



# LYNCH SYNDROME AUSTRALIA NEWS

FEB 2014

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## SYDNEY'S LIVING WITH LYNCH SYNDROME EVENT—FULL

It's only our second Living with Lynch Syndrome event and it is full to maximum capacity of 80 within the first week of registrations opening. Sadly, to this date, we have over 50 on the list of people who couldn't get in. The response was overwhelming, beyond our expectation. We can't thank Cancer Council NSW enough for providing their venue free of charge. Unfortunately the space is limited and Lynch Syndrome Australia is only a very new charity, we didn't have the funds to pay for a larger venue. This goes to show what a great need there is for an organisation like ours.

For those in NSW who missed out on this event, we are hoping to have another early

2015.

Living with Lynch Syndrome events in 2014 include;

South Australia - to be held at the Cancer Council SA, 24 May with details to be published on our website and Facebook page in mid February.

Victoria - to be held at the Cancer Council VIC in November. No date has been set for this event yet, but details will be posted on our website and Facebook page later in the year.

### A special thank you to:

Xibit Printing in Canberra for helping out with printing,  
Cancer Institute NSW for their help & Cancer Council NSW for the use of their venue and all their help.

## 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.

## LSA IS NOW A RECOGNISED CHARITY THROUGHOUT AUSTRALIA

With the help of TressCox Lawyers in Sydney, Lynch Syndrome Australia has finally obtained charity status in Australia and is a registered DGR. So that means, every donation over \$2.00 is tax deductible. LSA is an all-volunteer organisation and no person involved with it is compensated for their good

efforts. As such, our operational costs are minimal and all donations are utilised toward project based efforts. One hundred percent of donated funds are utilised toward LSA targeted projects and basic operating costs. Donations go toward our public awareness projects, providing GP's, practice nurses

and other healthcare professional with information on Lynch syndrome each year, exhibiting at trade shows, working with organisations to promote Lynch syndrome awareness and education, holding Lynch syndrome events throughout Australia, and distribution of publications.



*"The response was overwhelming beyond our expectation."*

## LSA'S NEW LOOK WEBSITE

Our bright new look website is here! We have been fortunate to have Lynch Syndrome International's Webmaster David Wakefield do some work on our website to give it a whole new fresh look and it looks great! Thanks to Myriad Genetics, we even have a Hereditary Cancer Quiz which is beneficial to both patients

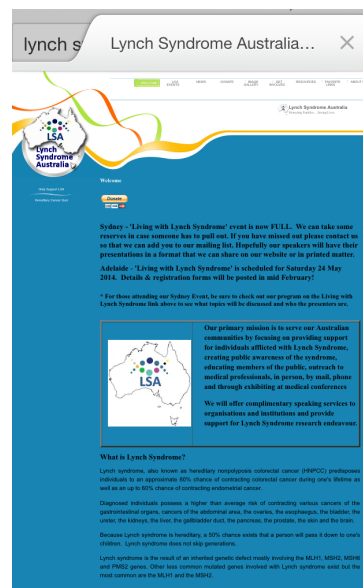
and doctors alike. The family history is the greatest, most underused health tool we have.

And....alas we have a

**Donations** page with Paypal and credit card capabilities for donating to a very worthy cause.

Keep up to date with LSA events!

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



## SOCIAL MEDIA

Facebook is a great way to find out about our latest events, keep in touch and spread the word.

[www.facebook.com/LynchSyndromeAustralia](http://www.facebook.com/LynchSyndromeAustralia)

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



## 22 MARCH - LYNCHSYNDROME AWARENESS DAY

Stand Up! Lynch Syndrome Hereditary Cancer Awareness Day will be 22 March 2014. What will you do to help other families live. Write [info@lynchsyndrome.org.au](mailto:info@lynchsyndrome.org.au) for free awareness materials to distribute to churches, friends, schools, today. Sell blue ribbons to help raise funds!

## RELAY FOR LIFE - TEAM LSA

We had our very first team representing Lynch Syndrome Australia in the Cancer Council's Relay For Life. Funds raised go directly to the Cancer Council. For us, it's an uplifting experience and a great way to raise awareness. We will supply brochures and a small banner for any Team LSA participating in the Relay For Life events.



## THE GREAT GATSBY THEMED BALL - SATURDAY 5TH APRIL FULLARTON, SA

### THE EVENT:

LSA's Board member, Eve Raets is hosting a fantastic fundraiser cocktail night – A GREAT GATSBY THEMED BALL! You're invited to come and join in on a fun night with games, raffles, auctions, food, drinks and dancing! Every dollar raised goes directly to Lynch Syndrome Australia to help create a brighter today and tomorrow for those affected and their families. Lynch Syndrome Australia is a 100% volunteer-run organisation so every dollar raised goes directly to their cause.

Entry is \$30 and includes all food, one complimentary drink, and entry into the 'best dressed' competition. There will be a great variety of beers, wines, champagne and cocktails on the night with each drink costing only \$2.50 each (exempting cocktails which are \$4.00 each).

The ball will be hosted at the Fullarton Park Centre located at 411 Fullarton Road, Fullarton SA.

Doors open at 7.30pm

If you would like to join in on this exciting event and help families with Lynch

Syndrome and reduce the cancer burden, you can purchase tickets and register by going to: [www.stickytickets.com.au/15169](http://www.stickytickets.com.au/15169)

The event is 18+ as liquor is provided but please feel free to encourage friends and family to come.

"Every dollar raised goes directly to Lynch Syndrome Australia to help create a brighter today and tomorrow for those affected and their families."





## LYNCH SYNDROME INTERNATIONAL REUNION

The 1st Annual International Conference of Lynch Syndrome International (LSI) is a 1-Day meeting that aims to address the real-time needs of survivors, previvors and those who care for them, and/or health care professionals who diagnose and manage those with hereditary cancers. Attendees will be able to attend a variety of sessions that cover topics affecting survivors, previvors, family members, medical professionals, including essential Information on research therapies and

opportunities to sign up for clinical registries and become involved in clinical trials.

On Friday, June 20th, will be a fun no-host meet-up, where you can meet with old friends and make new friends, from 7:00 p.m. to 9:00 p.m.

On Saturday, June 21st, the educational session will commence and continue throughout the day. An evening of frolic will occur, with our poolside Lynch Syndrome Family barbecue, boasting great food, a silent

auction, live entertainment and a whole lot of fun for big and little kids, alike! You never know who may show up here! We sure don't know, but what we can promise is it will be great!

**Book your next vacation at Disneyworld and join us for the Lynch Syndrome International Conference and Family Reunion in Orlando Florida!**



## THE AGENDA

Get out those those faulty and defective blue genes and wear them proudly at the Meet-Up, on Friday night, 2014, at the Buena Vista Palace. Get together with old friends and meet new ones at this no host get together, the night before our General Session.

Awaken the next morning to Florida sunshine as the Opening Session of the Conference will be bright and early.

The 2014 program will delve into specific genetic and healthcare needs of those with Lynch syndrome, including diagnosis, management, new treatment options,

clinical trials, cancer disparities, survivorship, research in the horizon and our care providers. Specific sessions in handling life with Lynch syndrome including complications of treatment will be offered, as well as valuable information in preparation for screenings, surgeries, etc.

This year's program will also feature information on existing clinical trials and encouraging registration for future research. This conference promises valuable information tailored for those with Lynch syndrome and an

active, busy day!

Afterward, get out, take a swim, relax and decompress a bit before the magic of the evening's activities begin with a fun filled Family Reunion Barbecue by the pool, with great food, a silent auction, an awards session and lively, fun entertainment and games for the kids! After all, Lynch syndrome is all about embracing life and fun is a very big part of it!

For more details got to:

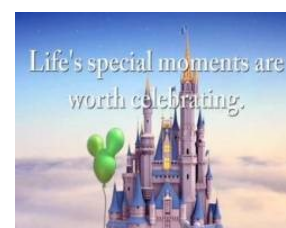
[www.lynchcancers.com](http://www.lynchcancers.com)

Or

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

And follow the links.

We would love to see you there!



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**QUICK FACTS ABOUT LYNCH SYNDROME**

- Approximately 10% of all cancers are hereditary.
- Approximately 145,000 people per year will have or has colon cancer and one in every 35 persons with colon cancer have Lynch syndrome.
- Approximately one in every 440 to 550 persons is affected by Lynch syndrome.
- The first step toward diagnosis is the taking of a comprehensive family medical history and/or universal molecular testing of all colorectal and endometrial cancers;
- The only true form of diagnosis of Lynch syndrome is through genetic testing.

**Genetic testing saves lives.**

**THE VERY FIRST LINE OF DEFENSE IN THE SURVIVAL OF LYNCH SYNDROME IS  
KNOWING ONE'S FAMILY HISTORY**

Lynch syndrome is inherited through families in an autosomal dominant manner. This means an inherited mutation of the mismatch repair gene, coupled with a normal gene will produce children that have an estimated 50-50 chance of contracting Lynch syndrome.

The ONLY way to diagnose Lynch syndrome effectively is first through a careful review of the family history. What the GP is looking for are three individuals, two of which are directly related to the third and who have sustained a Lynch cancer. (Colorectal Cancer, Endometrial Cancer, Gastric Cancer, Ovarian Cancer, Hepatobiliary Cancer, Pancreatic Cancer, Ureter Cancer, Renal Pelvic Cancer, Skin Cancer (Muir Torre), Prostate Cancer, some subsets of Breast Cancer and Brain Cancer.)

**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**