateblood.com.au/>

MISSION STATEMENT

The primary mission of Lynch Syndrome Australia (LSA) is to serve our Australian communities by focusing on providing support for individuals afflicted with Lynch syndrome, creating public awareness of the syndrome, educating members of the general public and health care professionals and providing support for Lynch syndrome research endeavours.

LSA, an all-volunteer organisation, is founded and governed by Lynch syndrome survivors, their families, and health care professionals who specialise in Lynch syndrome.

If diagnosed early, we believe Lynch syndrome survivors have favourable outcomes which enhance survival, the longevity and quality of life as well as the emotional well-being of the afflicted.

With the provisions of knowledge, caring and respect for those living with Lynch syndrome, coupled with a common theme of a prevalent positive attitude, we can be change agents, enhancing hope and survivability, impacting the life of countless thousands of people throughout Australia.



Lynch Syndrome
Australia

Many families. Many cancers. One common cause.