



LYNCH SYNDROME AUSTRALIA

AUGUST 2015

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Previvors are individuals who are survivors of a predisposition to cancer but who haven't had the disease. This group includes people who carry a hereditary mutation, a family history of cancer, or some other predisposing factor.

LYNCH SYNDROME SURVEY RESULTS ARE IN

“One in four respondents reported cancer in a family member under 30 years of age”.

This and more was revealed in the world-first survey of 465 Lynch syndrome cancer gene carriers conducted by Lynch Syndrome Australia (LSA). Australia is the first country to conduct a comprehensive investigation into the lived experience of Lynch syndrome patients.

Findings revealed striking similarity in the challenges and outcomes experienced by the 252 Australian and the 213 International participants. 59% of survey respondents reported a cancer in a family member under the age of 40 and more than 3 in 4 reported that they

themselves had experienced a cancer before age 50. The impact was evident in responses such as,

“The death of my daughter from colon cancer at 27 yrs could have been prevented if my father's genetic testing had been done sooner. [Her cancer] was diagnosed within weeks of his [genetic] diagnosis.”

The LSA survey targeted those known to carry one of the Lynch mismatch repair genes and was designed to examine the medical, emotional and financial experience of Lynch syndrome. Survey respondents highlighted the acute need to address the poor awareness of Lynch syndrome among GPs, in particular.

Only 19.7% of respondents reported GPs to be useful or very useful in obtaining information on Lynch syndrome, while 44% described GPs as ‘not useful’.

Further, the lack of understanding among general practitioners and specialists was identified as an important barrier to both diagnosis and the management of ongoing surveillance. Detailed results of the survey will be presented as part of a symposium on Lynch syndrome the Clinical Oncology Society of Australia (COSA) later this year.



NEW LOOK WEBSITE

During March, ahead of International Lynch Syndrome Awareness Day, LSA launched the first phase of our new website, designed to provide a more user-friendly environment and make access to

important information easier. This site is planned to undergo further development aimed at increasing national awareness and providing an informative platform to further engage with the national Lynch

syndrome community and health professionals. This new site will be a place to promote upcoming supporter events, educational events and keep up-to-date with some of the exciting advancements in

Lynch syndrome research and care.

The most important thing that our website is designed for is to reach you, so we welcome any constructive feedback or suggestions for the LSA site.

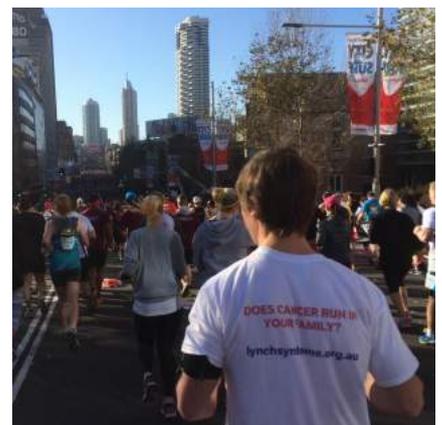


CITY2SURF

An amazing couple, Claudia Abbott and Ash Sutcliffe ran in the Sydney City2surf and not only raised awareness of Lynch Syndrome, they also raised well over \$2000, much needed funds for LSA.

Thank you Claudia and Ash for a job well done!

If you would like to fundraise for Lynch Syndrome Australia you can find the link on our website for mycause to create your fundraising campaign in 3 easy steps!



SYDNEY'S LIVING WITH LYNCH SYNDROME EVENT

Our fifth Living with Lynch Syndrome event was held in Sydney at The Hearing Hub at Macquarie University on 27 June. Feedback from the day; "All the speakers had something really valuable to say and I learnt so much from each and every one of them. I also felt so supported and not so alone being surrounded by the Lynch Syndrome families who stories so resonate with my own." "A good day and

great information" "Thank you for your amazing work. It was such a great day. " Thank you to Dr Archana Rao, Dr Hilda High, Dr Cameron Bell, Dr Natalie Taylor, Dr Tamarind Hamwood, Macquarie University, Cancer Institute NSW, Cancer Council NSW and Look Good, Feel Better. Of course thank you to the two attendees who shared their personal story of living with Lynch syndrome.

Everyone involved helped to make the day a great success!



LSA APPRECIATION AWARD

In our journey so far, as we have launched and developed Lynch Syndrome Australia, many exceptional health professionals have given freely of their time, advice and expertise. We wanted to recognize this tireless support we have pleasure to in honouring one such person, Sydney geneticist, Dr Kathy Tucker, the inaugural recipient

of the Lynch Syndrome Australia Appreciation Award. Kathy's support has been constant and her advice has been wise. Despite her busy schedule she is always available to provide us with her opinion and advice. Kathy, we are grateful for all that you do. Thank you!



Dr Kathy Tucker

LYNCH SYNDROME AWARENESS DAY



On International Lynch Syndrome Awareness Day, 22 March, some amazing people raising awareness and much-needed funds for LSA in a variety of inventive ways.

Selling Lynch syndrome ribbons, hosting morning teas, delivering patient & medical professional brochures and posters to their healthcare professionals – our Lynch syndrome supporters were

active all over the country. Tech company, Datacom, got behind us: selling ribbons and wristbands at their locations nationwide in the run-up to Awareness Day. All funds raised were matched by the company, through its match-funding scheme.



Thank you Datacom & Jamie!



Diagnosis not the end
Marg Vonarx's family history with cancer was her first i...
dailyadvertiser.com.au

Marg Vonarx doing her part raising awareness by contacting her local paper and sharing her story.



Director Eve Raets raising awareness at the Meyer Centre, Rundle Mall, Adelaide.

EMBRYO SCREENING: PRE-IMPLEMENTATION GENETIC DIAGNOSIS TESTING

Feedback from all our Living with Lynch events is essential. We are determined to design events that meet the changing needs of the Lynch community.

After all the Living with Lynch Syndrome events, one of the survey questions asks, "Was there any information you wanted to hear about that was not covered in the program?"

There have been regular requests for information about pre-implantation genetic diagnosis testing.

This is one response:

"Despite...political correctness, I do believe the association should include a section of the FUTURE as this will give people HOPE. Genetic Selection through IVF (whether you agree with it or not) PLEASE I beg you to inform people of it, let them choose if it is right or not. But let them know they can have the power to stop this gene ... The saddest part of the whole day (NSW conference) was to hear that beautiful young girl say she didn't want to have children because of it...Please include an IVF specialist in the

Brisbane seminar. Some families have now known about this for over 20yrs so we're now dealing with early '20's children making life-long plans. They must be given HOPE... Most members have learnt about this syndrome in their 30's 40's 50's 60's which is hard enough to cope with so let us help guide the teenagers and (those in their '20's through this too."

Our **Brisbane Living with Lynch Syndrome** event is scheduled for Saturday, 12 September at 8:30AM -2:30PM. It will be

held at the Translational Research Institute, 37 Kent St, Woolloongabba QLD 4102. Due to demand, we will be having a presentation on IVF and Embryo screening.



THE SPOOKTACULAR TRIVIA NIGHT A SUCCESS!

Early in February this year our Adelaide-based director, Eve Raets, along with Brooke Meakin, hosted a trivia night to raise funds for LSA. The haunted-house themed quiz provided an opportunity to engage with the wider Adelaide public and helped increase awareness of Lynch syndrome amongst the community. A successful evening of fundraising and friend-raised \$2000 for LSA activities.

If you want to host a fundraiser for LSA, download a copy of our fundraising guide on our website and feel free to speak to us about any exciting ideas you may have to help spread awareness in *your* community.

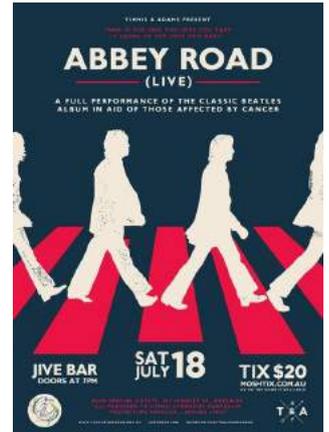


TIMMIS & ADAMS CHARITY CONCERT

Local Adelaide musicians Ben Timmis (ex Crisp featuring SIA) and Peter Adams came together 18 July for a full scale performance of the classic Beatles album 'Abbey Road' in aid of those affected by Lynch syndrome.

The concert featured a large cast of local and interstate musicians including Snooks La Vie, Leigh Stardust, Buffalo Boyfriend and many more.

All proceeds for the night went to Lynch Syndrome Australia. It was a great opportunity to enjoy this timeless album for our very worthwhile cause. Thank you Timmis & Adams and everyone involved.



LYNCH SYNDROME AUSTRALIA AMBASSADORS

We aim to raise awareness of Lynch syndrome across Australia and promote better education of the medical community. Much of our effort has focused on our national educational conferences and developing Lynch syndrome patient information and GP brochures. Through this, we are beginning to see a rise in the understanding of this genetic predisposition amongst health professionals, however, as was evident in our recent national survey, there is much more work to be done.

Members of the Lynch syndrome community in Australia are dedicated advocates for their own health and that of their family members and, as such, LSA is committing to combine the efforts

of our board of directors with that of the inspiring national community in the belief that we can make a larger impact together.

We are proud to therefore announce the **Volunteer Community Ambassador Program**. This national volunteer program will be the first of its kind and has been designed to empower individuals living with Lynch syndrome around Australia to be active ambassadors and advocates and to promote awareness of the condition in their community.

The program is currently being developed to a national standard and we are very excited about the hope and opportunities it will bring. To bring this program to life though, we need your help! Remember to

continue checking our website and Facebook page for regular updates about this program and if this sounds like something you would love to be a part of then please [contact us](#) to register your interest.



DR HENRY T LYNCH

In 1944, at only 16 years of age, Henry T. Lynch joined the United States Navy. He proceeded to serve in the European theater, the South Pacific battles and the Philippine liberation.

Two years later, after receiving his honorable discharge he began studies toward a baccalaureate degree. He graduated from the University of Oklahoma in 1951. Thereafter, in 1952, at age 24, he obtained his Master's degree in psychology from Denver University. He earned his medical degree at the University of Texas Medical Branch in Galveston in 1960, after completing all the coursework toward a Ph.D. in Human Genetics at Austin.

As an Internal Medicine resident at the University of Nebraska College of Medicine, Dr. Lynch met patients who had many family members who were affected by or who had died of the same type of cancer they themselves had been diagnosed with. Because of his strong background in genetics Dr. Lynch had the idea to look at cancer from a genetics perspective (he postulated that cancer could be hereditary) rather than from an environmental point of view (which at the time was the only acceptable cause for cancer in the medical circles). This idea became the main focus of his research for years to come.

In 1970, he applied for an NIH grant to study in more depth his ideas. In his grant

proposal, Dr. Lynch presented a family with numerous people affected with colon cancer. He clearly showed that there had to be some factor at work accounting for the more than frequent presence of cancer throughout the family. Nevertheless, the committee reviewing his grant did not agree with him and thoroughly rejected the idea that cancer could be hereditary.

For the next 20 years Dr. Lynch applied for many other grants and more often than not was rejected. He nevertheless continued his research on minimal funding convinced he would one day be able to prove that cancer can be hereditary.

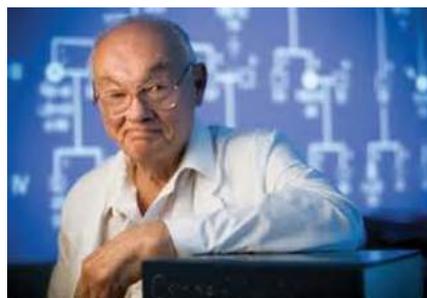
His painstaking record-keeping and compilations of family medical history data led him to identify cancer syndromes and their patterns of inheritance through generations of extended families. In the course of his work, Dr. Lynch developed what are today regarded as the cardinal principles of cancer genetics: early age of onset of the disease, specific pattern of multiple primary cancers, and Mendelian patterns of inheritance in hundreds of extended families worldwide.

With the discovery by other researchers of the genes that cause Lynch Syndrome, it is possible to predict with nearly 90% accuracy the risk of the disease in patients with direct germ-line mutations. With early detection, Lynch Syndrome and other colon

cancers are curable in 90% of patients. Dr. Lynch also demonstrated the Mendelian inheritance patterns for certain breast and ovarian cancers, now known as Hereditary Breast/Ovarian Cancer Syndrome; this work contributed to the discovery in recent years of the BRCA1 and BRCA2 breast cancer genes. *

Today, many families with Lynch syndrome survive thanks to thorough screening programs and early detection, and directly due to the dedication and determination of Dr Henry Lynch, his son, Dr Patrick Lynch, the support of his late wife and research colleagues.

* <http://medschool.creighton.edu/medicine/centers/hcc/welcome/>



Dr Henry T Lynch regarded as the "Father of Hereditary Cancer"

WHERE IT ALL BEGAN



Lynch Syndrome International was founded in the USA in 2009. It filled a void for those affected by one of the most prevalent hereditary cancer syndromes by providing networking, organization, and a voice that was greatly needed by those affected with Lynch syndrome. In 2008, when founder Linda Bruzzone was diagnosed with late-stage colon cancer, online information on Lynch syndrome was inconsistent and inadequate.

"I felt so alone. Nowhere could I find others online. It was frightening, as though we didn't exist. There was no support system for those with Lynch syndrome."

Linda filled that void herself. What was

begun in her home office is now hub of activity worldwide and, in addition to LSA, there are affiliations in the UK, Spain, Germany and Canada. In addition, there are other organizations and groups, together with committed, energetic individuals, all continuing the conversation and working in tireless advocacy both on social media and every day with the medical and media communities around the world. We are fortunate to be a small part of this global, committed community.

Thank you Linda for your passion, endless hours, triumphs and tears and getting us to where we are today. You took the first leap and made it all happen!



Linda Bruzzone Founder of Lynch Syndrome International

LYNCH SYNDROME AUSTRALIA

727 Granite Belt Drive
Cottonvale Q 4375



ABN: 73 166 101 480

www.lynchsyndrome.org.au

E-mail: info@lynchsyndrome.org.au

Phone: 041 607 0036 (After Hours)*



LynchSyndromeAustralia



@lynchsyndrome_australia

Instagram



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QUICK FACTS ABOUT 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. *(I know we had this in a previous newsletter, but it's a fact filled with hope so I wanted to share it again!)*
- The history of Lynch syndrome began way back in 1895 with a pathologist named Warthin and his seamstress who attributed her depression due to the many deaths in her family due to cancer. He assembled her pedigree which is known as Family G
- Lynch-associated cancers typically develop earlier in life than sporadic cancers. Lynch associated colon polyps tend to progress more rapidly to cancer: 1-3 years compared to ~10 years in the general population. That's why annual colonoscopies are so important.
- ~80% of polyps and cancers are located in the right colon.

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.

