



LYNCH SYNDROME AUSTRALIA RAISING AWARENESS AND FUNDRAISING

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LYNCH SYNDROME

- It is thought that there are approximately 20,000 Australians with Lynch syndrome. Sadly it's projected only 5% of those have been diagnosed, leaving 95% vulnerable and unaware.
- Lynch syndrome is not a rare disease, just very under diagnosed.

KNOWLEDGE IS POWER CAMPAIGN

Many of us with Lynch syndrome have had that dreaded experience – the moment when you mention Lynch syndrome to a health care professional and they look blankly in return.

It is estimated 95% of families in Australia with Lynch syndrome don't even know they are carrying a faulty gene, let alone passing it on to their children.

Health care professionals are the gatekeepers to advice, surveillance and survival and many of them have never even heard of Lynch syndrome. Our first ever campaign, **Knowledge is Power** was launched to coincide with Lynch Syndrome Awareness Day on 22 March and we are continuing to promote the campaign.

The **Knowledge is Power** campaign is aimed at encouraging health professionals to become familiar with the genetic risks and to pledge to help raise awareness of Lynch syndrome with peers and colleagues.

Healthcare practitioners can support the campaign via the Lynch Syndrome Website at <http://www.lynchsyndrome.org.au/> or Facebook page at <https://www.facebook.com/>

LynchSyndromeAustralia and encourage their colleagues to do the same. The campaign aims to have 200 active supporters from the healthcare profession by next year.

By joining the campaign health professionals will:

- Acknowledge that they understand Lynch Syndrome and the key groups at risk.
- Distribute Lynch syndrome information to patients, where appropriate
- Support awareness and education campaigns in their area, where that is possible
- Encourage at least 2 colleagues to support the Knowledge is Power campaign
- Support and advocate for more research into cancer prevention in Lynch syndrome gene mutation carries

Lynch Syndrome Australia has produced an information brochure for you to take to your next appointments with your health care team. To receive copies of the brochure please email tonir@lynchsyndrome.org.au

If each of us can persuade even one member of our health care team to click on the website or Facebook page and get the information on how to add their name to the declaration, we may well be

helping a fellow Australian on their way to advice, diagnosis and appropriate surveillance.

Health care professionals and researchers supporting Lynch Syndrome Australia's **Knowledge is Power** campaign so far.....

Professor Robyn Ward, Head of the Adult Cancer Program Lowy Cancer Research Centre, Prince of Wales Clinical School, UNSW. **Dr Daniel Buchanan**, Senior Research Fellow, Department of Pathology and Centre for Epidemiology and Biostatistics, University of Melbourne. **Dr David G. Hewett**, Associate Professor & Director, Medical Leadership Program, Gastroenterologist and Therapeutic Colonscopist, University of Queensland School of Medicine. **Dr Kathy Tucker**, Geneticist, Prince of Wales and St George, Hereditary Cancer Clinic. **Dr Rachel Susman**, Clinical Geneticist, Genetic Health Queensland, Royal Women's Hospital. **Dr Michael Gattas**, Clinical Geneticist, Genetic Health Queensland & Brisbane Genetics, Wesley Medical Centre. **Professor Andreas Obermair**, Gynaecological Oncologist, Royal Brisbane Women's Hospital & Greenslopes Private Hospital. **Jan Wakeling**, Associate Genetic Counsellor/Coordinator, QLD Familial Cancer Registry, Royal Women's and Children's Hospital - Genetic Health QLD. **Dr Rachel Susman**, Senior Genetic Counsellor, Royal Women's and Children's Hospital - Genetic Health QLD

ADELAIDE'S LIVING WITH LYNCH SYNDROME EVENT

Our third Living with Lynch Syndrome event was held in Adelaide at the Cancer Council SA on 24 May. Maybe it was the South Australian's laid back nature, but it was a struggle getting numbers this time. Two and a half weeks before the event we thought we might have had to cancel it. Another mail out was done and we got the numbers! We can't thank Cancer Council SA enough for providing their venue and for providing the catering and for the SA Clinical Genetic Services for the mail out to those on their Lynch syndrome registry.

To Professors Graeme Suthers, Martin Oehler and Graeme Young who all donated their time and provided us with their invaluable information, Thank you!

It's wonderful that big organisations and big name medical professionals are so supportive of us!

LSA's Eve Raets did a fantastic job facilitating the day and it was a huge success with lots of positive feedback.

Comments from Facebook;

"Thank you for a most enjoyable and informative day. Not only were the speakers fantastic but the opportunity to network with other people and hear their stories was well worth the effort to attend. We would definitely recommend this forum and look forward to future seminars."

"I agree with Robyn, thank you so much for organising today. The speakers were really informative & easy to listen to. It was really good to talk to other people with

Lynch Syndrome & also to meet some of my extended family who also attended. I would also be interested in attending future events."

"Fantastic and informative

and especially impressed with Eve, go girl!"

Again, a special thank you to:
Xibit Printing in Canberra
Cancer Council SA
SA Clinical Genetics Service



Professors Graeme Young & Graeme Sutherland



Professors Martin Oehler, Graeme Suthers, Cancer Council's Gill Miller & LSA's Eve Raets.

END OF FINANCIAL YEAR

The end of financial year is fast approaching. If you are able, would you please consider making a tax deductible donation to Lynch Syndrome Australia?

LSA is an all-volunteer organisation. Our success is directly attributed to the outstanding volunteers who are passionate in working with us. As such, our operational costs are minimal and one hundred percent of donated funds are

utilised toward public awareness projects, providing GP's, practice nurses and other healthcare professional with information on Lynch syndrome, exhibiting at trade shows, working with organisations to promote Lynch syndrome awareness and education, holding Lynch syndrome events throughout Australia, distribution of publications.

Currently, most of our cash funding is derived from the

generosity and passionate commitment of members of our Board of Directors. With our second event, Living with Lynch Syndrome being held in Sydney, the response was overwhelming, beyond our expectation, unfortunately over 50 people have missed out on this event. We can't thank the Cancer Council NSW enough for providing their venue free of charge, unfortunately the space was limited and as LSA is only a very new

charity, we didn't have the funds to pay for a bigger venue. Your donations will insure people living with Lynch syndrome won't have to miss out on valuable programs like this one. Every dollar counts!

**PLEASE CONSIDER
DONATING**

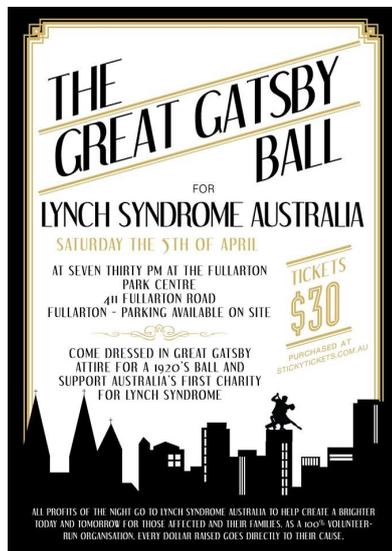
For more information on how to donate ;
info@lynchsyndrome.org.au

THE GREAT GATSBY BALL A SUCCESS!

The Great Gatsby Ball for Lynch Syndrome Australia was held in Adelaide in April. Over \$1700 was raised on the night. Thank you to all those who contributed to the night and helped to make the night a success!

A special thank you to Vero Photography for capturing the night at The Great Gatsby Fundraiser!

A very special thank you to our Eve Raets for all your hard work!



LYNCH SYNDROME AWARENESS DAY



On Lynch Syndrome Awareness Day, 22 March, we had some amazing people raising awareness and raising much needed funds for LSA.

Sales of Lynch syndrome ribbons, a morning tea and a display at a local bank helped us to raise over

\$700. It was our first year so wait until next year it'll be BIGGER!

It would be really great to get more people on board to help us raise funds and look for sponsors. At the moment we are struggling and it would ease the burden so we can do more!

Employees from Bendigo Bank Turrumurra nominated LSA as recipients of their employer's charitable monthly donation. If your employer has a program similar to this please consider us! We can provide you with information for your employer and colleagues.

RELAY FOR LIFE

Relay for Life is a great way to raise awareness. LSA will provide you with brochures & awareness bracelets and we also we have a Lynch syndrome banner that you can borrow for the weekend

if you are planning on doing a Relay. Funds that you raise go directly to Cancer Council in your state and not LSA, but we don't mind...you will be raising awareness of Lynch syndrome and

besides, the Cancer Council has always been so supportive of us!

LSA Relay teams so far;
Gladstone QLD 26-27 July
Macleay Valley, Kempsey NSW 11-12 October



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* 3-26 June only available via email

QUICK FACTS ABOUT LYNCH SYNDROME

- Women who are diagnosed with uterine cancer at 50 years of age or less have an 18% chance of having Lynch syndrome.
- Studies have revealed those with Lynch cancers experience a higher rate of survival than those with sporadic cancers. It is believed this may be due to the frequent surveillance testing and the detection of cancers before they become life threatening.
- Many studies have been conducted as to defining a proper diet to deter the growth of cancer. Though Lynch syndrome is hereditary, environmental factors do play into the propensity to contract cancer. A diet to deter cancer is simply eating good nutritional foods. It isn't all that different from eating a normal, healthy diet.
- Studies have found that people with Lynch syndrome who take aspirin regularly can reduce their risk of colon cancer and other Lynch-related cancers.



www.facebook.com/LynchSyndromeAustralia.



Instagram

You can find our Instagram @lynchsyndrome_australia exciting updates, news and some daily inspirational messages.



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.

