

# Annual Report 2014-2015



**Protecting Families**

**Saving Lives**

Lynch Syndrome Australia

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Annual Report 2014-2015

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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 with Lynch syndrome, helping educate health care professionals, raising public awareness of the syndrome 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 genetics, or the detection and treatment of Lynch syndrome cancers. We believe early diagnosis increases the chance of favourable outcomes, thus enhancing survival, longevity and quality of life, including emotional well-being, of individuals with Lynch syndrome.

With 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.

## Message from the Founding Director

Dear Friends,

2014-2015 has been another big year for Lynch Syndrome Australia. Naturally, like most charitable organisations, we have a wish list of activities we would like to pursue: awareness-raising activities, conducting *Living with Lynch Syndrome* events, support for our advocacy work with politicians, health professionals and cancer organisations as well as seeking specialist advice on legal, insurance and workplace discrimination issues on behalf of people with Lynch syndrome.

Lynch Syndrome Australia relies heavily on the generosity of individuals and organisations who donate their funds and time to raise awareness. A big thank you to those who have supported us over the year. In 2014, Cooper Energy from South Australia joined us as a corporate partner and are helping us make a difference with both funds and contributions of time and effort from both management and staff. Thank you, we value your support.

We acknowledge the efforts and dedication of our grassroots volunteers in what was a year in which good progress was made on improving knowledge of Lynch syndrome and helping to raise much needed funds.

To the medical professionals and researchers who gave their time to present at our *Living with Lynch Syndrome* symposiums, and those who we called on for support and advice during the year, we thank you.

I am truly humbled by our incredibly dedicated and talented team of directors who volunteer for Lynch Syndrome Australia. They not only work in their fulltime jobs and studies, but they work tirelessly after hours to meet goals and deadlines.

As you read this annual report, we hope it will remind you of our recent successes and energise you for the future as we still have a very long road ahead of us. We look forward to a rewarding year ahead as we continue to spread awareness and educate the general public and medical professionals, maintaining focus on the key priorities for those living with Lynch syndrome and those yet to be diagnosed.

For those of you who have committed time and energy to the success of this organisation, I thank you. For the many of you who are new to Lynch Syndrome Australia, I welcome you.

Warm regards

Beth Fairbank

Managing Director/Founder

## **Lynch Syndrome Australia Board Members 2014- 2015**

LSA's Board of Directors not only reflect a broad mix of business skills and expertise but are acutely aware of the challenges for individuals and families with Lynch syndrome. Board members include LS (cancer) survivors, previvors, caretakers, medical professionals and researchers of Lynch syndrome and related cancers.

In addition to setting the strategic direction of LSA and ensuring effective governance of the organisation, LSA board members are also actively involved in organising Lynch Syndrome Australia events, media engagement and liaising with relevant stakeholder organisations. All individuals involved with LSA are volunteers and receive no financial compensation for their benevolence and hours of effort. We are very grateful for their contributions.

Beth Fairbank, Founder-Managing Director, QLD.

Toni Rice, Secretary (from 20 November 2014), ACT.

David Fairbank, Treasurer, QLD.

Eve Raets, SA.

Susan Morris, NSW. (From 20 November 2014)

Sharron O'Neill, NSW. (From 15 January 2015)

Vivianne Gerard, QLD, Clinical Nurse Consultant, QEII Hospital (until 03 Aug. 2014)

Dr Yen Tan, Secretary, QLD, QIMR Berghofer Medical Research Institute (until 20 Nov. 2014)

Board meetings were held on:

17 January 2015 – via teleconference

26 June 2015 – face to face meeting

## Financial Status

LSA has met all reporting obligations as required by the Australian Charities and Not-for-profits Commission (ACNC) and Fair Trading QLD.

The financial report for 2014/15 is prepared and will be made available following audit.

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

Thanks to increasing donations from individuals, companies and to fundraising efforts LSA finished the year in a good financial position, while making remarkable progress over the year in promotion, advocacy and communications, as outlined through this Annual Report.

Donations can be made through the LSA website at [www.lynchsyndrome.org.au](http://www.lynchsyndrome.org.au)

## Highlights and Achievements

### Lynch Syndrome Awareness Day

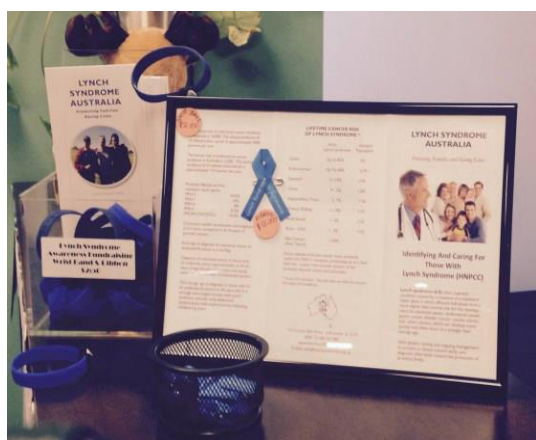
On International Lynch Syndrome Awareness Day, 22 March, some amazing people helped raise awareness and much-needed funds in a variety of novel ways.

Our Lynch syndrome supporters were active all over the country - selling Lynch syndrome ribbons, hosting morning teas, delivering patient & medical professional brochures and posters to their healthcare professionals and twitter and facebook followers celebrated awareness day by participating in a global Thunderclap.

Corporate supporters included technology company, **Datacom**, who supported LSA by selling ribbons and wristbands at their locations nationwide in the run-up to Awareness Day. All funds raised were matched by the company.



LSA's Director Eve Raets on Lynch Syndrome Awareness Day fundraising in Rundle Mall, SA.



Fundraising efforts included the sale of Lynch syndrome ribbons and wristbands.

Marg Vonarx doing her part to raise awareness of Lynch syndrome by contacting her local paper and sharing her story.





## Living with Lynch Syndrome Survey

In early 2015, LSA conducted the first comprehensive investigation into the lived experience of Lynch syndrome cancer gene carriers. Targeting individuals known to carry one of the mutated Lynch mismatch repair genes, this world-first survey sought to gain a better understanding of the physical, emotional, psychological and financial impact of having Lynch syndrome and to gain insights into how this affects the quality of life of people with this diagnosis.

The survey gathered responses from 465 Lynch syndrome cancer gene carriers around the world; 252 Australian and the 213 International participants. Despite national differences in cohorts and medical / health systems, the findings revealed striking similarity in the challenges and outcomes experienced by Australian and international participants.

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

The findings confirmed the younger age onset of ‘Lynch cancers’ with 59% of those surveyed reporting cancer in a family member under the age of 40 and more than 3 in 4 reporting that they themselves had experienced a cancer before age 50.

Despite this, many cited difficulties in obtaining a diagnosis of Lynch syndrome, primarily due to cost, delays or lack of awareness of testing options. 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.”*

Survey respondents highlighted an acute need to address the poor awareness of Lynch syndrome among medical professionals; 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’. Overall, poor understanding among GPs and specialists was identified as an important barrier to both diagnosis and the management of ongoing surveillance.

These were just some of the insights gained from the survey responses. Other key findings related to the magnitude of cost of annual surveillance and treatment, the poor quality of LS-specific information and the psychological wellbeing of individuals with Lynch syndrome.

The important insights provided by our survey results are being used to highlight key issues facing individuals with Lynch syndrome, to inform academic and medical research agendas and to assist LSA in our advocacy work to help improve the overall health, surveillance and care of people with Lynch syndrome.

Stakeholder interest in the findings has been high. Summarised survey results were presented at the Sydney Living with Lynch syndrome conference and LSA has also been invited to present a summary of the survey findings as part of a symposium on Lynch syndrome the Clinical Oncology Society of Australia (COSA) in late 2015.

Following more detailed analysis of the results, a report summarising the key findings will be provided on the LSA website late 2015.

## Living with Lynch Syndrome Events

LSA has continued to conduct the popular *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 by leading experts in the field, providing information on managing medical care, reducing cancer risk, and current research, as well as talks by geneticists and patients about challenges unique to families with Lynch syndrome. The events also provide an opportunity for those attending to network with other individuals affected by Lynch syndrome and to share their own experiences.

The **fourth Living with Lynch syndrome event** was held at the Victorian Cancer Council rooms in Melbourne on 22 November 2014. There was an overwhelming interest in the event, with over 70 individuals attending the event. The event was a huge success with attendees extending their thanks to the generosity of the presenters, the Victorian Cancer Council and those individuals who demonstrated courage in sharing their story living with Lynch Syndrome.

An enormous thank you to Professor Finlay Macrae (pictured with LSA Founding Director, Beth Fairbank), 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.

Feedback from Melbourne attendees;

*"Great conference. Speakers were brilliant." "Thank you for an informative, supportive day. I'm so pleased I came." "Fantastic speakers & very Informative. Thanks to all."*



**Our fifth Living with Lynch Syndrome event** was held in Sydney at The Hearing Hub at Macquarie University on 27 June. Again, the event was very well attended and our heartfelt thanks go to those speakers who volunteered their time and expertise.

Key speakers included: 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 also to the two attendees who shared their personal story of living with Lynch syndrome.

Everyone involved helped to make the day a great success.

Feedback from the Sydney 2015 Living with Lynch syndrome day included;

*"All the speakers had some-thing 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. "*



Top row: Dr Natalie Taylor and Dr Tamarind Haywood, Dr Cameron Bell, the Look Good, Feel Better team and Cancer Council NSW representatives.

Bottom row: Dr Archana Rao, Dr Hilda High, LSA Directors Eve Raets and Susan Morris

### Lynch Syndrome Australia 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.



## 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 2014. 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. LSA will be working with these organisations on common themes and issues.



Dan Tehan MP and Senator Deborah O'Neill launched The Australian Cancer Consumer Network (ACCN) at Parliament House in Canberra, forming the first umbrella organisation to represent cancer consumer groups.

## Developing consumer links

In addition to our engagement with the ACCN, LSA has identified a number of cancer and healthcare organisations with whom we could engage, either to raise awareness of Lynch syndrome or to realise mutual benefits to be gained from a collaborative relationship.

During 2014-2015 LSA Directors began to develop these relationships, attending meetings with a number of organisations including:

- NSW Cancer Institute
- Bowel Cancer Australia
- Networking NSW Primary Health Care Workshop
- And researchers from UNSW and Macquarie University



## Fundraising and Awareness

LSA is an all-volunteer organisation. We acknowledge and deeply appreciate all the health professionals, businesses and individuals who have contributed immensely toward LSA by donating their time and / or services, by promoting Lynch syndrome, or by making direct contributions to LSA projects.

The following fundraising events occurred in 2014-2015:

### Adelaide's City to Bay – Team LSA

LSA Director Eve Raets put a team together to enter the City to Bay Race. It was the very first ever Lynch Syndrome Australia team to participate in a sporting event.

The City to Bay Race was run in Adelaide on the 21st of September 2014. It was a wonderful opportunity to promote awareness of Lynch Syndrome in the community – both in Adelaide and across Australia via the event photos posted on our facebook page.



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

### City2Surf

Following suit, an amazing couple, Claudia Abbott and Ash Sutcliffe, donned LSA T-shirts and ran for LSA in the Sydney City2Surf event. They not only helped raise awareness of Lynch Syndrome, but they also raised well over \$2,000 for LSA.

Thank you Claudia and Ash for a job well done!



### The Spooktacular Trivia Night

Early in February 2015 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 friendship resulting in almost \$2,000 raised for the design and printing of LS promotional materials.



### Promotional material

Many of us with Lynch syndrome have had that 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. We have done this in a number of ways over the past year.

## 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)



### Medical Media

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 net-work 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!

## Information brochures

Lynch syndrome Information brochures have also been developed to provide essential information for both patients and for health professionals.



## Posters and banners

### Does cancer run in your family?



LSA commissioned the design and printing of posters (see right) that could be provided to GPs and medical clinics.

In addition, LSA have purchased promotional banners for use at LSA seminars, information days and fund raising events.



## LS Awareness Ribbons

LSA have purchased a selection of LS awareness ribbons and wrist bands. The awareness ribbons and wrist bands, which can be purchased for a small fee, are expected to increase awareness of Lynch syndrome as well as providing much needed funds to support the work of LSA.



## Communications

An integral part of LSA's Lynch syndrome awareness strategy is the development and use of social media opportunities. Throughout the year we have established a number of social media channels as summarised below.

### 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.

LSA is using the results of the LSA Survey (see p 8) and the insights from consultations with participants at Living with Lynch syndrome conferences and on our social media portals, with consumer organisations and with other key stakeholders, to inform the ongoing development of the website. This ensures we provide highly relevant and reliable content for site users.

The website is continuing to be developed and aims to provide important tools and resources for both patients and medical professionals, promote upcoming supporter events, educational events and keep up-to-date with some of the exciting advancements in Lynch syndrome research and care. That way the site will not only serve to increase public awareness of Lynch syndrome but also will provide an informative platform to further engage with the national Lynch syndrome community and health professionals.

The LSA website is at [www.lynchsyndrome.org.au](http://www.lynchsyndrome.org.au)

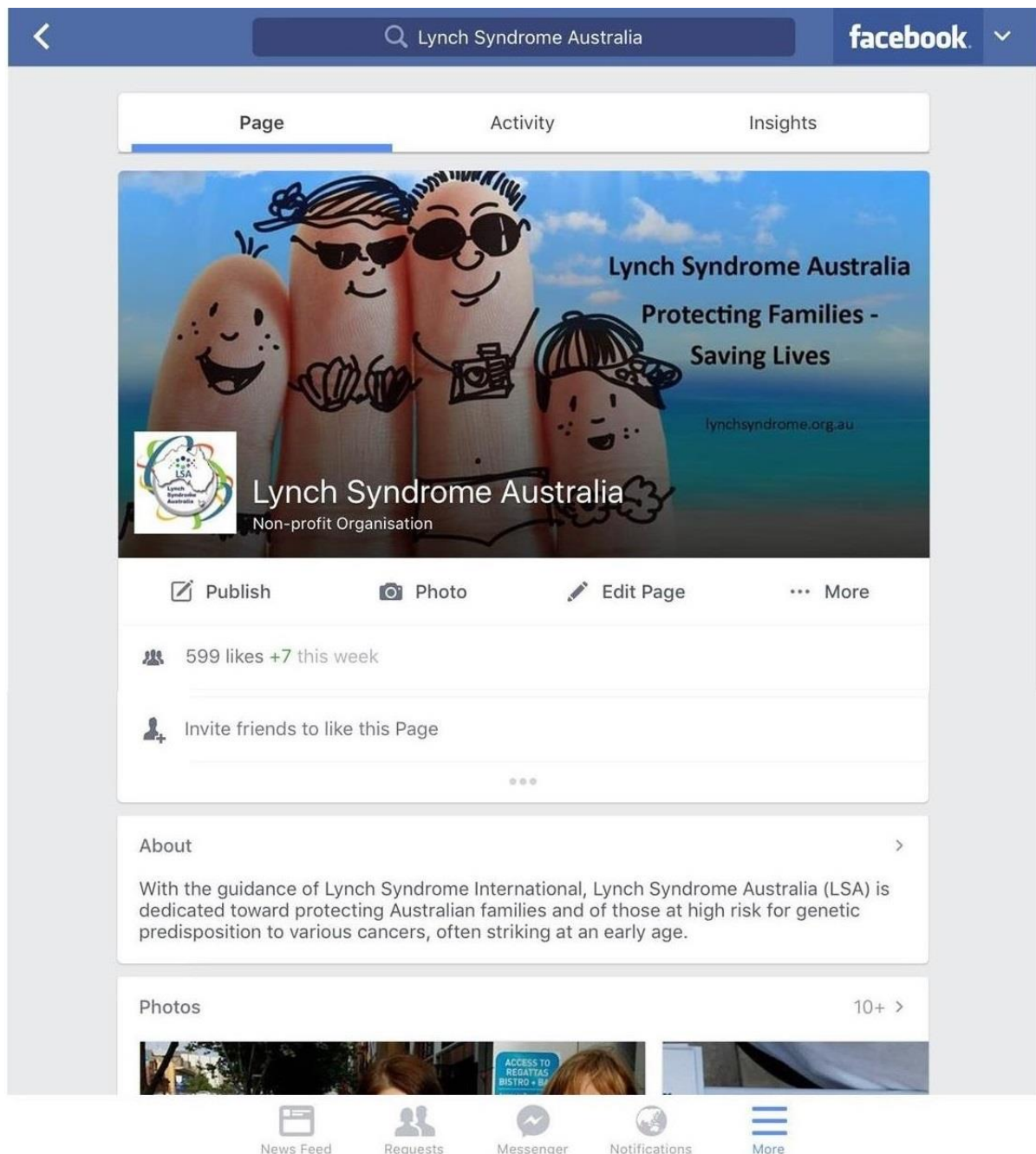




## Facebook

The LSA Facebook page at [www.facebook.com/LynchSyndromeAustralia](https://www.facebook.com/LynchSyndromeAustralia) has proven to be a useful means of connecting with individuals affected with Lynch syndrome.

From July 2014 to June 2015 the Facebook page had a reach of almost 80,000, average monthly engagement doubled in size, as did page likes. The site is a source of support and community and is updated regularly with research, awareness and health information for those with an interest in Lynch syndrome.



## Twitter



The Lynch Syndrome Australia Twitter account is LynchSyndromeAU. We engage on a daily basis with the medical world in general and with cancer control organisations, not for profits and advocates. Tweets are read by 140 followers, and regularly favourited, re-tweeted shared widely in Australia and internationally.

## Membership

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

In 2014-2015 LSA continued membership of:

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