



**Lynch
Syndrome
Australia**

Many families. Many cancers.
One common cause.



Taking Control: Surviving and Thriving National Lynch Syndrome Symposium 2018

Thursday 30th August, 2018

**Garvan Institute of Medical Research
Sydney**

Program

Who are we

Lynch Syndrome Australia (LSA) established in 2013 is a registered charity and an all-volunteer, survivor-led organisation that supports the many thousands of Australian families that carry the Lynch syndrome gene mutation.

Whilst other cancer organisations and charities concentrate on specific cancers, LSA concentrates on a genetic condition where people affected have a lifetime risk of many different cancers and sometimes more than one primary cancer at once.

LSA relies solely on donations.

What we do

- Raise awareness of Lynch syndrome amongst high risk groups, the medical profession and the general public
- Support research into Lynch syndrome to improve detection and surveillance
- Co-ordinate Living with Lynch syndrome events
- Provide presentations on Lynch syndrome
- Encourage and empower people to take charge of their own surveillance and general health
- Advocate for individuals with Lynch syndrome

LSA is governed by a Board of Directors and supported by a Scientific Advisory Committee.

Our Mission Statement

Our mission is simple: to serve Australians living with Lynch syndrome.

We offer practical support and the latest information

We educate and work with healthcare professionals

We tell the wider community about the challenges we face

We fight for more research, resources and recognition for everyone affected by Lynch syndrome

We are founded and governed by Lynch syndrome survivors and supported by healthcare professionals who understand the condition and its challenges.

When diagnosed early and properly supported, people with Lynch syndrome have a much better chance of surviving and thriving. We are dedicated to empowering the families involved, improving care and demanding respect for everyone living with this lifelong risk.

Get involved

LSA is always looking for enthusiastic volunteers. To find out more about volunteering contact info@lynchsyndrome.org.au

Program

8.30 -9.00

Registration

9.00-9.10

Introduction and Acknowledgement of Country
Beth Fairbank, Founding Director, Lynch Syndrome Australia

Professor Anne Duggan, Official Facilitator

Session 1: Innovating for better outcomes

1.1 Lynch syndrome – the big picture

9.10-9.35

Lynch syndrome and what it means in 2018: facts and figures for Lynch syndrome
Professor Mark Jenkins, Director of the Centre for Epidemiology & Biostatistics, School of Population & Global Health

1.2 Diagnosis

9.35-10.00

Lynch syndrome in the real world
April Morrow, PhD Candidate, Cancer Council NSW

10.00-10.25

Making it happen: approval for universal tumour testing and what it means for the healthcare system
Professor Barbara Leggett, Royal Brisbane Hospital, University of Queensland

10.25-10.50

Can we afford it? Cost-effectiveness of improved tumour testing for bowel, endometrial and ovarian cancers
Professor Karen Canfell, Director, Cancer Research Division, Cancer Council NSW

10.50-11.05

Falling through the cracks: how to make sure that those with Lynch syndrome are identified, informed and cared for
Dr. Natalie Taylor, Senior Research Fellow, Cancer Council NSW

11.05-11.20 **Morning break**

1.3 Risk and Prevention

11.20-11.40

It's a numbers game: busting the myths about Lynch syndrome cancer risk and which cancers are involved
Professor Finlay Macrae AO, Head of Colorectal Medicine & Genetics, Royal Melbourne Hospital, Secretary of International Society for Gastrointestinal Hereditary Tumours (InSiGHT)

11.40-12.05

Chemo-prevention – does it work and for whom?
Professor Finlay Macrae AO, Head of Colorectal Medicine & Genetics, Royal Melbourne Hospital, Secretary of International Society for Gastrointestinal Hereditary Tumours (InSiGHT)

Session 2: Managing and minimizing cancer risk

2.1 Surveillance

12.05-12.25

Current Lynch syndrome management guidelines across Australia

Associate Professor Katherine Tucker AO, Geneticist and EviQ advisor, Prince of Wales Hospital, Sydney

12.25-12.45

What is happening elsewhere in the world and what people are really doing to manage and minimise their risk

Toni Rice, Policy Director, Lynch Syndrome Australia

12.45-13.00

Genetics and life insurance – towards regulatory change in Australia

Dr Paul Lacaze, PhD, Head - Public Health Genomics, Monash University

13.00-13.45 **Lunch**

2.2 Minimising Risk

13.45-14.10

Lifestyle change, lifelong chance? An assessment of lifestyle changes and their impact on cancer risk

Dr Aung Ko Win, Genetic Epidemiologist, Centre of Epidemiology and Biostatistics, University of Melbourne

14.10-15.10

Diet and nutrition in cancer prevention

Wendy Watson, Nutrition and Cancer expert, Cancer Council New South Wales

Healthy living after cancer and healthy living with Lynch syndrome

Liz Hing, Healthy Living After Cancer Coordinator, Cancer Council New South Wales

Exercise - does it work in cancer prevention?

Anna-Louise Moule, Exercise Physiologist, Balanced Bodies Lifestyle Clinic

Cancer - a young person's burden?

John Friedsam, General Manager of Divisions, Canteen Australia

15.10 -15.25

Panel Question and Answers

15.25-15.45 **Afternoon Tea**

2.3 The Future

15.45-16.15

The new paradigm: Genomic cancer medicine and what it means for someone with Lynch syndrome, including cancer vaccine

Professor David Thomas, Director, Kinghorn Cancer Centre, Garvan Institute of Medical Research

16.15-16.30 **Meeting close**



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Mailing address

PO Box 292
The Summit, QLD, 4377

Email address

info@lynchsyntax.org.au

Phone number

Tel 0420 294 191