

# Living with Lynch syndrome

May 2017



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Back in 2015, 461 people around the world participated in our survey on living with Lynch syndrome, many of you subscribers to this newsletter. The results have been analysed and used to develop abstracts to leading cancer conferences, to inform our partnerships with research teams and cancer organisations and finally to draw up the first comprehensive report on Lynch syndrome in Australia. It includes recommendations for policy, service delivery and research to improve the lives of individuals living with Lynch syndrome and those who are yet to be diagnosed.

Action to improve the

lives of individuals with Lynch syndrome is long-overdue. Based on feedback from hundreds of people here and overseas, we know the challenges we all face are much the same the world over. Read our manifesto for action to improve how Australia cares for 85,000+ citizens join our campaigns over the next few months.

[Misdiagnosed, misunderstood and missing out](#)

This is just the start!

Lynch Syndrome Australia will be using the report as a basis for meetings with a number of key organisations over the next few months to facilitate change on be-

half of everyone living with Lynch syndrome.

"The International Society for Gastrointestinal Hereditary Tumours (InSiGHT) welcomes the report..." "Like you, we recognize a need to increase government public and professional awareness of Lynch Syndrome, especially as there is so much that can be done to prevent cancers occurring in Lynch Syndrome if appropriate public health and clinical practices are put into place.

We would be happy to work with you to enhance our common goal in recognition, managing and supporting families with Lynch Syndrome"

*"Lynch syndrome is poorly understood by clinicians and virtually unheard of by the general public."*

*"There are changes we all need to see: changes to help us meet these challenges together."*



## Misdiagnosed, misunderstood and missing out:

### Lynch Syndrome Australia's untold health story

## The Power of Partnership



KINGHORN  
CENTRE  
FOR CLINICAL  
GENOMICS



Partnership is critical to achieving the change we need, and, on the evening of 20<sup>th</sup> March, with the help of Genetic Alliance Australia and the team at Garvan Institute of Medical Research, Sydney, we were able to launch our report, *Misdiagnosed, Misunderstood and Missing Out: Australia's untold health story* to an audience of survey participants, patient advocates, researchers and representatives of leading cancer organisations in the glorious Curran Library. Dr Ian Frayling, a leading Lynch syndrome researcher from the UK, spoke passionately about the need to identify and help the 95% of those with Lynch

syndrome who are yet to be diagnosed.

Thanks to all our partners, supporters, including Professor David Thomas, Head of Cancer at the Kinghorn Cancer Centre and the team at [Garvan Institute of Medical Research](#), Dianne Petrie, OAM, Executive Director and colleague at [Genetic Alliance Australia](#) and of course our guest speaker, Dr Ian Frayling from [Cardiff University](#) in the UK. Most of all, to every one of the 461 survey participants around the world who made this report possible.



Lynch Syndrome Australia Director Susan Morris spoke about what needs to be done to help Australians living with Lynch syndrome.

## Lynch Syndrome on Health Report—ABC Radio



"You're never too young [or] too old for your first Lynch syndrome cancer." Another first to mark Lynch Syndrome Awareness Day in Australia - thanks to [ABC Radio National](#) Dr Norman

Swan and Dr Ian Frayling Cardiff University for an excellent update (7 mins) [here](#). The first time Lynch syndrome has been properly explored on the radio in Australia.

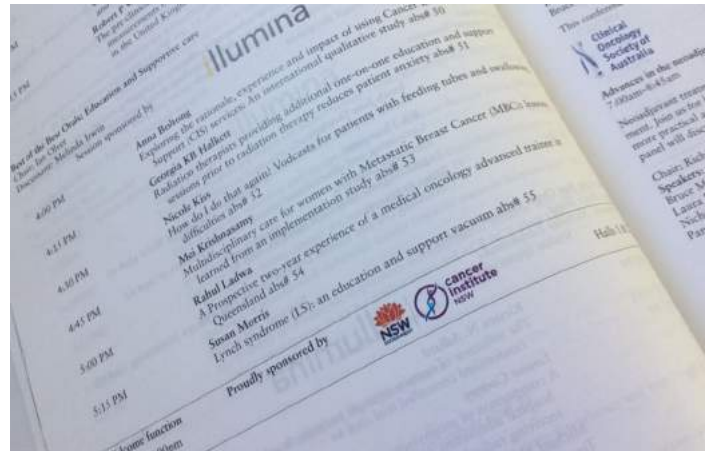
Lynch Syndrome on Health Report - ABC Radio  
80,000 Australians have a genetic abnormality - and they don't know it.  
RADIO.ABC.NET.AU

## Clinical Oncology Society of Australia (COSA)

*43% of Australians with Lynch syndrome must manage their own surveillance, because no group of healthcare practitioners collectively has the responsibility for helping us manage this lifelong cancer predisposition and navigate our way to the right surveillance and treatment.*

The team at LSA put together two abstracts for consideration at the annual conference of the Clinical Oncology Society of Australia, held in November 2016. One of the papers was accepted as a poster presentation and presented by Beth

Fairbank and the other for an oral presentation in the session on Education and Supportive Care. LSA Director Susan Morris presented and had the opportunity to discuss some of challenges faced by those of us living with Lynch syndrome and to educate cancer doctors, nurses, researchers and pharmaceuticals industry representatives from around the country about the Lynch syndrome patient's unique perspective.



## Awareness Day education at Flinders Medical Centre

Lynch Syndrome Australia was proud to present at the Lynch Syndrome Symposium on Tuesday 21st March at the Flinders Centre for Innovation in Cancer in South Australia.

Our director, Eve, spoke about the important advocacy work LSA is undertaking and the release of our consumer report. Eve describes the morning as, "an incredible opportunity to be present in a room with such dedicated and

committed professionals working in the field of Lynch syndrome". A big thank you to the wonderful Kathy Cornthwaite, Registered Nurse at Flinders Medical Centre, for organising the event and ensuring that Lynch syndrome continues to be talked about in the medical community. "The Symposium was a great success". 55 Health Professionals attended the day from all over Adelaide with lots of positive feedback.

### An invitation to attend the Lynch Syndrome Symposium

All students, clinicians, nurses and consumers are invited to attend the following:  
**Creating a Multidisciplinary team approach to identifying and treating patients with Lynch Syndrome.**  
 Date: Tuesday 21 March 2017  
 Time: 9am – 12:30pm  
 Location: Flinders Centre for Innovation in Cancer, Ground Floor Function Room

Morning tea will be provided.  
 Gold coin donation at the door (Flinders Foundation).  
 Please RSVP by the 14 March 2017 to [kathryn.cornthwaite@sa.gov.au](mailto:kathryn.cornthwaite@sa.gov.au) or phone: (08) 8204 6143.  
Please complete the registration form, CPD Points available.

Lynch Syndrome is an inherited genetic mutation which gives people an increased chance of developing certain cancers across their lifetime, often at a younger age than the general population.

Thousands of Australians are estimated to have Lynch Syndrome & over 90 per cent of individuals remain undiagnosed and at risk.

If you would like to learn more about this public health issue to help identify this vulnerable group of patients, and maybe save a life. Reserve your seat today!

## Spreading the Word



Lauren from Western Australia raised nearly \$2000 for Lynch Syndrome Australia with a head shave via her mycause fundraising page. The moment was topped off with an exhilarating downpour that was captured perfectly by her friend! Thank you Lauren for your great efforts in raising awareness and much needed funds. You look great with your new hair style! No more frizzy hair on those wet days!



You can setup a fundraising page and raise funds for Lynch Syndrome Australia via mycause with organised events, fun runs, swimming, climbing, walking etc...the possibilities are endless!

<https://www.mycause.com.au/charity/11984/LynchSyndromeAustralia>



On Lynch Syndrome Awareness Day Michele and Lainie armed with brochures and posters visited a number of medical centres and doctors' surgeries in their area west of Sydney. Well done ladies, great effort!



2,406 Views

SA Health  
March 22 at 3:34pm

Like Page

Today is #LynchSyndrome Awareness Day. Lynch syndrome is an inherited genetic mutation which gives people an increased chance of developing certain cancers - of...  
See More



Kathy Cornthwaite not only organised a Lynch syndrome symposium to educate health professionals she also created a short video talking about Lynch syndrome for the SA Health Facebook page. Well done Kathy: what a great way to reach out to our partners in the medical communities!

## Another South Australian First

On 30 July 2016, we held our 7th Living with Lynch Syndrome event, our 2nd to be held in Adelaide. Extending our reach to rural and remote Australia and making our conferences more accessible, this conference was our very first webinar. Attendees had the opportunity to access invaluable information from clinicians as well as interact and ask questions via the live chat

feature through the webinar with participants joining the event from the Northern Territory and Western Australia.

To Dr Nicola Poplawski, Professor Martin Oehler, Dr Deirdre Zander-Fox and Dr Daniel Worthley and those who shared their personal stories, thank you! Thank you to Gill Miller & Tania Plueckhahn, the Cancer Council SA for your generosity with the venue and making the webinar a

possibility. Your support means a lot to us. Everyone involved made the day a success! Many thanks to LSA Director Eve and also Charlie who ensured the day ran smoothly.



Adelaide Living with Lynch Conference with Live Webinar to reach all Australian Lynch Families

Since 2013, we have hosted many successful...  
LYNCHSYNDROME.ORG.AU

## Return to Melbourne: Living with Lynch Syndrome Revisited

In October 2016, we held our 8th Living with Lynch Syndrome event, the 2nd to be held in Melbourne. We would like to extend our heartfelt thanks to our hosts, Cancer Council Victoria, for their unstinting support for our Living with Lynch syndrome events since 2014. Their generosity in providing the venue and the necessary support staff has meant that we were able to bring this event to you at the lowest possible cost.

Brown, Prof Mark Jenkins and Professor Finlay Macrae, thank you for donating your time both on the day and in preparation for the event. Without our presenters we would not be able to bring you the latest updates about Lynch syndrome diagnosis and care. We thank them for allowing us to intrude into their personal and family time.

It's not easy talking about our family histories and our own health experiences and we would like to applaud each of our patient contributors for helping

to shed light on some of the major challenges faced by those with Lynch syndrome, their families and friends.

In particular, we would like to extend our thanks to Professor Finlay Macrae, acknowledged today for his efforts in support of Lynch Syndrome Australia since its inception and his ongoing work as a member of our Scientific Advisory Committee.

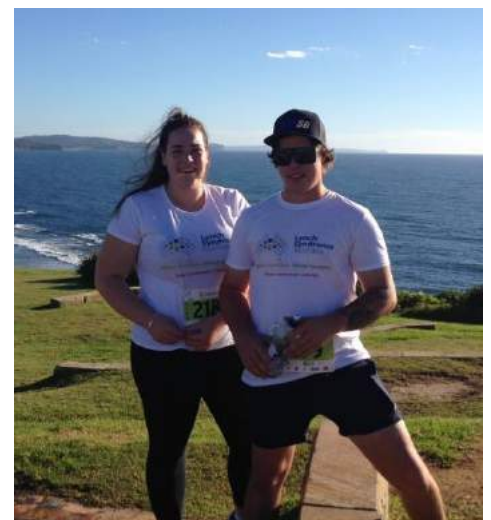


Professor Finlay Macrae

Dr Marion Harris, Lucinda Hossack, Assoc Prof Orla McNally, Penny Sanderson, Assoc Prof Gregor

## Beachside Fun (Run!)

Sunshine, ocean breezes and enthusiasm were in abundance on Sydney's Northern Beaches early one April morning as Team Lynch Syndrome went about setting the pace and spreading the word at the Cliffside Fun Run at Long Reef on Sydney's Northern Beaches on Sunday, 9<sup>th</sup> April. A huge thank you to the organisers, AVAAL 4 Life Foundation and the Mona Vale Surf Life-Saving Club, the sponsors, to Tanya Pace for getting the team together and seeing Lynch Syndrome Australia at the forefront, Susan Morris for her consistent efforts and, in particular, to Toni Rice and her Canberra crew, who made a seven-hour round trip just to help us raise awareness and take part in the 10km race. Well done and thank you to everyone involved.



## 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.



[Share your story](#)

Our founding director Beth Fairbank shares her personal story of Lynch syndrome in hopes to inspire others and improve awareness. See [Beth's story](#)



## Our caring community

The Lynch Syndrome Australia Community Support Group on Facebook is now up and running. The LSA Community Support Group provides a private forum to share experiences living with Lynch syndrome. We hope that, through it, you will feel more

connected and supported knowing that you are not alone.

Online support groups can be a great source of encouragement, a great way of connecting with others for practical and emotional support.

As a member, you can add friends and family affected by Lynch syndrome, to the group, once approved by the moderator. When joining, please read the 'terms & conditions' at the top of the page and ensure that all discussions align with the group guidelines. If you would

like to be added to the community, please send us a message with your email address (that is linked to your Facebook account) on our [LSA Facebook page](#) or in an email to [info@lynchsyndrome.org.au](mailto:info@lynchsyndrome.org.au) it's as easy as that!



## Lynch Syndrome Australia

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LynchSyndromeAustralia



Instagram

@lynchsyndrome\_australia



LynchSyndromeAU

Wishing you all the best

A special thank you to former directors Eve Raets and Sharron O'Neill for all their hard work and dedication to the cause of Lynch syndrome in Australia. Best wishes in all that you do!

Help us. We can't do it alone.

If your workplace has corporate giving, why not nominate Lynch Syndrome Australia! We are a totally all volunteer charity and we are relying on donations from you! Help us to raise money to raise awareness.

Click here to  
**DONATE NOW**



Join us – wherever you live!

Lynch Syndrome Australia operates as a totally volunteer, true non-profit in every sense of the word. Our success is directly attributed to the outstanding volunteers who are passionate in working with us. There are so many different ways you can get involved to make a difference! [Volunteer NOW!](#)

## 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.

