



**CURE OUR OVARIAN CANCER
CHARITABLE TRUST**

For the Year Ended
31st March 2021

ANNUAL REPORT 2021



HELPING WOMEN
LIVE BETTER,
LONGER LIVES

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ENTITY INFORMATION

NAME OF THE ENTITY

14/11/2018 Cure My Ovarian Cancer (Low Grade Serous) Charitable Trust

05/12/2018 Cure Our Ovarian Cancer (Low Grade Serous) Charitable Trust

Also known as: Cure Our Ovarian Cancer, Ovarian Cancer NZ

For the purposes of this document, consistent with general usage, when referring to low-grade serous ovarian cancer, this can be taken to include LGSOC, low-grade serous carcinoma, LGSC, LGS cancer and low-grade serous cancer. Cure Our Ovarian Cancer is also referred to as COOC.

TYPE OF ENTITY AND LEGAL BASIS

The Trust was registered as a Charitable Trust under the Charitable Trusts Act 1957 on 14th June 2018. The Trust was also registered with the Department of Internal Affairs Services as a Charity on 31st July 2018.

REGISTRATION DETAILS

Charitable Trusts Act Registration Number 2707031

DIA Charities Services Registration Number CC55925

Registration Date: 31/07/2018

THE ENTITY'S PURPOSE

The objects of the Trust are to:

- Encourage research globally into low-grade serous ovarian cancer by directly funding research and encouraging and assisting other charities and/or organisations to fund research.
- Improve the standard of care received by women with ovarian cancer in New Zealand.
- Other purposes consistent with these objectives

ENTITY STRUCTURE

The Trust operates from Dunedin. The Trust Deed states that there must be between two and five trustees. The Trust currently has two trustees that constitute the governance board. The existing Trustees have power to appoint further Trustees from members of the public who have an interest in the Trust's charitable purpose.

On the 2nd of August 2019 by Deed of Variation of Trust, a separate New Zealand Purposes Fund was created. On the 11th of October 2019 the trustees removed donee status from The Trust to avoid limits on overseas disbursement of donations from outside of New Zealand. The New Zealand Purposes Fund retains donee status.

Present members of the governing body are:

Jane Ludemann (Founder / Trustee)

Elsbeth Ludemann (Trustee)

SOURCES OF CASH AND RESOURCES

The Trust raises all its funds by way of donations from the general public.

FUNDRAISING METHODS:

Donations

Donations are received from individuals and organisations directly, and through our website

Fundraising

Members of the public and women with ovarian cancer fundraise on our behalf – through personal appeals, physical challenges, birthday fundraisers and a variety of other events and initiatives.

In September we run a global Step Up for Ovarian Cancer fundraising campaign.

Promotion

The trustees are available to speak to any group or individual and promote its aims through the website cureouvariancancer.org, information cards, blogs, articles and social media.

FUNDRAISER PROFILE:

TOGETHER APART MUSIC ALBUM RELEASE

Libby and her husband John used their unique skills to support research. John, a popular progressive rock musician, collaborated with artists around the world for the album, Together Apart. The digital album download is available for purchase through <https://johnholden.bandcamp.com/album/together-apart-charity-album>. It includes the new song, Circles – with lyrics based on Libby's experience of living with recurrent low-grade serous ovarian cancer. The proceeds support low-grade serous cancer research at the University of Edinburgh.

together apart

All proceeds will go to fund vital research into Low Grade Ovarian Cancer

get the brand new album featuring

John Holden	Michel St Pere
Oliver Day	Jon Camp
That Joe Payne	Sally Minnear
Peter Jones	Gavin Harrison
Marc Atkinson	Anneke Van Giersbergen
Oliver Wakeman	Vikram Shankar

includes a special track featuring all artists

purchase the digital album at johnholden.bandcamp.com

ENTITY INFORMATION

WHERE OUR DONATIONS COME FROM

Cure Our Ovarian Cancer receives donations from around the world including New Zealand, Australia, Canada, the United Kingdom, Switzerland, India and the United States.

LOCATION OF DONORS TO CURE OUR OVARIAN CANCER:



WHERE DONATIONS WILL BE USED

Donations made within New Zealand go to our New Zealand Purposes Fund and support local ovarian cancer awareness, advocacy and research within New Zealand.

Donations received through our Australian, Canadian, United Kingdom and American websites fund low-grade serous carcinoma research in the respective country of origin.

VOLUNTEERS

Our governing body is made up of volunteers, and all our fundraising activities are undertaken by volunteers. No trustee receives remuneration or a fee.

In particularly we gratefully acknowledge the assistance of:

- | | |
|---|---|
| Anne Reddington | Alasdair Sime |
| Harvie Green Wyatt Chartered Accountants | Rural Women New Zealand |
| Creative & Digital Agency Topham and Guerin | Jessica BeCraft and the Board of STAAR Ovarian Cancer |
| Go Media | Tash Crosby from Talk Peach Gynaecological Foundation |
| Clare deLore | Our Charity Partners |
| Zoe from On Format | Our Ovarian Cancer Communities |
| Brent Highman and Helen Westerbeke | |

MENTIONS IN THE NEWS

New Zealand

- <https://www.odt.co.nz/news/dunedin/call-action-over-ovarian-cancer-toll>
- <https://www.stuff.co.nz/national/health/300254544/ovarian-cancer-petition-thousands-call-for-better-diagnosis-funding>
- <https://www.odt.co.nz/star-news/star-national/ovarian-cancer-petition-thousands-call-better-treatment-diagnosis-funding>
- <https://www.odt.co.nz/the-star/ovarian-cancer-kills-woman-every-two-days>
- <https://www.odt.co.nz/news/dunedin/messenger-kept-home-message-gets-new-york>
- <https://www.rnz.co.nz/national/programmes/sunday/audio/2018764792/petition-pushing-to-redress-ovarian-cancer-imbalance>
- <https://www.rnz.co.nz/national/programmes/middayreport/audio/2018787717/petition-calls-for-improvements-in-ovarian-cancer-outcomes>
- <https://www.rnz.co.nz/news/national/438516/ovarian-cancer-petition-thousands-call-for-better-diagnosis-funding>
- <https://www.newshub.co.nz/home/new-zealand/2020/05/dunedin-woman-secures-free-times-square-billboard-to-mark-world-ovarian-cancer-day.html>

International:

- <https://globalnews.ca/video/6928136/late-sask-models-cancer-message-shines-on-massive-times-square-billboard?fbclid=IwAR2piaH9hSnLdEvsj-RyYtIjqUBznzxcw6hVVvbc1A9HYS8OurQltu8H9hfU>

CONTACT

Email

office@cureourovariancancer.org

Postal Address

PO Box 143, Dunedin Central,
Dunedin 9054, New Zealand

NEW ZEALAND

Website

CureOurOvarianCancer.org/nz
ovariancancer.org.nz

Facebook

facebook.com/ovariancancernz

Instagram

instagram.com/ovariancancernz

INTERNATIONAL (LOW-GRADE SEROUS CANCER)

Website

CureOurOvarianCancer.org

Facebook

facebook.com/CureOurOvarianCancer

Instagram

instagram.com/cureourovariancancer

Twitter

Twitter.com/Cure_Ovarian_Ca

OUR TRUSTEES



Jane Ludemann

BSc BOptom (Hons)

Jane was diagnosed with low-grade serous carcinoma in 2017 at the age of 32.

She is an experienced therapeutically qualified optometrist who has worked in both New Zealand and Canada, in private practice and within hospital ophthalmology departments. She completed additional training to gain civil aviation authority, glaucoma prescriber and diabetic retinal screener certification. She previously served as secretary of the Otago Branch of the New Zealand Association of Optometrists. In 2019 she retired to devote more time to Cure Our Ovarian Cancer.

Jane is an accomplished public speaker and has long been interested in research, global problems and science education. Before pursuing optometry at Auckland University she completed a science degree at Otago University and was awarded a Summer Research Scholarship at AgResearch. She represented Otago University at the World University Debating Competitions in Singapore. She was a participant in the THIMUN Youth Assembly (an international youth conference in the Netherlands) and an active volunteer for UN Youth New Zealand. In addition she was a five time Student Helper at Otago University Hands on Science – a week long camp designed to get young people enthusiastic about science.

On graduation, Jane gave back to the community as a volunteer for Land Search and Rescue in addition to voluntary optometry aid work overseas. She was part way through a Masters of Professional Accounting and Finance when she was diagnosed.

Since her cancer diagnosis she has completed university study in Cancer Biology, Advanced Immunology and Integrated Digital Marketing, in addition to reading every low-grade serous research paper she can find.

In 2020 she was a co-author of the **Invited Research Review: Low-grade serous ovarian cancer: State of the science**, published in the prestigious **Gynaecological Oncology Journal**.



Elspeth Ludemann

BA, Dip Journ

Elspeth graduated from Otago University with a Bachelor of Arts and Canterbury University with a Diploma in Journalism and has worked for newspapers, magazines and radio.

Elspeth is an experienced board member who has served on a variety of health, charity, community and government boards including: the Health Research Council (which is responsible for managing the NZ Government's investment in health research), Waitaki District Health Services (which operates Oamaru hospital), the Otago Community Trust (a philanthropic organisation), the Small Business Development Group (provides advice to the NZ Minister for Small Business) and is currently a trustee of the New Zealand Winston Churchill Memorial Trust (a philanthropic organisation).

In addition she has served in a voluntary capacity as committee member of North Otago IHC (which advocates for the rights, inclusions and welfare of all people with intellectual disability), secretary for North Otago Plunket (which provides support services for the development, health and wellbeing of children under five

in NZ) and Chair of SAMS (Standards and Monitoring Services, a Trust which supports and advocates for people with intellectual disabilities). She is currently a member of the Rotary Club of Oamaru.

She is also a Justice of the Peace and a registered marriage celebrant. She was awarded a New Zealand Suffrage Centennial Medal in recognition of her service to the community.

FOUNDING TRUSTEE'S REPORT



JANE LUDEMANN



Life with low-grade serous ovarian cancer is hard. I think you can only understand if you are living with it. For me personally, I find myself in the space of knowing I will probably die of cancer, but not right now, and not definitely but probably. I live with the side effects of treatment and surgery and I continue to witness friend after friend, woman after woman succumb to the disease. It is hard. But inspiration can be found in the darkest of corners.

At the end of 2019 I attended a funeral of a dear friend. She was 27 years old and she had just passed away from low-grade serous carcinoma. Kristen was extraordinary. Like too many with this cancer, she was diagnosed too young. Just 21 years old. Her short adulthood accompanied always by cancer.

Kristen was inspirational in so many ways - her enthusiasm for ovarian cancer advocacy and research was contagious. In addition to starting a Living Legacy to raise funds for low-grade serous research with Cure Our Ovarian Cancer, and co-opting all of her friends in - she also generously gave her time and story to many ovarian cancer charities and causes.

In particular, one really large cause. Dedicated government funding for ovarian cancer. Together with Ovarian Cancer Australia, and another amazing woman, Jill Emberson, they fought that fight and won. Securing over \$20 million in research funding for ovarian cancer, and another \$15 million for gynaecological cancer clinical trials. And as I sat mourning my friend and thought of all she had achieved, I decided I could find room in my life to do more.

There are tens of thousands of women living around the world with low-grade serous carcinoma. The work we do is crucial to improving their survival and the tens of thousands more who will be diagnosed in the near future.

With an incidence similar to cystic fibrosis in the Western World, I still find it unbelievable that when I was diagnosed there wasn't any lay person information on google, and little research. It is heartening to know that because of our work, and the huge commitment of a small group of researchers around the world, the situation is improving.

But here at home in New Zealand, we also face huge problems. Ovarian cancer is a significant health crisis but it's ignored. It is a cancer that kills more women than our road toll (which we spend \$100 million a year trying to reduce), yet most years the government funds no research. Women face significant barriers to be diagnosed. Too many have never heard of it. Australians have access to ten times as many clinical trials and live a lot longer than kiwis.

And so this year, in addition to our national distribution of ovarian cancer symptoms posters, and medical education for GPs - Cure Our Ovarian Cancer NZ decided to step up into a more active role in New Zealand and be a voice for women locally living with ovarian cancer.

It's rather a lot of hats, for a small volunteer charity with few funds. But we think the New Zealand public will have big enough hearts to allow us to grow and do both roles justice.

And so this year has been the busiest yet. We've funded some amazing research, and have exciting projects in the pipeline. Including plans to bring a clinical trial to New Zealand, holding \$150 000 of NZ funds in reserves. With less treatment options than many countries, this has the potential to give kiwis crucial extra time with their loved ones.

We secured a 300m long billboard in New York Times Square to publicise low-grade serous ovarian cancer - the space and creative work were all donated. We welcomed our newest charity partner in America STAAR Ovarian Cancer. We took a petition to the New Zealand parliament and stepped up our advocacy. All during a pandemic, which created significant challenges, not least for fundraising.

I'm excited to share the achievements of the charity. I hope our supporters are proud of all they have helped achieve. And I look forward to sharing the story of another good friend, who together with her family and friends did something really incredible.

It is after all, the beautiful women with this horrible cancer that inspire us to keep fighting.

Jane Ludemann

Founding Trustee of Cure Our Ovarian Cancer



≡
KRISTEN LARSEN



≡
JANE LUDEMAN SPEAKS OUTSIDE NEW ZEALAND PARLIAMENT

WORLD EXPERT'S STATEMENT ON LOW-GRADE SEROUS CARCINOMA



≡
DR DAVID GERSHENSON

As we slowly emerge from the global pandemic, the future could not look brighter for women with low-grade serous carcinoma. Yes, COVID slowed the progress of research. For several months, clinical trial accrual suffered because medical institutions put studies on hold but gradually brought them back online. Laboratory-based research probably took the biggest hit, with investigators prevented access to their laboratories for a prolonged duration.

So why the optimism? More than ever before, a growing number of physicians and scientists have become interested in low-grade serous carcinoma research, and pharmaceuticals are increasingly focused on developing new therapies for this rare cancer. Although clinical trials for rare cancers tend to be few and far between, we are witnessing a change in this space.

An increasing number of publications on the topic and, most importantly, the tremendous efforts by charities and patient advocacy groups like Cure Our Ovarian Cancer in promoting awareness and fundraising, have played a major role in positioning low-grade serous carcinoma more prominently.

Many challenges remain, but I have never been more hopeful that we will significantly impact this cancer through an even greater concentration on molecular biology investigations, enhanced international collaborations, and the conduct of innovative clinical trials.

Dr David Gershenson

Professor and past chair of Gynaecologic Oncology and Reproductive Medicine,

**The University of Texas
MD Anderson Cancer Center**

“
More than ever before, a growing number of physicians and scientists have become interested in low-grade serous carcinoma research.
”

ABOUT CURE OUR OVARIAN CANCER

Cure Our Ovarian Cancer is the only global organisation dedicated to improving the survival of low-grade serous carcinoma, and the only ovarian cancer charity in New Zealand.

We are passionate about improving survival for the tens of thousands of women world-wide with low-grade serous carcinoma, many of whom are diagnosed in their 20s and 30s - and for all women in New Zealand with ovarian cancer.

LOW-GRADE SEROUS CARCINOMA

LOW-GRADE
SEROUS CARCINOMA
IS THE **4TH**
MOST COMMON
OVARIAN CANCER

IT DISPROPORTIONATELY
**AFFECTS
YOUNGER
WOMEN**

WITH CURRENT
TREATMENTS
MOST WOMEN'S
CANCER
WILL RETURN

THE AVERAGE
SURVIVAL IS
9 YEARS

OVARIAN CANCER IN NEW ZEALAND

OVARIAN CANCER
KILLS MORE
WOMEN
THAN THE
ROAD TOLL,
SUICIDE &
MELANOMA

90%
OF KIWIS CAN'T
NAME A SINGLE
SYMPTOM

ON AVERAGE
WOMEN WITH
OVARIAN CANCER
HAVE TO VISIT
THEIR DOCTOR
3-5 TIMES
BEFORE BEING
TESTED

MOST YEARS THE
GOVERNMENT
DOESN'T FUND
ANY OVARIAN
CANCER RESEARCH

STATEMENT OF SERVICE PERFORMANCE

LOW-GRADE SEROUS OVARIAN CANCER RESEARCH

MAKING IT EASIER TO DONATE TO RESEARCH:

In addition to accepting donations directly we have partnered with respected charities and organisations to create pathways to donate directly to low-grade serous cancer research.

New Partners:

- STAAR Ovarian Cancer (United States)

Existing Partners:

- The Gynaecological Cancer Research Trust (otherwise known as the Graci Foundation) (New Zealand)
- Australia New Zealand Gynaecological Oncology Group (ANZGOG) (Australia)
- The BC Cancer Foundation (Canada)
- The University of Edinburgh (United Kingdom)
- Memorial Sloan Kettering Cancer Center (United States)
- The University of Texas MD Anderson Cancer Center (United States)

RAISING FUNDS FOR LOW-GRADE SEROUS RESEARCH:

ANZGOG	BC CANCER FOUNDATION	GRACI
\$51,787.00 AUD	\$63,694.82 CAD	\$850.00 NZD
MEMORIAL SLOAN KETTERING CANCER CENTER	THE UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTER	THE UNIVERSITY OF EDINBURGH
\$1,300.00 USD	\$16,357.00 USD	£9795.00 GBP

RAISING THE PROFILE OF OVARIAN CANCER AND LGSC INTERNATIONALLY



ASHLEY STANDS IN TIMES SQUARE NEW YORK

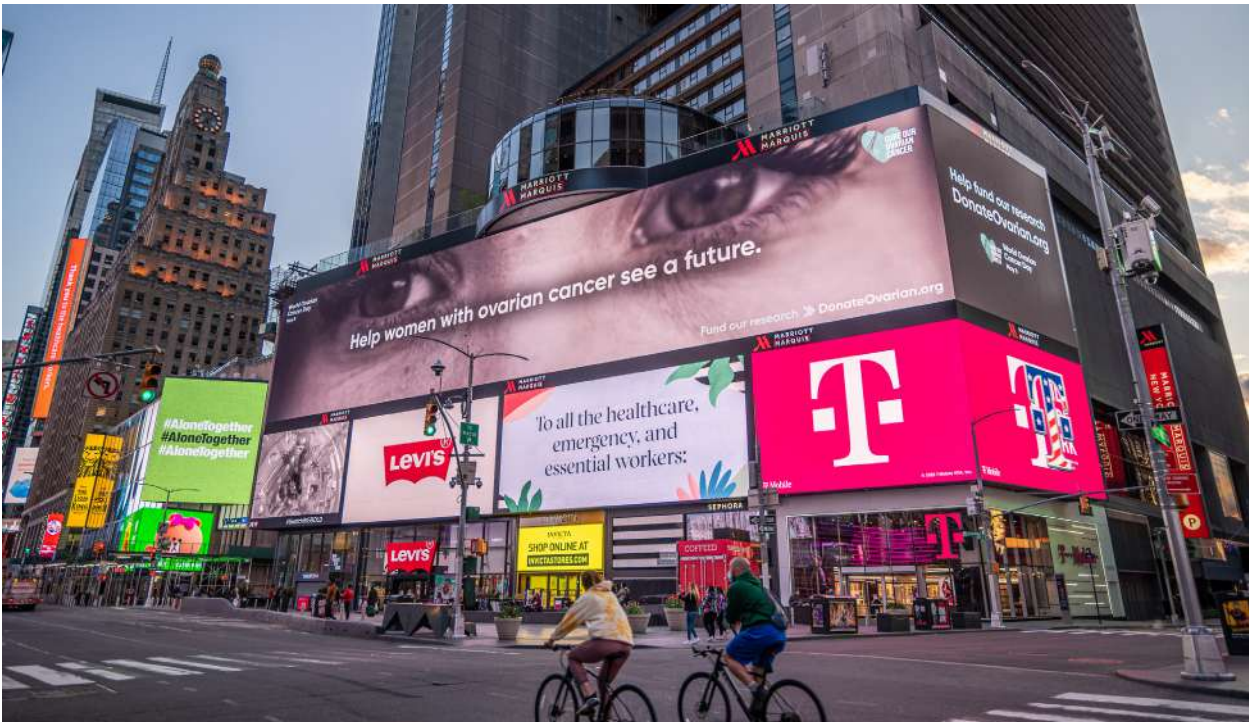
WORLD OVARIAN CANCER DAY

On May 8th the low-grade serous cancer (LGSC) community had plans to celebrate world ovarian cancer day (WOCD) by joining together in New York Times Square to raise awareness.

New York Times Square holds special meaning because a high-profile young Canadian model named Elly Mayday (nee Ashley Luther) stood in the square in a bikini in 2018 to promote WOCD. Ashley used her modelling profile to speak up about ovarian cancer. She sadly passed away in early 2019. Her story inspired Brianna from our LGSC community to stand in her stead.

For 2020, the LGSC community was keen to have a large presence to honour Ashley, and raise awareness of LGSC and ovarian cancer. Unfortunately, the pandemic meant this was not possible.

Instead thanks to several generous companies who donated time and services, we secured a 300m (80ft) long billboard for the day. The billboard featured Elly Mayday and the tag line: Help Women With Ovarian Cancer See A Future. Fund Our Research. The campaign was successful in getting media coverage in Canada and New Zealand.



300M LONG BILLBOARD IN TIMES SQUARE NEW YORK

FUNDING RESEARCH:

NEW ZEALAND:

NEW:

Cure Our Ovarian Cancer and Graci jointly funded a \$28 131 research grant which was awarded to a project led by Dr Mak Sarwar at the University of Otago called 'Correlating molecular alterations in low-grade serous carcinoma (LGSC) to patient outcomes in New Zealand'. The study will examine genetic abnormalities in previously collected samples from LGSC patients to understand and identify the prevalence of clinically actionable molecular abnormalities in New Zealand LGSC patients compared to those found overseas.

ONGOING:

Ongoing: Research continues on Dr Kenny Chitcholtan of Otago University's project "Investigating novel therapeutic targeted drugs in low-grade serous ovarian cancer that is effected by tumour microenvironment." The project seeks to better understand how low-grade serous ovarian cancer responds to a class of drugs called MEK inhibitors, using a newly developed laboratory model called organoids.

Cure Our Ovarian Cancer is also holding \$150 000 in reserve with the intention of underwriting the cost of bringing the ANZGOG clinical trial discussed below to New Zealand

HOW FUNDS RAISED OUTSIDE OF NEW ZEALAND ARE BEING USED:

AUSTRALIA

Funding raised by Cure Our Ovarian Cancer will help give people with low-grade serous carcinoma more treatment options.

Our Australian charity partner ANZGOG is currently in negotiations for funding and development of the first specific low-grade serous carcinoma clinical trial to be initiated in Australasia.

'We are looking forward to the completion of the Phase I trial of this combination, so we can take the next step and test this treatment approach in more women with low-grade serous carcinoma. We are hopeful that this trial will increasing our understanding of LGSC and provide more effective treatment options.' - Professor Anna de Fazio

The trial, called ALEGRO is a phase II trial and will investigate two new combination drugs. The drugs belong to a class of treatments called MEK inhibitors and BRAF inhibitors.

"We hoped to announce the project last year, but the Covid epidemic contributed to significant delays. There is still a lot of work that needs to be done before the trial can begin but this is an exciting advance for low-grade serous carcinoma. We hope the trial will give women facing a difficult prognosis precious extra time. We are grateful for ANZGOG's hard work to make this a reality." - Cure Our Ovarian Cancer Founder Jane Ludemann

UNITED KINGDOM

All funds raised for Low Grade Serous Ovarian Cancer (LGSOC) research in the UK are being directed to the Edinburgh Cancer Research Centre, part of the University of Edinburgh, to support Professor Charlie Courley and his team who are focussed on understanding the genetic and genomic origins of low-grade serous ovarian cancer, and, how this information can be used to better detect and treat this disease.

The funds raised to date will be used to employ a part-time researcher to develop better laboratory models for drug screening. They hope this will help identify the next generation of drugs to be used for trials in patients with LGSOC.

CANADA

The donations we raise in Canada support BC Cancer's ovarian low-grade serous cancer (LGSOC) research programme.

The program is overseen by Dr Mark Carey (Gynaecologic Oncologist) and Dr Chen-Han Lee (Gynaecological Pathologist and PhD). The LGSC team includes two research scientists, one master's student and three technicians who collaborate with research teams internationally and within Canada.

Their BC laboratory is an important source of LGSC models for international research. To date they have developed, and maintain over 20 unique LGSC cell lines and 4 distinct LGSC models. Grown from Canadian cancer samples, they can be found in LGSC laboratories around the world - as far away as the UK and New Zealand.

In addition their laboratory research includes preclinical testing of drugs to improve the treatment of LGSOC. And the use of multiomic technologies and bioinformatics to identify novel disease drivers and drug target candidates.

In the past twelve months they produced new low-grade serous cancer research models and collaborated internationally to identify key drivers and therapeutic vulnerabilities of LGSC and potential biomarkers for MEK inhibitors - among other achievements.

They have also led the development of the Canadian LGSC database which aims to track and link clinical outcomes and treatment results across Canada with pathology and molecular data. The laboratory is involved in on-going efforts to translate laboratory research into clinical trials for Canadian LGSC women.

UNITED STATES

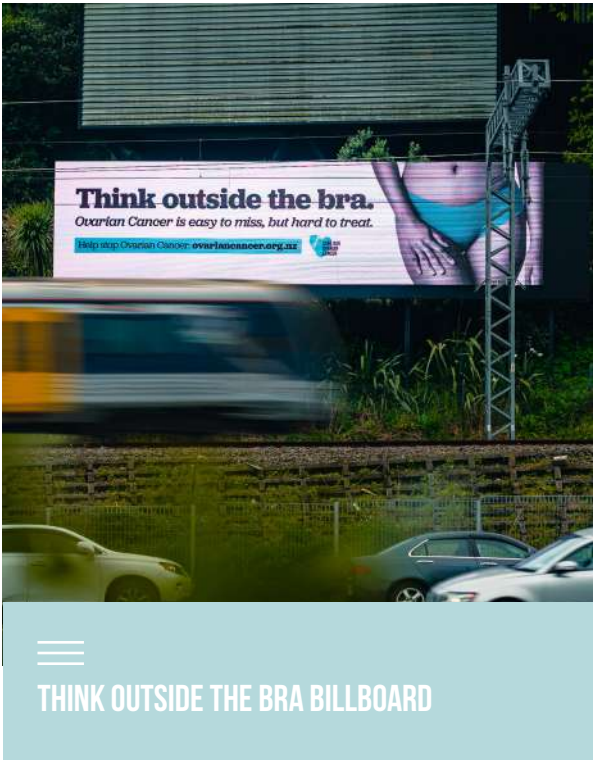
Cure Our Ovarian Cancer and STAAR Ovarian Cancer have jointly contributed \$70 000 to fund our first American project with The University of Texas MD Anderson Cancer Center which is a world leader in low-grade serous carcinoma (LGSC) research. They were instrumental in helping identify LGSC as a unique cancer in 2004. Their research has formed the basis for many of the current LGSC treatment recommendations.

The project is entitled: **Estrogen Signaling in Low-Grade Serous Carcinoma (LGSC)** and seeks to better understand how LGSC can use estrogen to grow and spread – and identify potential targets to improve treatment options.



PROJECT LEAD DR KK WONG PHD, PROFESSOR OF THE UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTER

IMPROVING OUTCOMES



NEW ZEALAND AWARENESS

During Gynaecological Cancer Awareness Month in September we were generously donated billboard space across the country to raise awareness of ovarian cancer. The tagline ‘Think below the bra - ovarian cancer is easy to miss and hard to treat’ highlighted the difference in awareness and survival relative to breast cancer - and the need for people to be proactive if they experience symptoms.

In January Rural Women New Zealand nominated ovarian cancer as their cause for the year, helping us educate the rural community.

In February, as part of Ovarian Cancer Awareness Month, ovarian cancer symptoms posters were sent to medical practices nationwide, in addition to a medical education resource we developed with local specialists.

In March we had a tent at the Upper Clutha A&P Show to raise awareness of ovarian cancer and raise funds for COOC.

We were able to get ovarian cancer in the local news seven times throughout the year.



2021 AND 2020 OVARIAN CANCER SYMPTOMS POSTERS AND EDUCATION ON DISPLAY AT A GP PRACTICE IN MOTUEKA

NEW ZEALAND ADVOCACY

Lead a Parliament Petition:

Ovarian cancer in New Zealand faces significant inequalities. In March, with Tash from Talk Peach we presented a petition to parliament calling for changes to be made to improve the survival of NZ women. We built the website ovariancancer.co.nz to educate the public about the issues and collected 8907 signatures. The petition stated:

That the House of Representatives urge the Government to support the development of ovarian cancer (OC) awareness/education campaigns for the public and health professionals; ensure women with OC symptoms have timely access to testing; improve access to approved therapies and clinical trials; and dedicate funding to OC research.

Ovarian cancer is the least survivable women’s cancer in NZ. It kills more women than the road toll. The majority of women are unable to name a single symptom before they are diagnosed and there are significant barriers to access detection tests. On average women with ovarian cancer need to visit their doctor 3-5 times before being tested.

We are advocating for ovarian cancer symptoms education to be incorporated into the cervical screening program. For better access to funded ultrasounds and for better clarity and consistency around diagnosis guidelines.

NZ’s five year survival rates are 5% less than Australia - that’s about 15 women every year who would still be alive if they lived in Australia. NZ has far less access to fewer funded drugs and clinical trials. NZ sits at the bottom of the developed world for per-capita spending on modern medicines. We are supporting Patient Voice Aotearoa’s advocacy to double Pharmac funding, and advocating for funding in particular for an anti-VEGF inhibitor, PARP inhibitor (expanded access) and caelyx. In addition we are asking the government to set aside specific funding for ovarian cancer clinical trials.

Ovarian cancer’s survival rates are less than half prostate cancer. 40 years ago they were almost the same. The difference is research funding. Australia, Canada and the US have dedicated ovarian cancer research funding. Most years New Zealand funds none, a stark comparison to the \$100 million a year we spend on reducing the road toll (which kills less women). We urgently need to fund dedicated ovarian cancer research.

Alongside the petition we compiled a selection of NZ women’s stories which were shared with all the Members of Parliament, and the Te Aho O Te Kahu Cancer Control Agency and Ministry of Health.

Work on our submission to the Health Select Committee is on-going.



CROSSES REPRESENTING WOMEN WHO HAVE DIED FROM OVARIAN CANCER AT NEW ZEALAND PARLIAMENT

KELLY'S STORY

Kelly was one of the incredible and brave women who gave us permission to share her story in a booklet with politicians, the Ministry of Health and Te Aho O Te Kahu Cancer Control Agency as part of our petition presentation. This is her story:

Kelly is a working mother of a three and a five year old. She spent two years trying to get help from her GP until January 2020 when, despite being unable to eat because she felt full and tired, her stomach got bigger. Her doctor suggested she had a possible personality disorder and should watch her diet and get better sleep. In April 2020, two weeks into lockdown, the pain finally got too much and she went to ED. She was 38 years old.

Once at ED, I was once again told to go home with laxatives and diet advice. But suddenly the doctor changed her mind when hearing of my discharge and sent me for a scan. At this stage I looked nine months pregnant and could barely walk. The screen lit up with a mass the size of a full grown baby – I burst into tears – tears of joys that there was something there – that I wasn't crazy.

I had a 3L tumour growing in and around my organs. I was sent for an operation a few days later (after blood tests showed it to be benign) to have it removed along with an ovary and fallopian tube and thought that was the end of it. Until a week later when I got the phone call from the surgeon to tell me I had cancer – mucinous adenocarcinoma of unknown origin. I was blown away. I had no concern that a cyst would be cancerous!

The next few months are a blur. I was distraught – I have two young boys, the type of cancer doesn't generally respond to chemo. I had another operation to stage me, do washings, take biopsies and check other organs and was sent home a day later. I was in no way able to look after myself so my husband had to. I was taking so many painkillers I couldn't keep track, let alone get out of bed – for four weeks!

I was given the all clear two months after my visit to ED but recommended chemo as there was a chance minute cells were still somewhere in my body. The only option given was this chemo or "wait and see". Ultimately I decided against the lifelong side effects of chemo over the small chance it may make. any difference. I had to do a lot of research because all I had heard was mucinous do not respond to chemo. The oncologist didn't really divulge too much about this in our meeting, just that he would do the chemo if he was in my position and when I brought him my evidence he said it was my choice and as there was no evidence any disease was left, he supported me. But my story doesn't end there.

I ended up having a mental breakdown – I was damaged goods – a now 39 year old who couldn't have more children, who had cancer and was still fatigued and I felt like I took ages to recover. I mapped out my suicide, dying was all I ever thought about – I drive past the cliff I planned to one day drive over every single day. Once I'd refused chemo, any psychological or other help disappeared. Friends assumed I was ok, life went on for everyone else and when they found out I wasn't ok, I was just told how I should stay positive and think of my children, how I'm so lucky – no one quite gets the stress of a cancer diagnosis and its life-long effects.

Every pain I have is cancer. It follows me around everywhere I go. And I can't help but wonder – if the first doctor I went to had been able to get me a scan, (and send me for the correct blood tests) would the tumour have even been cancerous? It had over a year, maybe two to grow. Has the medical professional let me down in the worst possible way? And when will it come back? Is it already here?

- Kelly, mucinous adenocarcinoma, New Zealand



Before I even knew about Cure Our Ovarian Cancer, it helped me through my worst day. When I was told I had cancer, I was asked if it would be ok to give my cells to a researcher to help improve outcomes in my specific cancer. I was trying to find a silver lining but it seemed impossible until I heard that my situation might help someone else's.

Cure Our Ovarian Cancer funded that research with the help of all the amazing woman worldwide. I am forever grateful my cells could help.

Fast forward 18 month I could not imagine my life without the support and knowledge of the Facebook group and thanks to Jane we have the most up to date information on the webpage. Forever inspired and grateful for Cure Our Ovarian Cancer.

- Lin, low-grade serous ovarian cancer, New Zealand

“ This charity has the most comprehensive and credible online library of resources when it comes to the latest research and information on LGSOC . I signpost it to all health care professionals because I know that they will get the most up to date information to assist in their clinical practice. This enables people worldwide to benefit in the best ways possible. ”

- Diane, low-grade serous ovarian cancer, United Kingdom

I'd describe myself as an average person. I'm a wife, a teacher and have 2 kids. I don't have any amazing hobbies or anything particularly amazing about myself...and after my diagnosis, I have realised that that is enough. I am quite happy with having a great family and good friendships.

Before I was diagnosed I saw a Cure Our Ovarian Cancer symptoms poster. Despite checking off the symptoms, I didn't think I had ovarian cancer! I was diagnosed at stage 1C which is relatively early. I want people to know that if there is any doubt - you should get it checked.

A challenge with ovarian cancer is the worry it will come back. With every little pain you feel like you are not able to fully relax. But it's also brought me closer to friends and I received support from many people, which was a humbling but proud experience.

- Andrea, Mucinous Ovarian Cancer, New Zealand



AMY MACRAE'S STORY



IN HER OWN WORDS:

“
I’ll go on
”

YOUR NAME:

Amy Macrae

DATE OF DIAGNOSIS:

September 2017

AGE AT DIAGNOSIS:

32

COUNTRY:

Canada

I AM:

The mother of a beautiful 3 year old girl, a wife, a Kindergarten behaviour and special needs teacher, a sister, a daughter

THE CANCER WAS FOUND WHEN:

My husband and I went to a fertility clinic in attempts to have a sibling for our daughter. An ultrasound picked up a strange mass in my uterus, which I was told was probably just a fibroid. After two surgeries, I was diagnosed with metastatic low grade ovarian cancer.

HOW YOUR DONATIONS WOULD IMPACT ME:

New treatments could mean I could be here for my daughter for longer. I’ve been told it’s most likely I will have a dramatically shortened life span, which has altered our family’s plans for the future. Your donations would help fund research that could lead to new treatments and hopefully a cure for this terrible disease.

WHAT I’D SAY TO SOMEONE ELSE GOING THROUGH THIS:

Be gentle to yourself. Allow yourself to cry. To be angry, to say it’s unfair. Time has a way of eventually dulling the pain and allowing you to go on, even when you think you won’t be able to.

“I can’t go on. I’ll go on.” – Samuel Beckett



AMY’S LIVING LEGACY:

In 2019 Amy visited the BC Cancer low-grade serous laboratory to learn more about their efforts to improve the survival rates of women with her cancer. She wanted to support their efforts to help women have more time.

In her last days she requested a page be set up on the Cure Our Ovarian Cancer website as a living legacy to honour her. Amy passed away peacefully on June 1, 2020.

To date Amy’s living legacy has raised almost \$100,000 for research.

“ This cancer has taken from me more than I ever could have imagined. But it has also made me more grateful than I ever have been for the simple things. **Outcomes for this disastrous disease haven’t improved in over 50 years.** We need to demand new research and more funding, on par with the resources available to help my sisters with breast cancer. I am grateful for every day I have here and I encourage you to help me change the outcomes for future women with this disease. ”

- Amy

HER IMPACT:

Amy MacRae, in her kind, gentle, and determined ways fought a courageous battle against cancer. Through her heroic efforts, Amy leaves a legacy that will allow us to continue her fight. The funds donated in Amy’s honour will be used to solely support research on a rare type of ovarian cancer called Low-Grade Serous Ovarian Carcinoma (LGSOC). Our research program was founded by generous patient donors, their families, and their friends. Thanks to Amy and the ongoing support of many others affected by this disease, we are one of the few laboratories in Canada and worldwide making LGSOC our research priority. Women with LGSOC have played a key role in raising awareness, advocating for better treatments, and supporting research on this cancer. We will continue to work on behalf of these women and Amy to discover better ways to diagnose and treat LGSOC.

Dr. Mark Carey, M.D., F.R.C.S.C. • Clinical Professor

Division of Gynaecologic Oncology • Vancouver General Hospital • Vancouver Coastal Health (VCH)



**AMY MACRAE PASSED AWAY ON THE
1ST JUNE, 2020 AT AGE 35.**

AMY MACRAE'S STORY

FROM AMY'S HUSBAND:

Our experience with Amy's cancer was heartbreaking and devastating. We were initially filled with hope, due to Amy's access to the best treatment options available, but that hope was dashed as options ran out. Hope was replaced with grief and grief has slowly transitioned into resiliency.

Low Grade Serous Ovarian cancer impacted every aspect of Amy's life – her goals and dreams, motherhood, her career. Amy showed remarkable poise and strength as she navigated her various surgeries and treatments – always putting on a brave face and a big smile for our daughter. Trying to reassure not only our daughter, but the rest of the family as well. Amy was brave up to, including and after the day she took my daughter's hand and told her Mommy would have to die soon.

We feel deeply thankful for the healthcare that Amy received – our truly caring medical system left no stone unturned. Amy's final months in palliative care were difficult – and profoundly impacted by COVID. Treatment and visitation options were limited and there was a constant fear in the air. The palliative care doctors and nurses worked tirelessly to give Amy as much comfort and quality of life as possible in her final weeks.

Now, over a year since Amy's passing, I still grieve every day. I think about Amy's final months. I wish there had been more we could have done.

But I also feel grateful for my daughter's resiliency – as she enters Grade 1, a happy, healthy, confident little girl. I feel grateful for the family and friends that continue to surround us and support us. Amy's parents and siblings were an unstoppable support network throughout Amy's illness and remain so to this day. My daughter has several strong female role models that she looks up to - her Grandmother and Aunt, and Amy's best friends who remain close to us, including women Amy met during cancer support therapy who have become a part of our tribe.

Through resiliency, hope has returned. The hope is that Amy's legacy and the funds raised in her honour will help researchers find new and better treatments for Low Grade Serous Ovarian Cancer. Based on the feedback from researchers, there will be breakthroughs in treatment and part of Amy's legacy will be the contribution she made to raise awareness and funds in her final weeks as well as the funds donated in Amy's honour, by hundreds of people all over the world.

Garreth MacRae



APPROVAL OF FINANCIAL REPORT

CURE OUR OVARIAN CANCER (LOW GRADE SEROUS) CHARITABLE TRUST

The Trustees are pleased to present the approved financial report including the historical financial statements of Cure Our Ovarian Cancer (Low Grade Serous) Charitable Trust for year ended 31 March 2021.

APPROVED

A handwritten signature in black ink, appearing to read 'Jane', written over a horizontal blue line.

Jane Ludemann
Trustee

A handwritten signature in black ink, appearing to read 'Elspeth', written over a horizontal blue line.

Elsbeth Ludemann
Trustee

STATEMENT OF FINANCIAL PERFORMANCE

CURE OUR OVARIAN CANCER (LOW GRADE SEROUS) CHARITABLE TRUST

As at 31 March 2021

Revenue	Notes	2021	2020
Donations, fundraising and other similar revenue	1	172,423	160,759
Total Revenue		172,423	160,759

Expenses	Notes	2021	2020
Expenses related to public fundraising	2	4,587	8,015
Costs related to providing goods or services	2	13,637	12,825
Grants and donations made	2	67,024	85,659
Total Expenses		85,247	106,499
Surplus/(Deficit) for the Year		87,176	54,260

This statement has been prepared without conducting an audit or review engagement, and should be read in conjunction with the accounting policies and notes to the Performance Report

STATEMENT OF FINANCIAL POSITION

CURE OUR OVARIAN CANCER (LOW GRADE SEROUS) CHARITABLE TRUST

As at 31 March 2021

Assets	Notes	2021	2020
Current Assets			
Bank accounts and cash	3	225,771	137,728
Debtors and prepayments	3	6,435	4,635
Total Current Assets		232,206	142,363
Total Assets		232,206	142,363

Liabilities	Notes	2021	2020
Current Liabilities			
Creditors and accrued expenses	4	5,916	3,249
Total Current Liabilities		5,916	3,249
Total liabilities		5,916	3,249
Total Assets less Total Liabilities (Net Assets)		226,290	139,114

Accumulated Funds	Notes	2021	2020
Accumulated surpluses or (deficits)	5	226,290	139,114
Total accumulated Funds		226,290	139,114

This statement has been prepared without conducting an audit or review engagement, and should be read in conjunction with the accounting policies and notes to the Performance Report

STATEMENT OF CASH FLOWS

CURE OUR OVARIAN CANCER (LOW GRADE SEROUS) CHARITABLE TRUST
As at 31 March 2021

Cash Flows from Operating Activities	2021	2020
Donations, fundraising and other similar receipts	170,624	156,472
Payments to suppliers	(15,557)	(17,591)
Donations or grants paid	(67,024)	(85,659)
Total Cash Flows from Operating Activities	88,043	53,222
Net Increase/(Decrease) in Cash	88,043	53,222

Bank Accounts and Cash	2021	2020
Opening Cash	137,728	84,506
Closing Cash	225,771	137,728
Net change in cash for period	88,043	53,222

This statement has been prepared without conducting an audit or review engagement, and should be read in conjunction with the accounting policies and notes to the Performance Report

STATEMENT OF ACCOUNTING POLICIES

HOW DID WE DO OUR ACCOUNTING?

BASIS OF PREPARATION

The entity has elected to apply PBE SFR-A (NFP) Public Benefit Entity Simple Format Reporting - Accrual (Not-For-Profit) on the basis that it does not have public accountability and has total annual expenses equal to or less than \$2,000,000. All transactions in the Performance Report are reported using the accrual basis of accounting. The Performance Report is prepared under the assumption that the entity will continue to operate in the foreseeable future.

The Performance Report is presented in New Zealand dollars.

GOODS AND SERVICES TAX (GST)

The entity is not registered for GST. Therefore all amounts are stated inclusive of GST (if any).

INCOME TAX

Cure Our Ovarian Cancer (Low Grade Serous) Charitable Trust is wholly exempt from New Zealand income tax having fully complied with all statutory conditions for these exemptions.

BANK ACCOUNTS AND CASH

Bank accounts and cash in the Statement of Cash Flows comprise cash balances and bank balances (including short term deposits) with original maturities of 90 days or less.

CHANGES IN ACCOUNTING POLICIES

There have been no changes in accounting policies. Policies have been applied on a consistent basis with those of the previous reporting period.

NOTES TO THE PERFORMANCE REPORT

1. Analysis of Revenue	2021	2020
Donations, fundraising and other similar revenue		
Donations collected for expenses	13,901	20,245
Donations general	158,522	140,514
Total Donations, fundraising and other similar revenue	172,423	160,759

Breakdown of Cure Our Ovarian Cancer Total Donations collected for research by region	2021	2020
New Zealand	65,105	124,225
Australia (\$130 AUD*)	136	103
Canada (\$26, 761 CAD*)	27,413	1,454
Europe (60 € EUR*)	105	205
UK (£189 GBP*)	364	3,885
USA (\$23,504 USD*)	35,392	10,421
International (\$20,462 USD*)	30,007	221
Total Breakdown of Cure Our Ovarian Cancer Total Donations collected for research by region	158,522	140,514

* Total donated in foreign currency - donations are converted at the time of transation to NZD

2. Analysis of Expenses	2021	2020
Expenses related to public fundraising		
Promotion and Marketing	1,873	6,903
Website	2,714	1,112
Total Expenses related to public fundraising	4,587	8,015
Costs related to providing goods or services		
Administration and overhead costs	717	0
Advocacy & Awareness	6,940	5,414
Financial Reporting Costs	1,301	1,431
Legal expenses	0	3,780
Payment Processing Fees	4,678	2,199
Total Costs related to providing goods or services	13,637	12,825

2. Analysis of Expenses continued.	2021	2020
Grants and donations made		
Donations to Research via Charity Partners	67,024	10,659
NZ Research Grants (see note 7)	0	75,000
Total Grants and Donations made	67,024	85,659

Recipients of Donations to Charity Partners		
Australia New Zealand Gynaecological Oncology Group	0	359
BC Cancer Foundation (\$27,042 CAD)	29,326	905
The University of Texas MD Anderson Cancer Center (\$24,147 USD)	33,682	9,396
University of Edinburgh (£2036 GBP)	4,016	0
Total Recipients of Donations to Charity Partners	67,024	10,660

Recipients of NZ Research Grants		
Dr K Chitcholtan - University of Otago	0	75,000
Total Recipients of NZ Research Grants (see note 7)	0	75,000

3. Analysis of Assets	2021	2020
Bank Accounts and Cash		
Australia	126	0
Canada	0	234
Europe	178	33
Expenses Account	938	1,518
NZ Purposes Trust	193,153	130,018
UK	0	105
US / International	31,376	5,821
Total Bank Accounts and Cash	225,771	137,728
Debtors and prepayments		
Donations for expenses receivable	5,901	3,245
Donations general receivable	534	1,390
Total Debtors and prepayments	6,435	4,635

4. Analysis of Liabilities	2021	2020
Creditors and accrued expenses		
Creditors and accrued expenses	5,916	3,249
Total Creditors and accrued expenses	5,916	3,249

5. Accumulated Funds	2021	2020
Accumulated Funds		
Opening Balance	139,114	84,855
Accumulated surpluses or (deficits)		
Current year earnings	87,176	54,260
Total Accumulated surpluses or (deficits)	87,176	54,260
Total Accumulated Funds	226,290	139,114
Total Accumulated Funds	226,290	139,114

Funds are being held for a research project in the near future.
Refer to 'Funding Research/'New Zealand' in Statement of Financial Performance for details.

6. Reconciliation of New Zealand and International Revenue and Expenses	2021	2020
Revenue sourced in New Zealand	79,006	144,470
Expenses of New Zealand origin	7,489	92,276
Accumulated funds of New Zealand origin	71,517	52,194
Revenue sourced Internationally	93,417	16,288
Expenses of International/Undesignated origin	71,433	10,882
Accumulated funds of International origin	21,984	5,406
Running Total	93,501	57,600
Overhead Expenses for both New Zealand and International activities	6,325	3,341
Current Year Earnings	87,176	54,260

To ensure we wholly fulfil the IRD requirements for our NZ Purposes fund we have taken a conservative approach to classifying expenses of NZ origin and only included those items that were explicitly and solely for NZ purposes. Any doubt resulted in an expense being classified as International/Undesignated.

7. Commitments

The Trust has signed a Memorandum of Understanding with the GRACI (Gynaecological Cancer Research Trust) Foundation to make available up to \$10,000 for the Cure Our Ovarian Cancer / GRACI low grade serous research grant. The grant has been awarded to Dr Mak Sarwar at the University of Otago

There are no other commitments as at 31 March 2021 (Last year - nil).

8. Contingent Liabilities and Guarantees

There are no contingent liabilities or guarantees as at 31 March 2021 (Last year - nil).

9. Related Parties

	2021	2020
Donations		
Trustees and close family members - Donations general	10,000	3,034
Trustees - Donations for expenses	13,901	3,245
Total Donations	23,901	6,279
Expenses		
Trustees - Expenses paid on behalf of the charity	5,901	3,245
Total Expenses	5,901	3,245

The Trustees provide 40-60 hours per week of time and skills to the oversight and operation of the Trust at no charge.

10. Events After the Balance Date

There were no events that have occurred after the balance date that would have a material impact on the Performance Report (Last year - nil).

11. COVID-19 Pandemic

On 11 March 2020, the World Health Organisation declared a global pandemic as a result of the outbreak and spread of COVID-19. This caused a disruption to the activities of the Trust, including raising funds for low-grade serous research and funding research.



MARIANNA



TONYA



AMY



JENNY



KRISTEN



JANE



KIM



ALISI



BRANDI



KILEY THOMPSON



cureourovarycancer.org