



# LYNCH SYNDROME AUSTRALIA RAISING AWARENESS

DECEMBER 2014

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## LYNCH SYNDROME SURVEY

Lynch Syndrome Australia (LSA) will be conducting a survey to gain a better understanding of the physical, emotional and psychological impact of having Lynch syndrome and how this affects the quality of life of people who have been diagnosed. This survey will help LSA to determine our strategic direction. We invite anyone who has been diagnosed with Lynch syndrome or who maybe undergoing testing to participate in the survey. The survey will

take approximately 30 minutes to complete.

The results of the survey will be used to highlight the issues individuals with Lynch syndrome have and to assist LSA in our advocacy work to help improve the overall health, surveillance and care of people with Lynch syndrome.

In accordance with Australian privacy law, your responses will be treated in strictest confidence. The results of this survey will be aggregated, no identifying details will be

disclosed to any other third party and your anonymity will be protected.

In the coming weeks we'll be sending you the online link to the survey. Alternatively, you can request a hard copy of the survey by contacting [info@lynchsyndrome.org.au](mailto:info@lynchsyndrome.org.au)

## MEDICAL MEDIA

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

One of the main aims of Lynch Syndrome Australia is to raise awareness of Lynch syndrome with health professionals. Medical Media has kindly given us an opportunity work

towards achieving this aim and engage with health professionals through donating an electronic poster to be delivered through lunch rooms in doctors surgeries across Australia.

The Medical Media digital newsletter network spans nationally though metropolitan and regional Australia across 6 states and 2 territories.

Our Lynch Syndrome poster was viewed during September in 541 medical centres for a total of 801,403 plays. It's one great way to get our message out to protect families and save lives!

Medical Media will be running another campaign for us in 2015. Thank you Medical Media!

## 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.

## CANCER?

Don't just look at the individual.



Different cancers can run in families.

Lynch Syndrome. Find the link.

(HNPCC)

LYNCH SYNDROME AUSTRALIA

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



**LYNCHSYNDROME INTERNATIONAL'S FAMILY REUNION**

Lynch Syndrome Australia Directors attended the first international conference and reunion held by Lynch Syndrome International. The self-funded event was held in Orlando Florida on 21 & 22 June. This program offered an opportunity for those attending to increase their knowledge and share their experiences in a comfortable and friendly family orientated atmosphere while making new contacts.

It was a hands-on, one day educational event for survivors, previvors, family members, physicians, nurses, medical students and genetic counsellors. We were able to learn the most essential, updated information on Lynch

syndrome from world experts, including: Dr. Henry T. Lynch, Dr. Patrick Lynch, Dr. Clement Richard Boland, Dr. Stephen Gruber and many other esteemed global experts.

The second part of the conference had breakout sessions which gave an opportunity for more detailed information on subjects of greater interest for individuals so that they were able to "tailor" the information they wanted to hear more of.

Lynch Syndrome Australia Directors were able to develop more international contacts and gain an understanding of what other national groups are doing about Lynch Syndrome in their countries.



Dr Henry Lynch



David Fairbank, Susan Morris, Toni Rice, Leigh Drummond, Dr Henry Lynch and Beth Fairbank.

**WORKPLACE GIVING**

More and more businesses are giving to support charities. If your workplace nominates a different charity each week, month or year, why not nominate Lynch Syndrome Australia. We are a fully registered charity and are entitled to receive tax

deductible donations and have deductible gift recipient (DGR) status. For more information on how you can donate, contact us at: [info@lynchsyndrome.org.au](mailto:info@lynchsyndrome.org.au)

HELP US  
PROTECT FAMILIES  
AND SAVE LIVES  
**DONATE**



## MELBOURNE'S WORKSHOP

Our fourth Living with Lynch Syndrome event was held in Melbourne at the Cancer Council Victoria on Saturday 22 November. We can't thank Cancer Council Victoria enough for being so supportive in providing their great venue and to Katherine Lane for all your help. A special thanks to the familial and genetics registries for helping us with mailing out registration forms, without their support we would not have had such a great response with over 70 individuals registered for the day.

An enormous thank you to

Professor Finlay Macrae, Dr Michael Bogwitz, Dr Kym Reid and Associate Professor Gregor Brown who all donated their time and provided us with their invaluable information, to make our Living with Lynch Syndrome conference a success! For those who shared your personal experiences, thank you! It's a tremendous help knowing we are not alone. Presentations at the Melbourne event were filmed. These presentations will be available to view on the Lynch Syndrome Australia website

[www.lynchsyndrome.com.au](http://www.lynchsyndrome.com.au) in

the near future.

Feedback from attendees;

*"It was great that I could meet you yesterday even though it was a busy time for you. All the sessions were appropriate and informative we both loved Gregor explaining the colonoscopy procedure. I will be having my scheduled one on Friday. Thank you for all the work you have done for the LS cause."*

*"Great conference. Speakers were brilliant."*

*"Thank you for an informative, supportive day. I'm so pleased I came."*

*"Great conference with fantastic speakers & very Informative. Thanks to all."*

For those of you who have not had the opportunity to attend a Living with Lynch Syndrome event, stay tuned. We are planning to run more events in 2015.



Beth Fairbank & Finlay Macrae

## LYNCH SYNDROME AUSTRALIA GOES TO PARLIAMENT HOUSE

Lynch Syndrome Australia was invited to join nearly 30 cancer groups who are now part of the Australian Cancer Consumer Network (ACCN). A launch of the ACCN was held at Parliament House in November. Part of the launch was the release of the ACCN first of its kind Who's Who directory.

The directory is designed to

enable Parliamentarians and their staff to understand the different cancer networks and provide up to date, relevant and timely information and links to people with cancer, their families and their carers.

LSA's Directors Susan Morris and Beth Fairbank had the opportunity to meet others from various cancer groups,

representing cancers that are associated with Lynch syndrome. Not surprising, they had not heard of Lynch syndrome. We will however be working with these organisations on common themes and issues.

We also struck a cord with national Parliamentarians, we have already set up a meeting

with one senator in the New Year.



Senator Deborah O'Neill, Dan Tehan MP and Sally Crossing



The Australian Cancer Consumer Network with Senator Deborah O'Neill, Dan Tehan MP and Sally Crossing at Parliament House



## LYNCH SYNDROME AWARENESS DAY

Lynch Syndrome Awareness Day is 22 March. We need some energetic people to raise awareness and raise some much needed funds for LSA.

How can you help?

Order brochures now to take to your general practitioner and healthcare professionals, expressing how important it is to take family histories and learn about Lynch syndrome.

Contact your local newspaper and tell your story! It's easy, they ask the questions and if you get stuck, refer them to

[www.lynchcancers.com](http://www.lynchcancers.com) for more information. It's always a good idea to ask the reporter if you can read the story before it goes to print, just in case there is misinformation.

Host a morning tea at your work get everyone to wear blue and buy a Lynch syndrome ribbon or wristband. Ask for a gold coin donation for morning tea. Contact us and we can supply you with ribbons and wristbands

Ask your bank if they donate to charities or ask if can put up

blue balloons and a table with sweets for a gold coin donation and Lynch syndrome ribbon or wristband for \$2.50.

22 March is a Sunday but feel free to organise an event during the week. If you have more great ideas on how to raise awareness in your community please let us know

[info@lynchsyndrome.org.au](mailto:info@lynchsyndrome.org.au)

so we can help you and share your ideas with others.



LSA treasurer, David Fairbank doing his bit to raise awareness with the help of the town crier at the Budburst Festival near Stanthorpe QLD.

## ADELAIDE'S CITY TO BAY—TEAM LSA

LSA Director Eve Raets put a team together in the City to Bay Race. It was the very first ever Lynch Syndrome Australia team to participate in The City to Bay Race in Adelaide on the 21st of September.

It was a wonderful opportunity to meet and greet as well as to show support and promote awareness of Lynch Syndrome

always exciting things happening in cities and towns that provide opportunities for Lynch Syndrome Australia to increase community engagement. If you live in South Australia, team Lynch Syndrome Australia will be back next year and be prepared for many more community events around Australia in 2015!



LSA's Director Eve Raets (far right) and her team in the City to Bay raising awareness.



*Warmest thoughts and best wishes for a wonderful holiday, good health and a very happy new year.*

**LYNCH SYNDROME  
AUSTRALIA**

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LynchSyndromeAustralia



Instagram

@lynchsyndrome\_australia



LynchSyndromeAU

**Are you getting your annual surveillance?**

Being diagnosed with Lynch syndrome may seem absolutely overwhelming... there is so much to learn and so much to think about.

Because persons with Lynch syndrome have a higher risk of different types of cancer, it is important for them to be vigilant in managing and monitoring their health. Part of this process is called surveillance and it refers to watching the condition of different organs in the body that may have a higher risk of cancer.

Some of the surveillance steps include; Colonoscopy, Endoscopy, CA -125 for women, Urine Cytology, Dermatological screening, etc...

While there is an entire team of health professionals that includes GPs, gastroenterologists, gynaecologists, etc... *responsibility for your health ultimately falls to one person... YOU.*

Become empowered through education. Learn about your condition and the guidelines for monitoring and participating in your care. Make recommended lifestyle changes and keep appointments to actively monitor your health and affect outcomes. Do what needs to be done to manage your own health.

\*lynchsyndromeinformation.blogspot.com

**ANNUAL REPORT**

The LSA 2013-2014 annual report is available on the LSA website at [www.lynchsyndrome.org.au](http://www.lynchsyndrome.org.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.*



**P R O T E C T I N G   F A M I L I E S   -   S A V I N G   L I V E S**