

Annual Report 2013-2014



Protecting Families

Saving Lives

Lynch Syndrome Australia

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Annual Report 2013-2014

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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, longevity and quality of life as well as 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.

Founding Directors Report

Dear Friends,

2013-2014 has been a huge year for Lynch Syndrome Australia. We became a recognised charity in Australia. We at Lynch Syndrome Australia have been welcomed and greatly assisted by Cancer Councils, Hereditary Cancer Registries and medical professionals in various states which has helped us to establish our place in the medical and cancer community. We have been reaching out to those in our communities with Lynch syndrome, by hosting Living with Lynch Syndrome information days, giving those with Lynch syndrome a chance to review medical updates and current research with the experts, talk about challenges unique to families with Lynch syndrome and most importantly, manage their medical care and reduce their cancer risk.

Our Board of Directors has been working hard to find new and innovative ways to bring awareness to the general public and medical professionals. This year, the activities and opportunities seemed to multiply with each passing month as we reached out and improved the understanding of Lynch syndrome. The passion and dedication of our Scientific Advisory Board and those medical professionals with whom we collaborate has been exemplary. We cannot thank you enough.

My deepest thank you to all of you who are dedicated to those with Lynch syndrome, who supported us and contributed immensely this year to Lynch Syndrome Australia, by donating time, services, in-kind donations, promoting Lynch syndrome, or contributing directly to Lynch Syndrome Australia projects. Know that I truly understand that our successes would not have been possible without your efforts.

As Managing Director and member of a remarkable Board of Directors, I am confident that Lynch Syndrome Australia will continue to help those living with, and finding those who are yet to be diagnosed, with Lynch syndrome.

Thank you for your continued support of Lynch Syndrome Australia in helping us to protect families and save lives.

Warm regards

Beth Fairbank

Managing Director/Founder

Lynch Syndrome Australia Board Members 2013- 2014

LSA Directors and Board members represent survivors, previvors, caretakers, medical professionals and researchers of Lynch syndrome.

LSA Directors are working directors and actively direct and organise events within Lynch Syndrome Australia. All individuals involved with the organisation are volunteers and receive no compensation for their benevolence and hours of effort. We are very grateful for their contributions.

Beth Fairbank, Founder-Managing Director, QLD, Previvor

Toni Rice, Director, ACT, Survivor (August 2013)

Vivianne Gerard, Director, QLD, RN/RM, Clinical Nurse Consultant, QEII Hospital

Dr Yen Tan, Secretary, QLD, PhD MSc MLS (ASCP) MAIMS, QIMR Berghofer Medical Research Institute

Eve Raets, Board Member, SA, Previvor (October 2013)

David Fairbank, Treasurer, QLD, Care Giver

Dale Chatwin, Director, QLD (to February 2014)

Board meetings were held via teleconference on:

31 August 2013

18 January 2014

Volunteers

LSA is an all-volunteer organisation. Thank you to all the health professionals, businesses and individuals who have contributed immensely toward LSA by donating time, services, promoting Lynch syndrome, or via direct contributions to LSA projects. A special thanks to:

- Cancer Council NSW in particular Susan Goldie for supporting the Living with Lynch Event in Sydney, March 2014
- Presenters at the Sydney the Living with Lynch Event in Sydney, March 2014 including
 - Karen Eaton – Greenwich Hospital
 - Dr Rhonda Farrell – Royal Hospital for Women & Prince of Wales Private Hospital
 - Dr Kathy Tucker – Prince of Wales & St George Hereditary Cancer Clinic
 - Dr Cameron Bell – Royal North Shore Hospital & University of Sydney
 - Professor Robyn Ward- Prince of Wales Clinical School, Lowy Research Centre & University New South Wales
 - Mrs Emma Edwards – Westmead Familial Cancer Service
- Cancer Institute NSW, in particular Felicity Devitt and Claire Brauer for your support in promoting the Sydney event
- Cancer Council SA, in particular Gill Miller for supporting and promoting the Living with Lynch Event in Adelaide, May 2014
- Presenters at the Adelaide Living with Lynch Event in Adelaide, May 2014 including
 - Professors Graeme Suthers, Head of the SA Clinical Genetics Service, SA Pathology at Women's & Children's Hospital
 - Martin Oehler, Director, Department of Gynaecological Oncology, Royal Adelaide Hospital
 - Professor Graeme Young, Senior Lecturer, Chair, BCA, Gastroenterologist Flinders University
- Kate Dunlop, Director, The Centre for Genetics Education NSW Health
- Xibit printers, Canberra
- TressCox Lawyers
- Bowel Cancer Australia
- Medical Media
- The Australian Primary Health Care Nurses Association (APNA)
- Susan Morris
- Tarlia Misst – Studio T Graphic Design
- Leigh Drummond
- Tawni Jones
- Amy Farrington
- Jillian Carter
- Sharron O'Neill

We would like to acknowledge Lynch Syndrome International, in particular Linda Bruzzone for their continued support.

Donations

In December 2014 LSA obtained charity status and deductible gift recipient status in Australia.

Currently, most of our cash funding is derived from the generosity and passionate commitment of members of our Board of Directors. Donations will ensure LSA will be able to deliver support to people living with Lynch syndrome.

Donations can be made through the Lynch Syndrome Australia website at www.lynchsyndrome.org.au

Highlights and Achievements

Knowledge is Power Campaign

LSA launched our first ever campaign, Knowledge is Power to coincide with Lynch Syndrome Awareness Day on 22 March. The Knowledge is Power campaign is aimed at encouraging health care professionals to become familiar with the genetic risks and to pledge to help raise awareness of Lynch syndrome with peers and colleagues.

By joining the campaign, health care 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 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 carriers.

Health professionals were invited to visit the LSA website or Facebook page and add their name to the declaration. LSA aim to have 200 health professionals support the campaign by March 2015. To date, a total of 10 health professionals have supported the campaign and signed the declaration.

Living with Lynch Syndrome Events

LSA has been conducting a number of Living with Lynch syndrome events. . The events are designed to provide an educational opportunity for individuals and families living with Lynch syndrome. The program includes medical updates with the experts, talk about challenges unique to families with Lynch syndrome as well as information on managing medical care, reducing cancer risk, and current research. The events also provide an opportunity for those attending to share their experiences and meet other individuals affected by Lynch syndrome.

The second Living with Lynch syndrome event was held at the NSW Cancer Council rooms in Sydney on 15 February 2014. There was an overwhelming interest in the event, with the event full to maximum capacity of 80 within the first week of registrations opening. Unfortunately, over 50 missed out on attending the event. The event was a huge success with attendees thanks to the generosity of the presenters, NSW Cancer Council and those individuals who demonstrated courage in sharing their story living with Lynch Syndrome. LSA plan to hold another event in Sydney early in 2015.



Key Presenters from the Sydney Living with Lynch Syndrome Event – From left: Dr Cameron Bell, Dr Kathy Tucker, Dr Rhonda Farrell and Professor Robyn Ward.

The third Living with Lynch syndrome event was held in Adelaide at the Cancer Council SA



on 24 May. LSA’s board member Eve Raets facilitated the day. The event was a huge success thanks to the generosity of the presenters, the Cancer Council SA and those individuals who demonstrated courage in sharing their story about living with Lynch Syndrome.

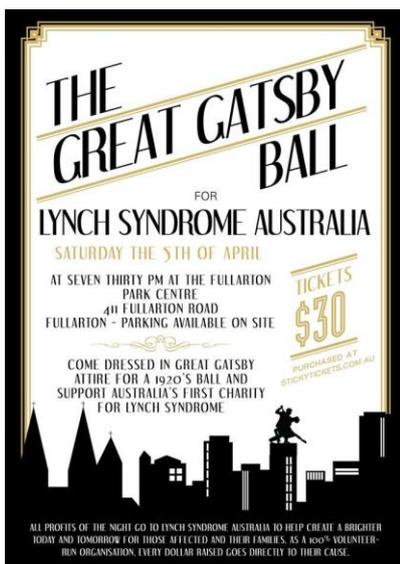
Prof Martin Oehler, Graeme Suthers, Gill Miller & Eve Raets

Comments from attendees included:

“Thank you for a most enjoy-able 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.”

The next Living with Lynch event will be held in Melbourne in November 2014.

Great Gatsby Ball



The Great Gatsby Ball for LSA was held in Adelaide in April 2014. Over \$1700 was raised on the night. The event was a great success thanks to all those who contributed and helped to make the fundraiser a success! LSA’s Eve Raets did a fantastic job organising the ball.

Relay for Life

LSA was represented in the Cancer Council's Relay for Life on 7 & 8 September 2013 in Warwick Queensland. Funds raised by the Lynch Syndrome Australia team went directly to the Cancer Council. The event was an uplifting experience for team members, providing a great way to raise awareness of LSA.

Lynch Syndrome Awareness Day

Lynch Syndrome Awareness Day was celebrated on 22 March 2014. Volunteers raise awareness and much needed funds for LSA. Sales of Lynch syndrome ribbons, a morning tea and a display at a local bank helped to raise over \$700. It was our first year celebrating Lynch Syndrome Awareness Day and we hope next year's event will be bigger.

Lynch Syndrome International Family Reunion

LSA Directors attended the first international conference and reunion held by Lynch Syndrome International in Orlando Florida on 21 & 22 June. LSA directors attending the reunion self-funded the trip. The reunion offered an opportunity survivors, previvors, family members, physicians, nurses, medical students and genetic counsellors to increase their knowledge and share their experiences while making new contacts. LSA Directors 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 included breakout sessions which gave an opportunity for more detailed information on subjects of greater interest for individuals.

LSA 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.



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

Communications

To raise awareness of Lynch syndrome, LSA have used a number of social media channels.

Website

The LSA website received a new look in 2014 thanks to the generosity of Lynch Syndrome International's Webmaster David Wakefield.

Included in the new look website is a Hereditary Cancer Quiz (provided by Myriad Genetics) which is beneficial to visitors interested in assessing their cancer risk.

The website has proven to be a useful site for both individuals and health professionals with over 90,000 visits. The website includes information on LSA events, updates on the Knowledge is Power campaign, news articles as well as a donation page.



The LSA website is at www.lynchsyndrome.org.au

Facebook

The LSA Facebook page at www.facebook.com/LynchSyndromeAustralia has proven to be a useful link to individuals affected with Lynch Syndrome.



The Facebook page has over 200 likes and is regularly updated with posts from Australia and post highlighting international research from the Lynch Syndrome International Facebook page and website.

Instagram



Instagram

This year LSA established an Instagram account - Instagram @lynchsyntax_australia which includes updates, news and some daily inspirational messages.

Promotional material

Information brochures



*Protecting Families
Saving Lives*

A Lynch Syndrome Family

Lynch syndrome: (n.) a hereditary condition which exposes families to an extremely high risk of contracting a litany of very aggressive cancers, often occurring at a younger than average age.

To learn how this family is affected by Lynch Syndrome and what you can do to protect yourself and your family, please read more and visit us at lynchsyntax.org.au

Lynch syndrome Information brochures have been developed for patients and for health professionals. The health professionals brochure has been distributed to genetic centres, general practitioners at the PNCE Conference in Sydney (through the generosity of Medical Media) and to Primary Health Care Nurses attending the Australian Primary Health Care Nurses Association Conference (through the generosity of the Australian Primary Health Care Nurses Association).

LYNCH SYNDROME AUSTRALIA



Protecting Families and Saving Lives

Identifying And Caring For Those With The Lynch Syndrome (HNPCC)

Lynch syndrome (LS) noun: a genetic disorder caused by a mutation in a mismatch repair gene in which affected individuals have a much higher than normal risk for the development of colorectal cancer, endometrial cancer, gastric cancer, bladder cancer, ovarian cancer, and a litany of other often rapid developing, extra colonic cancers which often occur at a younger than average age.

With genetic testing and ongoing management to prevent or detect cancers early, one diagnosis often leads toward the protection of an entire family.

Awareness Ribbons

LSA have awareness ribbons and wrist bands available. We hope the awareness ribbons and wrist bands which can be purchased for a small fee will increase awareness of Lynch syndrome as well as providing much needed funds to support the work of LSA.



Posters and banners

HEREDITARY CANCERS - LYNCH SYNDROME

Don't assume the different cancers in your family are not related...

Colon, endometrial, stomach, pancreas, kidney/ureter tract, hepatobiliary tract, gastric tract, prostate, ovarian, gall bladder duct, brain, small intestine, breast and the skin.



Lynch Syndrome
Australia
Protecting Families -
Saving lives

Does Cancer Run in Your Family?

Find out at www.lynchsyndrome.org.au

LSA have purchased a number of banners to be used at events and fund raisers.

Membership

LSA continue to work closely with Lynch Syndrome International. LSA Founder-Managing Director Beth Fairbank, is now in her third year as a director for Lynch Syndrome International.

In 2013-2014 LSA became members of:

- The Consumers Health Forum of Australia
- Cancer Voices NSW
- Cancer Voices Australia
- Health Consumers of Rural and Remote Australia