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Australia's untold health story: Lynch syndrome

A new health report from consumers reveals over 80,000 Australians, at increased risk of developing one or more often-aggressive primary cancers in their lifetime, don't actually know that they're at risk from a hereditary cancer gene.

Lynch Syndrome Australia Founding Director, Ms Beth Fairbank said only 5% of Australians with Lynch syndrome have been diagnosed.

"It's imperative that people with the gene are diagnosed early in order to increase cancer prevention and early detection. For a person with the gene, they have a 70% chance of developing a Lynch syndrome-related cancer (including bowel, endometrium, pancreas, stomach, breast, prostate, kidney and skin cancer)," said Ms Beth Fairbank, Lynch Syndrome Australia Founding Director.

Lynch syndrome is a mistake (mutation) in a gene that should be repairing cells and affects whole families across generations. When people with Lynch syndrome develop cancer, they often have more than one cancer and their cancer develops far more quickly.

Lynch Syndrome Australia has released ***Lynch syndrome: Australia's untold health story,*** a report that calls for a number of important recommendations to improve diagnosis, risk management and support. It draws on the findings of a world-first study of the lived experience of people with Lynch syndrome and outlines responses from the 251 Australian participants. The findings reveal many Australians with this condition are misdiagnosed, misunderstood and are missing out on essential and appropriate care and support," said Ms Fairbank. "Things must change."

"First and foremost, we are calling for all bowel and endometrial tumours to be tested when cancer is first diagnosed. This is our best chance of identifying families who may be at risk." said Ms Fairbank.

GPs and other health professionals must play a greater role in identifying people who have this inherited risk and should be encouraged to take a comprehensive family cancer history. Other recommendations involve establishing a national register to help individuals and to aid research;

setting up centres of excellences and providing risk management and psycho-social care, especially designed for the unique needs of the 1 in 280 Australians who carry this mutation.

“Lynch Syndrome Australia is building working relationships with peak bodies, policy-makers and cancer organisations to make sure that tens of thousands of Australians are no longer misdiagnosed and misunderstood.” said Ms Fairbank.

The full report can be found at: www.lynchsyndrome.org.au

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About Lynch Syndrome Australia

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 does this by:

- raising awareness of Lynch syndrome amongst health professionals and the public
- hosting ‘Living with Lynch syndrome’ events, seminars and conferences
- developing tools and resources for families and health professionals to help those affected to manage their medical care and to reduce their cancer risks and
- actively engaging in and contributing to the health care reform process, both as a peak body and in collaboration with other consumer organisations to ensure the unique needs and concerns of families with Lynch syndrome are recognised, understood and given due consideration.

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

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