

## NEWSLETTER March-April • 2024 a voice for women's health

## KILLER CANCER FLIES UNDER THE RADAR



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## Gender Inclusivity and the Language Used in Our Newsletter

The Auckland Women's Health Council acknowledge that not all people with breasts, vaginas, and other female organs and anatomy identify as women/wāhine.

We include transgender boys or men, intersex and non-binary people who have female organs and anatomy in the cohort of people our articles are about or aimed at.

In the *Newsletter*, the terms wāhine/women and female are used throughout most articles. It is not our intent to be exclusionary and these terms are used for ease of reading sometimes complex articles.

We know that many "women's health issues" apply to transgender boys or men, intersex and non-binary people and we want those New Zealanders to know that that our articles are for you as well as those who identify as women/wāhine.

## Ignoring the Desperate Need for Regulation

## Repealing the Therapeutic Products Act

By Sue Claridge

The Coalition Government is going to repeal the Therapeutic Products Act 2023.

The Therapeutic Products Act 2023 (TPA) is a massive piece of legislation that replaced the outdated 42 year old Medicines Act, and several other pieces of legislation, bringing the regulation of medicines, medical devices and other therapeutic products kicking and screaming into the 21st century. The legislation was accompanied by the hopes and dreams of health consumers that we would have a system that would both keep us all safer from the harms that come with medical care, plus access to the best that the pharmaco-medical industry has to offer.

Repealing the TPA was on the coalition Government's 100-day plan.<sup>1</sup> It hasn't happened yet – despite it now being long past the end of the Government's first 100 days in power – but they are still going ahead<sup>2</sup> with this shortsighted repeal that smacks of "throwing the baby out with the bath water", and it is listed on the 100 Day Plan completion document.<sup>3</sup>

The National Party always opposed the TPA; in the Health Select Committee report<sup>4</sup> on the Therapeutic Products Bill, their views were that that the legislation is an overreach and not fit for purpose. Some of their concerns had been addressed or partially addressed through the public consultation process and update of the content and wording of the Bill. However, they were unhappy enough with the legislation that repealing the Act was one of 49 actions that were urgent enough in their minds to address in their first 100 days in Government.

The National Party does not support direct to consumer advertising (DTCA) and are also concerned with issues around software as a medical device. Regarding NHPs, in the report the National Party said:

"We have seen no compelling evidence for substantive and significant or serious harm from natural health products. We are concerned for the cost of compliance on small manufacturers and retailers.

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Further, the view of thousands of submitters opposing this part of the bill has not been respected with the failure of the Labour majority select committee to wait for a report-back of an official Government working group on the impact of the bill on small business that would have further informed committee deliberations."<sup>4</sup>

National's coalition partners, Act and New Zealand First, are not fond of the TPA either.

- ACT oppose the Act because in their view it:
- offers a tangle of red tape and crippling compliance costs.
- the bill would create a Regulator whose excessive costs, regulatory overreach, and missed opportunities for added benefits did not justify a departure from the status quo.
- creates a needless barrier to accessing therapeutic products by imposing New Zealandspecific approval requirements for products which have already met international standards. Conversely, New Zealand manufacturers are disadvantaged by being faced with regulatory requirements not faced by those offshore.<sup>4</sup>

New Zealand First was out of Parliament during the 2020 to 2023 term in which the TPA was passed, but Party leader Winston Peters has long opposed the sort of regulation of natural health products that the TPA imposes, and "has been credited as the handbrake on previous attempts at regulating natural health products in 2007 and 2017."<sup>5</sup> Repealing the TPA was a New Zealand First 2023 election policy<sup>6</sup> and they have been ardent supporters of repealing the Act since reaching a coalition agreement with National on the 24<sup>th</sup> of November 2023.

The Auckland Women's Health Council agree with National on DTCA and also on the impact on natural health products. However, we are generally in support of the TPA, as we had set out in detail in our written submissions on the Bill.<sup>7</sup> The existing Medicines Act 1981 is well past its 'use-by-date', and it was enacted before many critical developments in medical practice and therapeutic products. It significantly predates many technological developments outside medicine (such as the internet), that have had a major impact on the way in which consumers and health services providers interact and practice, and how information is disseminated.

The current regulatory system, particularly for implantable medical devices, is not working. We support the regulation of therapeutic products across their lifecycle; this is important for implantable medical devices and medicines that, despite short term safety studies and follow-up, may, and often do, cause harm many years after implantation or prescribing.

While there were many failures and inadequacies in the Act that was finally passed,<sup>8</sup> it did represent a small step towards an improved regulatory environment that would ultimately improve patient safety.

One of two greatest concerns with the TPA as it was enacted, was the transitional provisions in the Bill that ensured that we would have to wait another six and a half years from when the Act was passed in Parliament before sponsors of implantable medical devices were held accountable for the lack of safety of their products. We said at the time that it is vital that we have temporary legislation or regulation that covers those medical devices already identified as causing harm, and provides for an immediate reassessment of their safety, quality and performance, or force them to be withdrawn until such time as they can undergo a full market authorisation under the new Act.<sup>7, 8</sup>

However, in the TPA at least we had a piece of legislation that had the potential to offer improved regulation of implantable medical devices, albeit one we had to wait some time for.

We recently contacted the Hon Casey Costello, Associate Minister of Health and the Minister responsible for actioning the repeal of the TPA, asking for clarification on a number of issues around the repeal.

The Government intends to undertake a repeal of the TPA in its entirety; as a result the legislation that it replaced – Medicines Act 1981, the Dietary Supplements Regulations 1985 and Sunscreen (Product Safety Standard) Act 2022 – will be reinstated.<sup>2</sup>

In our communications with Minister Costello we said that "it is clear that the Medicines Act 1981 is incredibly out of date and simply not fit for purpose in a medicines and medical devices landscape that has seen exponential changes over the last 43 years."

We asked what the Government plans to replace the Medicines Act, and soon to be repealed Therapeutic Products Act, with to ensure the safety and health of the people of Aotearoa New Zealand.

We were told that "The Ministry of Health is providing the Government with advice on the future options for regulation to ensure health products do what they claim, are of high quality, and that regulation does not make them inaccessible or unaffordable. Regulation should also support innovation and economic opportunities for New Zealand."  $^{\ensuremath{\mathcal{Z}}\xspace}$ 

So, after twenty years of multiple attempts to update the regulation of medicines and other therapeutic products, including a failed attempt in the 2000s to adopt a joint approach with Australia, we are back to square one. We are again reliant on the now 43 year old Medicines Act, a Clayton's\* regulation of implantable medical devices, and an antiquated passive reporting system for adverse reactions.

Law firm, AJ Park, believe that the TPA will be repealed some time in 2024, and that natural health products will be excluded from any consolidated therapeutic product regulation and will be likely to remain subject to the Dietary Supplements Regulations 1985.<sup>9</sup> Suppliers of natural health products will have to continue to "avoid ascribing a therapeutic purpose to such products to avoid them being regulated as "medicines" under the Medicines Act."<sup>9</sup>

Additionally, MedSafe will not be replaced by the "Therapeutic Products Act Regulator" but will probably be required to approve medicines at a quicker rate.<sup>9</sup>

However, of particular concern is that "medical devices will not be subject to any consolidated therapeutic products regulation" and will "remain subject to the much simpler requirements of the Medicines (Database of Medical Devices) Regulations 2003."<sup>9</sup>

Under our current legislation and regulations, Aotearoa New Zealand substantially accept implantable medical devices based on approval by the FDA. Here, Medsafe only carries out the bare minimum of evaluation of medical devices. The only requirement is that the manufacturer or importer lists it electronically on Medsafe's WAND (Web Assisted Notification of Devices) database within 30 days of it being first supplied. The Medicines Act contains no pre-market requirements for their assessment and approval whatsoever. Medsafe does not review any clinical or other information about a device, such as warnings or adverse event reports.

\* For those not old enough to remember the Clayton's brand marketing campaign in New Zealand in the 1970s and 1980s, it was for a non-alcoholic, non-carbonated beverage coloured and packaged to resemble bottled whisky. The tagline was "the drink you have when you're not having a drink". Referring to something as a "Clayton's" it is a way of saying that it looks like you've got the real deal when in fact what you have is an ersatz or dummy thing, or something that is obviously ineffective. In an interview with Radio New Zealand, health law expert, Laura Hardcastle, laid bare the serious deficiencies in the way that implantable medical devices are handled in Aotearoa New Zealand saying that:

- medical devices are largely unregulated;
- they have to be registered with Medsafe via an online database, WAND, but there is no pre-market assessment;
- there is no formal requirement for "untoward events" involving medical devices to be reported.<sup>10</sup>

"As medical technology advances, those gaps are only going to get worse," Ms Hardcastle said.<sup>10</sup>

Medical Technology Association chief executive Cushla Smyth complained that the TPA would have caused long delays for patients in accessing medical breakthroughs.<sup>10</sup> Clearly, greater profit as fast as possible is the major concern for manufacturers, rather than taking adequate time, clinical trials and pre-market assessment that would go further towards ensuring that health consumers are safer from harm.

Most New Zealanders have very little understanding of how poorly implantable medical devices are regulated here (and overseas) and incorrectly assume that they are safe from harm from such devices, because 'surely our government wouldn't allow defective, harmful and inadequately tested devices to be used here.'

To gain an understanding why our reliance on the US regulatory system leads to devastating harm we recommend starting with the documentary *The Bleeding Edge*<sup>11</sup> that was reviewed in the <u>AWHC</u> <u>November Newsletter</u>. Additionally, we include on the following page, a review of the regulations for medical devices in the US, a process upon which Aotearoa New Zealand heavily relies in allowing the use of medical devices in this country.

There are many reasons that Aotearoa New Zealand needs new legislation to properly regulate therapeutic products, but the most significant in terms of protecting New Zealanders from harm, is the introduction of a robust regulatory regime for implantable medical devices.

We have seen harm caused in Aotearoa New Zealand by faulty pacemakers, metal-on-metal artificial joints, contraceptive implants including Essure, breast implants, and surgical mesh. The devastating harm caused by these, and other implantable medical devices, will continue without proper and robust regulation and post marketing surveillance.

## Medical Device Regulation in the US

By Prof. Joanna Manning, Professor of Law at the University of Auckland

Originally included in the <u>AWHC Submission on the Therapeutic Products Bill</u> with permission from Prof Manning.

There are two main avenues for medical devices to be sold on the market legally in the US; "approval" and "clearance."<sup>12</sup> Some classes of device have to be approved, rather than cleared.

Under the first, a manufacturer applies for Pre-market Approval (PMA) by submitting detailed information of the results of laboratory studies and "clinical investigations involving human subjects" i.e. randomised clinical trials, as well as manufacturing processes.<sup>13</sup> The FDA assesses its safety and effectiveness in terms of the statutory requirements ("reasonable assurance of its safe and effective performance").14 It is applicable to class III devices, which pose the highest risk. Only approximately one percent of medical devices receive a PMA. Medical devices with PMA are entered onto the PMA database, which is publicly accessible and searchable.

The other route is the 510(k) pathway, which allows manufacturers to fast-track FDA approval without having to conduct expensive and time-consuming testing and randomised clinical trials. The FDA's commitment is that the product will be "cleared" for sale within 90 days of application. The basis for clearance is the manufacturer demonstrating "substantial equivalence" of the new device to that of an already legally marketed ("predicate") device for the same intended use. The purpose of the 510(k)

International research has found that globally, implantable medical device regulation is unfit to protect patients from harm. In Aotearoa New Zealand, like many other countries, grossly inadequate regulation of medical devices has led to catastrophic levels of harm being inflicted upon health consumers.

The <u>Implant Files</u> investigation<sup>15</sup> was the first-ever global examination of the medical device industry, and it found that health authorities across the globe have failed to protect millions of patients from poorly tested implants. The investigation found that when flaws are found in medical deprocess is not to assess safety and effectiveness, but simply to determine whether the FDA agrees with the manufacturer's claim that the device is substantially similar to a predicate device already

## **On Predicate Devices...**

Dr Deborah Cohen, Associate Editor of the BMJ, explained that the reliance on predicate devices results in "what we call a daisy chain. And then, quite often what you found is that some of these predicate devices, as they call them... have been actually recalled from the market because they've been failing."<sup>11</sup>

"So, even if the device was recalled because it was dangerous, you can still use it as a predicate and get your device cleared because it's substantially equivalent. So, there's a lot of problems with that 510(K) system. And that's how metal-on-metal hips got on the market," explained Dr Rita Redberg, Editor of JAMA Internal Medicine.<sup>11</sup>

> on the market. Technically the 510(k) process is intended for moderate-risk (class II) devices, but some risky class III devices are determined to be class II because the manufacturer is able to demonstrate substantial equivalence. The vast majority (between 95 and 98 percent) of medical devices used on patients on sale in the US received clearance through the 510(k) process with the result that they have never been used on a single patient and have received little government scrutiny.

> vices, and safety alerts and recalls are triggered, all too often these warnings fail to reach doctors and patients. Recalls, withdrawals and bans on devices are not uniformly applied from country to country, causing confusion and raising risks to patients where insufficient action is taken.

> The *Implant Files* state that "Doctors and manufacturers often fail to report adverse events, and when they do the information can be unverified and incomplete. And over large swaths of the planet, health authorities refuse to disclose information about harm to the public – or just never collect it in the first place."<sup>15</sup>

Aotearoa New Zealand was one of the countries specifically mentioned. Our regulators facilitated significant harm to New Zealanders because they failed to do their jobs properly!

The Therapeutic Products Bill represented not only the means by which our lawmakers might ensure that we have a regulatory regime that protects our citizens from dangerous implantable medical devices, but could also have put Aotearoa New Zealand in a position to lead the rest of the world to a better future for everyone who is recommended an implantable device by their health practitioner.

In repealing the Therapeutic Products Act 2023, the Coalition Government have placed New Zealanders in harm's way for the foreseeable future and they do not appear to have any plans to rectify the situation.

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- 8. Claridge S, 2023: <u>Limited Good News, Overall Disappointment</u>, AWHC July 2023 Newsletter.
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- 10. Hill R, 2024: <u>Patient safety advocate 'horrified' at government's</u> <u>plans to drop Therapeutic Products Act</u>, *Radio New Zealand*, 19 February 2024.
- The Bleeding Edge, Kirby Dick (Director), Netflix, 2018 (currently available to view online at <u>https://vimeo.com/286151015</u>. A Transcript of the documentary is available on the <u>AWHC</u> <u>website</u>.
- 12. Low risk Class I devices, such a bedpans and tongue depressors, are generally exempt from the regulatory process and can be marketed without receiving FDA clearance. Manufacturers of class I devices must register them and list their generic products with the FDA.
- 13. See Title 21 of the Code of Federal Regulations, part 814.20(v)(B)
- 14. Food, Drugs and Cosmetic Act, s 514(2)(A).
- 15. ICIJ, 2018: Medical Devices Harm Patients Worldwide as Governments Fail on Safety, *The Implant Files*, International Consortium of Investigative Journalists.

## Help Us Continue Our Work

Auckland Women's Health Council relies on community funding grants and donations to keep our organisation functioning and to pay for operating expenses.

We need your help to continue our important work for the women/wāhine of Aotearoa New Zealand.

For many years we charged a small membership subscription; members received our *Newsletter* as part of this fee. In 2021, we decided to make subscription to our *Newsletter* and membership of the Council free. People can subscribe to the *Newsletter* without becoming a member and receive the *Newsletter* directly into their email inbox. We continue to make it freely available on our website from the date of publication. We strongly believe in the importance and value of the information that we provide, the analysis and gendered perspectives on health, and we want all women/wāhine to have access to this without the burden of cost.

Membership applications remain subject to the approval of the Executive Committee, as set out

in our constitution, but we no longer ask for the payment of membership fees or a subscription. We hope that those who believe in our work and are able to, will support us with a donation when they can. However, we don't want financial considerations to limit membership.

We have made <u>donating to the Auckland Women's</u> <u>Health Council</u> easier for those able to support us financially. We don't ask for a specific amount, but because we are a registered charity, any donations of \$5 or over are eligible for a New Zealand charitable giving tax credit.

There are two ways that you can donate money directly to the AWHC: through internet bank transfer or via Givealittle using your credit card. <u>Information on</u> <u>making a donation through either of these methods</u> <u>is provided on our website</u>. Thank you in advance to all those who can support us through a donation.



## Killer Cancer Flies Under the Radar

**By Sue Claridge** 

- Abdominal bloating
- Eating less and feeling fuller
- Abdominal, pelvic or back pain
- Seeding to pee more often or more urgently
- Changes in bowel habits
- Fatigue<sup>1</sup>

It would be easier to count the wāhine who haven't experienced these symptoms than those who have. At least individually, they could be symptomatic of any one of many health issues, both fleeting or longer term; mild or serious.

But... they all could be the symptoms of ovarian cancer.

"The symptoms of ovarian cancer are often vague and ill-defined and overlap with symptoms of much more common disorders such as dyspepsia, irritable bowel syndrome, [and issues with] menstruation and menopause. This makes early diagnosis a challenge as well."<sup>2</sup>

As well as the above list of symptoms, indigestion, abnormal vaginal bleeding or discharge, unexplained weight changes and painful sex are also possible symptoms of ovarian cancer.<sup>1</sup>

Originally, the title of this article referenced ovarian cancer\* as a "silent killer". While far too many wāhine and health practitioners are insufficiently aware of the

#### Author's note:

This article on ovarian cancer is one of the longest and most in-depth articles published in the Auckland Women's Health Council Newsletter to date. It became apparent as I undertook the research for this article, as it will become apparent to readers, that it is vital that the gynaecological cancers (other than cervical cancer), get far greater attention, particularly ovarian cancer. Far too many women are either unaware of ovarian cancer or know little about the symptoms. Sadly, many GPs seem to lack sufficient awareness of the disease to respond in a timely manner and ensure prompt diagnosis in women when they do present with symptoms. Opportunities within the health system to raise awareness in both women, and their health practitioners, are being missed, and as a result many women die prematurely. The disturbing statistics on ovarian cancer in Aotearoa New Zealand justify the space we have dedicated to the disease in this edition of the Newsletter.

In this article the terms wāhine/women and female are used throughout. It is not our intent to be exclusionary and these terms are used for ease of reading a sometimes complex article. We acknowledge that not all people with ovaries identify as women/wāhine and we include transgender boys or men, intersex and nonbinary people who have ovaries in the cohort of people this article is aimed at and who are at risk of ovarian cancer.

<sup>\*</sup> NZ data on ovarian cancer often includes "other uterine adnexa". The adnexa is the region adjoining the uterus that contains the ovary and fallopian tube, as well as associated vessels, ligaments, and connective tissue. Additionally, "there is increasing evidence that much of what was traditionally thought of as ovarian or peritoneal cancer in fact originates in the fallopian tube. In this article the term "ovarian cancer" includes other uterine adnexa.

symptoms of ovarian cancer, the moniker "silent killer" perpetuates the idea that ovarian cancer is without symptoms for a prolonged period of time or not present until the cancer is advanced.

Cure Our Ovarian Cancer\*, in their 2022 National Ovarian Cancer Report, write that historically, ovarian cancer was often regarded as symptomless, despite the majority of women/wāhine experiencing classic symptoms for a prolonged period of time.<sup>3</sup> The report goes on to say that at least one of Aotearoa New Zealand's medical school libraries still hosts textbooks incorrectly stating that 'most patients with ovarian cancer experience no symptoms' ".<sup>3</sup>

The idea that ovarian cancer is a "silent killer" is a myth, says Dr Barbara Goff. She says that the "more clinicians and primary-care providers recognise the early signs, instead of "blowing them off" as just gastrointestinal problems or nerves, the more lives will be saved."<sup>4</sup>

"Many healthcare professionals are seemingly unaware of the symptoms typically associated with ovarian cancer, so misdiagnosis remains common," noted Goff, in her an editorial in the *Journal of Obstetrics and Gynecology*.<sup>5</sup>

This persisting belief, and the fact that many symptoms may be mistaken for other conditions, leads to frequent misdiagnosis. The *National Ovarian Cancer Report* says that "women/people [visit] their doctor again and again, only to be misdiagnosed".<sup>3</sup> The Ovarian Cancer Foundation NZ says that common misdiagnoses include irritable bowel syndrome, constipation, urinary tract infections, menopause, gastritis and even depression, stress or needing to lose weight.<sup>1</sup>

Awareness of symptoms of ovarian cancer is poor among women, with as few as 14% being familiar or very familiar with symptoms, and even in a highrisk population there was a low level of awareness (24%) of symptoms.<sup>6</sup>

Studies have found that although health practitioners have a generally better knowledge of symptoms "knowledge deficits were still found. The inability to finish a meal and early satiety were only identified by 59% and 64%, respectively."<sup>6</sup> This inadequate familiarity with symptoms among health professionals inevitably results in delays in diagnosis.<sup>6</sup>

Cure Our Ovarian Cancer's 2020 survey suggests almost 50% of women/wāhine in Aotearoa New Zealand wait more than three months to be

#### OVARIAN CANCER SIGNS & SYMPTOMS

- Unexplained fatigue
- Unexplained weight gain or loss
- Changes in bowel habits, such as constipation
- Increased abdominal size or persistent abdominal bloating
- Abdominal or pelvic (lower tummy) pain
- Appetite loss, feeling full quickly or indigestion

 Urinary changes, such as frequency or urgency

## Women/wāhine are tragically unaware of four out of five gynaecological cancers

Almost every woman/wāhine will have heard of breast and cervical cancer. These are the highprofile cancers, the ones that get all the media coverage. These are the two female cancers for which there are screening programmes. Many women don't know that alongside cervical cancer there are four other gynaecological cancers — ovarian, uterine, vulval and vaginal. Ovarian cancer affects more women than cervical cancer does and is more deadly than breast cancer.

A 2022 survey in the UK found that 34% of people can't name a single gynaecological cancer and only 2% of people can name all five gynaecological cancers. A subsequent survey found that only 7% of people said they had a good knowledge of gynaecological symptoms before they or a loved one experienced them.

Other research has shown that as few as 41% of people mention gynaecological cancers when asked which cancers they have heard of. Cervical cancer was most frequently mentioned (28%), followed by ovarian (12%) and endometrial cancer (11%).

In Aotearoa New Zealand, a survey of women who had been diagnosed with ovarian cancer found that 32% had never heard of ovarian cancer prior to their diagnosis, 59% had heard of it but didn't know any of the symptoms, while only 9% knew any symptoms.<sup>3</sup>

<sup>\*</sup> Now known as the Ovarian Cancer Foundation NZ

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diagnosed with ovarian cancer after presenting to their doctor with symptoms, and for 20% diagnosis takes longer than 12 months.<sup>3</sup> This is in stark contrast to the situation in Australia, where "time to clinical diagnosis was less than 2 months for 39% of women; 61% were diagnosed within 3 months, and almost 80% were diagnosed within 6 months. Only 4% were not diagnosed until more than 1 year after symptom onset."<sup>7</sup>

The survey of women/wāhine with ovarian cancer, mentioned above, also asked respondents about delays in discussing their symptoms with their doctors, and how long it took to be referred for blood tests and ultrasounds (see Diagnosis in opposite column) and how long it took to be diagnosed. Only 8% went to their doctors immediately (within one month), 44% between one and three months, and 44% took be-tween three months and one year to see their doctor.

While 42% of women/ wāhine were referred for tests on their first or second doctor's visit, 31% had three to five visits before being referred for further tests, 16% had 6-10 visits and for 11% of women they had to visit their doctor more than ten times before the doctor referred them for diagnostic tests.<sup>3</sup>

Twenty-six percent were diagnosed within a month, a further 28% within three months, and a further 23% within a year; 22% of women had their diagnosis delayed by a year or more and of those two thirds were delayed by more than two years.<sup>3</sup>

In another study, almost half (48%) of all women/ wāhine with ovarian cancer experience an emergency diagnosis,<sup>8</sup> where they are diagnosed through a visit to a hospital emergency department rather than through a primary care provider. This happens despite many women experiencing symptoms for months or in some cases years, before their diagnosis. Aotearoa New Zealand has the worst emergency ovarian cancer diagnosis rates of comparable health systems in the world, and 42% of women/wāhine with an emergency diagnosis will be dead within a year compared to 17% diagnosed via primary care.<sup>8</sup>

## Ovarian Cancer: Types, Diagnosis, Treatment

Ovarian cancer is not a single disease – there are over 30 different types and each one requires individualised treatment. Two thirds of women have high grade serous ovarian cancer, while the remaining one third of diagnoses involve one of the rarer types, such as low-grade serous, clear cell, germ cell or small cell ovarian cancer.<sup>9</sup> It is now believed that many ovarian cancers, including the most common high-grade serous carcinomas, frequently originate from precursor lesions in the fallopian tubes.<sup>10, 11</sup> This is important with regard to potential preventive approaches (see Prevention on page 13).

The <u>Ovarian Cancer Foundation NZ have an excellent</u> <u>webpage</u> setting out more detailed information on the different types of ovarian cancer, including symptoms for each, diagnosis, risk factors, treatment (funded and unfunded), clinical trials and recurrence.

There is no screening test for ovarian cancer. Professor of Obstetrics and Gynecology, Barbara Goff, says that "[f]or the past 25 years, scientists have tried to identify a screening test to detect ovarian cancer in its earliest stages, when the chance of cure is high. Unfortunately, multiple clinical trials with hundreds of thousands of participants have failed to identify an effective way to screen for ovarian cancer."<sup>12</sup>

Unfortunately, studies have shown that some women – as many as 40% in one UK survey<sup>13</sup> – are of the mistaken belief that cervical smears can test for or diagnose ovarian cancer,<sup>6, 14</sup> but this is not the case and cervical screening is completely unrelated. Some



doctors will do a physical exam at the time of a cervical smear and palpate the abdomen, which may pick up an ovarian mass, but cervical screening itself is of no diagnostic benefit in ovarian cancer.

Disturbingly, one survey of health professionals in the US found confusion about Pap smears even among clinicians "with 33% of healthcare providers incorrectly identifying an abnormal Pap test as a symptom of ovarian cancer."<sup>6</sup>

Upon presenting with symptoms indicative of ovarian cancer, a woman's doctor will likely do a physical pelvic exam. If the doctor finds something – for example a mass or lump in the vicinity of the ovaries – they should refer a woman for further tests. However, a normal pelvic exam does not mean there is no ovarian cancer and if symptoms persist women should request further testing.<sup>15</sup>

Diagnosis typically involves ultrasound (usually transvaginal ultrasound) and the CA-125 blood test, which looks for a specific protein in the blood that may be elevated because of ovarian cancer.

"Ovarian cancer is more likely if the result is 35 units/mL or higher. However, most people with an elevated CA-125 result do not have ovarian cancer, and some people with ovarian cancer have a normal blood test; this is more common in younger people with ovarian cancer and early-stage ovarian cancer."<sup>15</sup>

Treatment depends on the type of ovarian cancer and stage – how far the cancer has spread. Standard treatment involves surgery, with the removal of ovaries and fallopian tubes (salpingo-oophorectomy) and possibly the uterus. Other tissue and organs may also be removed if the cancer has spread.<sup>9</sup> Surgery may be followed by chemotherapy.<sup>6</sup>

Other treatments include targeted drugs and radiation. Patients may also qualify for participation in clinical trials.<sup>9</sup>

## Late Diagnosis

Ovarian cancer is one of a number of cancers that are typically diagnosed late, when the cancer has spread beyond the tissue or organ in which it originated.

Often ovarian cancer is diagnosed very late, when it has already metastasised — by the time women/ wāhine present to their doctors with symptoms and are actually diagnosed, there are significant limitations on the ability of treatment to send the cancer into remission and the prognosis is often poor with limited survival time.

A 2023 study found that delays in diagnosis were contributed to by multiple factors, including:

- women's delay in recognising symptoms and seeking care, often a consequence of lack of knowledge about early signs of ovarian cancer;
- missed opportunities during healthcare encounters, due to misattribution of a woman's symptoms by their physicians, and underestimation by doctors of symptom severity.<sup>14</sup>

"Tumour stage at diagnosis is an important factor determining the patients' survival, which is threefold higher in women diagnosed at Stage I compared to Stages III–IV. Unfortunately, most women and other people with ovaries are diagnosed with Stage III or Stage IV cancer."<sup>16</sup> Studies have shown that 70 to 75% of cases diagnosed at stage III or IV where the cure rate is less than 30%.<sup>17</sup>

A study published in the journal *Gynecologic Oncology* in 2020, said that "[o]varian cancer continues to be diagnosed at advanced stage with high fatality rates. A significant contributing factor is lack of clear alarm symptoms." The study "explored the association of symptoms, routes and interval to diagnosis and long-term survival in a population-based cohort of postmenopausal women diagnosed with invasive epithelial tubo-ovarian cancer."<sup>18</sup>

The main symptoms considered were loss of appetite/feeling full, abdominal/pelvic discomfort or pain, increased abdominal size or bloating and change in bowel habit; abdominal pain, loss of appetite/feeling full, were significantly associated with increased mortality.<sup>18</sup>

Ultimately, this study illustrated the complexity of diagnosing ovarian cancer at an early enough stage that would improve prognosis and survival. Increasing numbers of symptoms is associated with poorer survival, as is emergency presentation to doctors or hospitals. While the study supports the need to fast track treatment, they also found that the time interval between initial onset of symptoms and diagnosis did not independently influence survival once other factors such as age, stage and type of ovarian cancer were considered.<sup>18</sup>

The researchers found that "to decrease deaths from ovarian cancer, it is critical we remain focussed on understanding disease biology, exploring preventative strategies, refining the current screening strategies by incorporating novel tests and optimising surgical and adjuvant treatment." However, they could not exclude the possibility of better outcomes in those who are aware and act on symptoms compared to those who do not.<sup>18</sup>

A Harvard Medical School statement advises that "any woman who experiences one or more of these complaints almost daily for more than a few weeks should see a clinician for a pelvic exam."<sup>31</sup>

It is critical that to improve outcomes and reduce mortality from ovarian cancer women pay attention to symptoms that do not go away fairly quickly, and insist on follow-up investigation of persistent symptoms rather than allow themselves to be "fobbed-off" or reassured by their health care professionals. Notwithstanding variations in risk factors for the different types of ovarian cancer, there are a range of non-modifiable and modifiable risk factors for ovarian cancer, and the modifiable risk factors offer some opportunities for prevention, at least at a population level.

While globally the life-time risk is only about 1 to 2%, the high mortality and low five-year survival rate makes an understanding of risk factors important in terms of both increased scrutiny of high-risk women/wāhine, and implementing whatever preventative actions are feasible.

The highest rates of ovarian cancer occur in postmenopausal women/wāhine, so age is one of the most significant non-modifiable risk factors for the disease.<sup>20, 21</sup>

Geographically, Dr Marliyya Zayyan writes that the highest incidence is "found among white females in Northern and Western Europe and in North America" but she makes particular note of the high incidence in New Zealand.<sup>21</sup>

Various studies show that approximately 20% of women with ovarian cancer carry one of the two BRCA gene mutations (BRCA1 and BRCA2), which are also responsible for a significantly increased risk of breast cancer. Sundar *et al.*, write that by the age of 70 the lifetime risk of ovarian cancer in women with a BRCA1 mutation is as much 85%, and in women with a BRCA2 mutation it is as much as 84%.<sup>20</sup>

However, the majority of cases of ovarian cancer have no known genetic link.

A woman's hormonal history has a significant impact on her risk, with the more ovulatory cycles a woman/wāhine has over her lifetime increasing



her risk, a concept referred to in some of the medical literature as 'incessant ovulation'. The hypothesis is that "that recurrent minor trauma caused to the ovarian epithelial surface as a result of ovulation increases the risk of malignant transformation."<sup>22</sup> Early menarche – especially under the age of 12, late menopause, infertility or no pregnancies, all increase the number of ovulatory cycles and thus raise the risk of ovarian cancer.

Conversely, anything that reduces the number of ovulatory cycles reduces the risk of ovarian cancer, including increasing numbers of pregnancies and live births, longer duration of breastfeeding, use of oral contraceptives, and late menarche and early menopause.<sup>20, 23, 24</sup>

A 2017 study that investigated rates of ovarian cancer in US and Australian women of European descent found that ovarian cancer rates were increasing until the generation of women who were the first to use The Pill. Incidence then declined dramatically "such that rates for the 1968 cohort [of women] were about half those of women born 45 years earlier.<sup>25</sup> However, the researchers found that "incidence rates are likely to stop falling and may even increase with changes in the prevalence of other factors such as tubal ligation and obesity."

Infertility – either because of the lack of pregnancies or because of the use of fertility drugs – has been associated with an increased risk of ovarian cancer, particularly those women who received fertility treatment but failed to conceive.<sup>21, 24</sup>

There is also evidence that there is a higher risk of ovarian cancer in those with endometriosis<sup>22</sup> and pelvic inflammatory disease.<sup>26</sup>

There are several modifiable risk factors for ovarian cancer, including obesity (especially in postmenopausal women), tobacco use in some subtypes of ovarian cancer, and use of hormone replacement therapy (HRT).<sup>20, 22, 26</sup> HRT is believed to enhance oestrogen-induced proliferation of ovarian cells and therefore increase risk, and the association was found in multiple studies using different HRT formulations (e.g. oestrogen alone, oestrogen and progesterone continuously, oestrogen and progesterone sequentially).<sup>22</sup> One study showed a 40% increase in ovarian cancer for HRT users (which amounts to one additional case of ovarian cancer for every 8300 users),<sup>27</sup> 60% of ovarian tumours have been found to be oestrogen-receptor positive.22

The authors of a 2022 'umbrella' review found "evidence that diabetes increases the risk of ovarian cancer incidence", and that the "use of metformin was found to have highly suggestive evidence for a lower ovarian cancer risk."<sup>22</sup>

From a dietary perspective, higher consumption of vegetables is associated with a reduced risk of ovarian cancer, while higher consumption of saturated fat increases risk.<sup>26</sup> Studies have also shown that vitamin D may offer a protective effect but the data is not conclusive at this time.<sup>26</sup> With regard to exercise and physical activity, studies have found "a nearly 20% lower risk for the most active women compared to the least active" and that "prolonged sedentary behaviour, high levels of total sitting duration, and chronic recreational physical inactivity have all been noted to increase risk."<sup>26</sup>

A more controversial risk factor, but one for which there is increasing scientific evidence, is the use of talcum powder. Epidemiological evidence indicates an association with talc use and increased risk of ovarian cancer.

A 2006 meta-analysis of 21 studies found an approximately 35% increase in risk with genital exposure to talc<sup>28</sup>, and this was subsequently confirmed in a 2016 study that found genital talc use was associated with an increased risk of 33%, with a trend for increasing risk with increasing number of years of use.<sup>29</sup>

#### Prevention

In their 2017 paper, researchers from the Moffitt Cancer Center in Florida, discuss the modifiable risk factors – personal lifestyle choices – that will make a practical difference to the chance that an average woman (with no known genetic risk factors) will develop ovarian cancer.<sup>26</sup> They suggest that women wanting to reduce their risk will have between two and four pregnancies\*, take oral contraceptives for between five and ten years\*, will forgo the use of hormone replacement therapy for menopausal symptoms and maintain her BMI at 24 or lower.<sup>26</sup> A woman aiming to reduce her risk would also breastfeed her babies, engage in regular physical exercise, and not smoke tobacco.<sup>26</sup>

In 2015, the Society of Gynecologic Oncology set out recommendations for preventing ovarian cancer:<sup>10</sup>

- oral contraceptive use;
- tubal sterilisation;

<sup>\*</sup> This author acknowledges that there are many other health and social factors to consider in make such lifestyle choices. This 'ideal' prevention strategy for ovarian cancer is based entirely on the evidence of risk factors not other health and social issues.

- risk-reducing salpingo-oophorectomy<sup>†</sup> in women at high hereditary risk of breast and ovarian cancer;
- genetic counselling and testing for women with ovarian cancer and other high-risk families;
- opportunistic salpingectomy after childbearing is complete (at the time of elective pelvic surgeries, at the time of hysterectomy, and as an alternative to tubal ligation) for non-high risk women.

## Screening for Ovarian Cancer

To date, screening for ovarian cancer is not viable. Unlike cervical screening, which can actually prevent the development of invasive cancer as well as pick up cancer early enough to cure it, studies into screening for ovarian cancer have failed to find any survival benefit.

A very large trial of 78,216 women aged 55 to 74 years investigated the feasibility of screening for ovarian cancer between 1993 and 2010.<sup>30</sup> Fifty percent of participants were assigned to undergo annual screening (CA-125 for six years and transvaginal ultrasound for four years), and 50% usual care, at 10 screening centers across the US. The usual care group was not offered annual screening with CA-125 or transvaginal ultrasound but received their usual medical care. Participants were followed up for a maximum of 13 years for cancer diagnoses and death until February 28, 2010.<sup>30</sup>

Ovarian cancer was diagnosed in 212 women in the intervention group and 176 in the usual care group; there were 118 deaths caused by ovarian cancer in the intervention group (56%) and 100 deaths (57%) in the usual care group. However, 3285 women received false-positive results and 1080 underwent surgical follow-up, of whom 163 women experienced at least one serious complication (15%).<sup>30</sup>

There was no statistically significant reduction in mortality from ovarian cancer as a result of the screening, yet there was significant harm caused to women who received false positives in the screening group. In addition, there was no benefit seen in stage shift – that is, diagnosis of ovarian cancer at an earlier stage that would typically result in better outcomes. In fact, the total number of advanced stage cancers was greater in the intervention group (163) than in the usual care group (137).<sup>30</sup>

The study researchers concluded that annual screening for ovarian cancer with simultaneous

CA-125 and transvaginal ultrasound does not reduce the death rate in women at average risk for ovarian cancer, but does increase invasive medical procedures and associated harms.<sup>30</sup>

Unfortunately, research into ovarian cancer screening since this large study has not yielded any more positive outcomes. Presentations at the 11<sup>th</sup> Biennial Ovarian Cancer Research Symposium in 2017 demonstrated that effective screening remains elusive.<sup>31</sup> More recently, another very large study, conducted in the UK and involving 202,638 women, came to similar conclusions as the US study, with no reduction in mortality as a result of screening. The UK researchers concluded that population screening for ovarian and tubal cancer for average-risk women using CA-125 testing and transvaginal ultrasound should not be undertaken.<sup>32</sup>

A study published in early 2024, which investigated a much smaller cohort of women (7,856) who were screened using the CA-125 blood test and transvaginal ultrasound, found a marked stage-shift with more cancer being detected earlier; however, this research did not investigate the impact on mortality from ovarian cancer.

Internationally, there are currently no recommended screening programmes.<sup>33, 34</sup>

## Ovarian Cancer in Aotearoa New Zealand

In Aotearoa New Zealand, ovarian cancer is the sixth most prevalent cancer among women/wāhine (behind breast cancer, colorectal cancer, lung cancer, melanoma and uterine cancer) and with similar rates to Non-Hodgkin Lymphoma.<sup>35, 36</sup>

However, the death rate from ovarian cancer is very high compared with other cancers; it competes with pancreatic cancer for 'honours' as the fourth biggest cancer killer in women/wāhine. Like ovarian cancer, pancreatic cancer has often metastasised by the time it is diagnosed.

From 1948 when data was first collected, through to the late 1990s, there was a steady increase in the number of ovarian cancer diagnoses.<sup>35</sup> From 2000 to 2021 there has been fluctuation in the rate of diagnoses per 100,00 women, but there was no significant increase in the incidence of ovarian cancer (see graph on page 15). Similarly, the death rate since 2000 has fluctuated but the overall change is very low, perhaps insignificant, with an increase of about 0.5 women/wāhine per 100,000.

However, the number of deaths does not provide the complete picture. What is as important in the context of ovarian cancer deaths is the mortality rate,

<sup>+</sup> surgical removal of fallopian tubes and ovaries.

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## Ovarian Cancer in New Zealand

- 1 woman is diagnosed every day
- 1 woman dies every 34 hours
- Ovarian cancer kills more women than all other gynaecological cancers combined
- There is no screening test for ovarian cancer - so it's essential to know the symptoms

[earn more] ovariancancerfoundation.org.nz

and these statistics are depressing. Only pancreatic cancer and lung cancer have a higher mortality rate. On absolute numbers, ovarian cancer claims fourth place, but based on the mortality rate, it is the third biggest cancer killer of women/wāhine. The number of deaths each year over the twenty years to 2018 (the last year for which cancer death data is available) expressed as a percentage of the number of new diagnoses in that year shows that only pancreatic (90%)\* and lung cancer (80%)\* have a higher average death rate in women/wāhine than ovarian cancer (66%).

It is important to note that this is a somewhat crude calculation because there is a variable delay between diagnosis and death, so the deaths in any given year are unlikely to be among those diagnosed in the same year; however, these figures give us a decent indication of the percentage mortality.

#### Age

From 2000 to 2021, we can see that incidence of ovarian cancer has remained relatively consistent across the various age groups over time; there have been no sudden changes in incidence, just relatively small variations from year to year (see graph on page 16). Incidence is consistently highest in perimenopausal and menopausal women (45-64), followed by women of 75 years and over. This latter group is significant as the number of women in this age groups, for example, in the 2018 census there were 170,604 women 75 years and over, while in the 45-64 year old age group there were 613,377.

Ovarian cancer is not common, but cannot be described as rare either, in the 25-44 year age group, with an average of 32 diagnoses in this group between 2012 and 2019. However, it is rare in the under 25s with an average of seven diagnoses per year.

Deaths are highest in the over 75 age group, followed by 45-64 years and 65-74 years. Death is rare in under 25s, with fewer than one death per year.

Deaths per 100,000 women/wāhine in each age group is a more accurate way of considering mortality, as the numbers of women/wāhine in each age group may vary considerably as the population ages. Age-standardised death rates show a steady increase in deaths per 100,000 women in each five year age



Ovarian cancer registrations and deaths from 1950 to 2021. Note: data for the decades 1950s to 1990s that data has been averaged over the decade; death data was only available from 1955 to 2018. Analysis of source data from Health New Zealand.<sup>35</sup>

Pancreatic and lung cancer data was derived from Te Whatu Ora's Cancer Web Tool<sup>48</sup>; ovarian cancer data was derived from Health New Zealand tables<sup>33</sup>.



group from 30 years of age up to 85+, with the death rate increasing more rapidly as the population ages.<sup>35</sup>

**Ovarian cancer registrations by age group 2000 to 2021.** Source: New Zealand Cancer Registry data provided as Excel tables of cancer registration and deaths numbers and rates for malignant neoplasm of the ovary and other uterine adnexa.<sup>35</sup>



**Ovarian cancer deaths by age group 2000 to 2021.** Source: New Zealand Cancer Registry data provided as Excel tables of cancer registration and deaths numbers and rates for malignant neoplasm of the ovary and other uterine adnexa.<sup>35</sup>

Age	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+
Average deaths per 100,000 women 2000 to 2018	1	1	3	5	11	15	22	29	40	44	58	69

Age-standardised death rates for ovarian cancer per 100,000 women in each age group from 30 to 85+ years from 2000 to 2018. Source: New Zealand Cancer Registry data provided as Excel tables of cancer registration and deaths numbers and rates for malignant neoplasm of the ovary and other uterine adnexa.<sup>35</sup>

### Ovarian Cancer in Wāhine Māori and Pāsifika

In research for this article, data provided by Health New Zealand,<sup>35</sup> data available on the online Cancer Web Tool,<sup>36</sup> and the medical literature, were consider -ed in order to gain an understanding of how wāhine Māori and Pāsifika are impacted by ovarian cancer.

It is difficult to obtain a clear picture of the impact of ovarian cancer on wāhine Māori and Pāsifika; that is whether or not incidence and mortality is significantly higher than for non-Māori, non-Pāsifika, or not. Data provided by Health New Zealand includes cancer of the ovary and other uterine adnexa – a wider category than just cancer of the ovary.<sup>35</sup> The data on incidence and mortality by ethnicity that is available on the Cancer Web Tool<sup>36</sup> includes only ovarian cancer but is provided over five-year periods rather than year by year.

The following two graphs provide incidence of, and deaths from, ovarian cancer by ethnicity per 100,000 women over the last fifteen years of data in periods of five years. Wāhine Pāsifika have the highest incidence of ovarian cancer and Asian women the lowest. This is consistent with the findings of researchers from the Centre for Public Health Research, Massey University, who analysed







Age standardised ovarian cancer deaths per 100,000 by ethnicity 2007 to 2021. Source: Cancer Web Tool.<sup>36</sup>

data on all women registered with ovarian cancer on the New Zealand Cancer Registry between 1993 and 2004, for a 2009 paper in the *Journal of Epidemiology and Community Health*.<sup>37</sup> They found that the incidence of ovarian cancer was highest in wāhine Pasifika, intermediate in wāhine Māori, and lowest in non-Māori, non-Pasifika women; mortality rates showed the same pattern. However, the more recent data available shows a more complicated pattern of mortality, with a significant decline in mortality from 2007-2011 to 2017-2021 according to the Cancer Web Tool<sup>36</sup>, with mortality for both wāhine Māori and Pāsifika dropping below that of European and other women in 2012-2016, only to rise slightly in 2017-2021.

Cleverly *et al.* found, in a 2023 paper in the *New Zealand Medical Journal*, that survival rates among wāhine Pāsifika were considerably better than European women at one year (Pāsifika 74% vs European 67%), three years (54% vs 42%) and five years (48 vs 33%).<sup>38</sup> Sadly, five-year survival is appallingly low for both Pāsifika and European women.

Jefferys *et al.*, wrote in a 2005 paper that there was improved five-year survival rates among wāhine Māori (60%) and Pāsifika (51%) compared to non-Māori/non-Pāsifika women (42%).<sup>39</sup> They concluded that the "apparent survival advantage among Māori for ovarian cancer was fully explained by stage at diagnosis," that is, that Māori were being diagnosed earlier, leading to better outcomes.

They did not offer any explanation for why wāhine Māori might be diagnosed earlier, especially as they did point out the inequities faced by Māori in accessing health care "and that Māori are medically under-served in New Zealand", factors which one would assume would disadvantage early diagnosis among Māori and therefore reduce survival rates. However, they did suggest that "[s]elective migration of terminally ill Pacific cancer patients to the Pacific would artificially inflate their survival rate [in New Zealand]," which may explain some of their results.

While a 2020 paper by Gurney *et al.*, found that wāhine Māori with ovarian cancer are 62% percent more likely to die than non-Māori women<sup>40</sup> this may be strongly influenced by the much lower mortality rate among Asian women. When compared with the mortality rate of New Zealand European and other women (MELAA\*), the data provided by the Cancer Web Tool shows that between 2007 and 2021, Māori mortality was only 14% higher in the years 2007-2011, 12% lower in the years 2012-2016, and 28% higher

\* Middle Eastern/Latin American/African

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in the years 2017-2021, than mortality in women of New Zealand European and MELAA ethnicity.<sup>36</sup>

	2007-2011	2012-2016	2017-2021
Asian	2.25	2.46	2.24
Māori	6.77	4.33	4.77
Pāsifika	6.41	4.83	4.89
NZ European and Other	5.95	4.91	3.72

*Mortality rates for ovarian cancer per 100,000 of population in Asian, Māori, Pāsifika, and NZ European and other ethnicities from 2007-2021.* Source: Cancer Web Tool.<sup>36</sup>

The researchers from Massey University's Centre for Public Health Research,<sup>37</sup> found that there was no significant association between socioeconomic deprivation and tumour grade or stage. Wāhine Māori were more likely to be diagnosed earlier and seemed to have better prognostic factors. The average age at diagnosis was also lower in wāhine Pāsifika and Māori.

Some research suggests that while ovarian cancer incidence increases with age among women of European/Caucasian descent, women from non-European ethnicities may have higher incidence at younger ages.<sup>21</sup> A review of the data from Health New Zealand tables<sup>36</sup> for numbers of new diagnoses appears to show a trend consistent with those findings.

However, when the age standardised rates per 100,000 women are considered, it seems that the rates are indeed much higher for wahine Maori in the older age groups; it is simply that the number of women between 64 and 74, and over 75 years of age are much smaller than the general population; life expectancy for wahine Maori women is lower than for all other ethnicities in Aotearoa New Zealand.41 For example, for every 100,000 Māori girls born, at age 65 on average only 82,892 will still be alive compared with 93,327 women of European descent. At age 75 the average is 63,617 and 84,425 respectively and at 85 years it is 33,483 for Māori and 59,409 for women of European descent.<sup>42</sup> The preponderance of diagnoses in younger wahine Māori may well be simply because more wāhine die before they reach old age when the risk of ovarian cancer is highest.

From to 1998 to 2018 the mortality rate in wāhine Māori was about 53%. Again, this is a crude indicator of the mortality rate as there is a variable delay between diagnosis and death, so the deaths in any given year are unlikely to be among those diagnosed in the same year.

#### Prognoses and Progress

A 2019 study found that compared with six other high-income countries (Denmark, Norway, Australia, UK, Ireland and Canada) New Zealand made poorer progress in cancer control (i.e. increased survival, decreased mortality and incidence) in ovarian cancer than all of the other study nations.<sup>43</sup>

Between 1995 and 2014, we had the lowest increase in five-year ovarian cancer survival at only a 4.4% increase in survival across all age groups, compared with the highest achievers Canada (10.2% increase in survival), the UK (9.8%) and Norway (9.2%).<sup>43</sup> We performed a little better in women under 75 years with a 5.9% increase in five-year survival (UK 12%; Denmark 11.2%; Ireland 11.1%). However, we went backwards in women over 75 with a 0.9% reduction in five-year survival between 1995 and 2014. Only Canada did worse at -2.7%, while all other countries improved survival in elderly women.<sup>43</sup>

Five-year survival rates for ovarian cancer in New Zealand women/wāhine under 75 hovers around 40%, while it is only about 16-18% for over 75s; most of the other countries have seen a steady increase to, or close to, 50% survival at five years for those under  $75.^{43}$ 

Aotearoa New Zealand lags behind other comparable countries in improving outcomes for women/ wāhine with ovarian cancer in four major areas:<sup>3</sup>

- Preventable delays in ovarian cancer diagnosis: there needs to be greater awareness among both women/wāhine and GPs about the symptoms of ovarian cancer (as discussed in Ovarian Cancer: Types, Diagnosis, Treatment on page 10 and Late Diagnosis on page 11).
- **Better treatment:** while many ovarian cancers cannot be cured, improved treatments and more funded treatments would increase survival. There are multiple drug treatments for different types of ovarian cancer funded in the UK and/ or Australia that are not funded in Aotearoa New Zealand, including Niraparib, Olaparib, Rucaparib, Bevacizumab, Caelyx, and Trametinib. Some women pay privately for access to these drugs; those without the financial capability to pay privately go without.
- Limited clinical trials in which Aotearoa New Zealand women/wāhine are able to participate: the National Ovarian Cancer Report reveals that there are only five clinical trials running in this country compared with 45 trials in Australia meaning that few New Zealanders have access to the most up to date treatments.<sup>3</sup>
- Lack of research both here and internationally: while ovarian cancer is the leading cause of

gynaecological cancer death, research is disproportionately under-funded in Aotearoa New Zealand and overseas, but research funding is worse off here than elsewhere. Since 2011, Australia has invested AUS\$71 million in ovarian cancer research<sup>44</sup> while during the same period, through the Health Research Council, Aotearoa New Zealand invested a total of \$18,000 in ovarian cancer-specific research.<sup>3</sup> A 2021 Te Aho o Te Kahu report found that research into ovarian cancer was significantly underfunded in Aotearoa New Zealand relative to its mortality rate compared with other cancers, such as breast, cervical and uterine cancer.<sup>45</sup>

Since the publication of the *National Ovarian Cancer Report* in 2022, the Health Research Council has approved funding of almost \$850,000 for research into new drug therapies for ovarian cancers,<sup>46, 47</sup> still millions of dollars short of the Australian research investment even allowing for the five times greater population.

## The Ovarian Cancer Foundation Petition to Parliament

Jane Ludeman was diagnosed in 2017 with low-grade serous ovarian cancer — a rare and poorly survivable form. In 2021, she presented a 7000+ signature petition to Parliament calling for national diagnostic guidelines for ovarian cancer to be developed, better



treatment options, and more government funding. At the time, a survey undertaken by Cure Our Ovarian Cancer found that "90 percent of women could not name a single symptom of ovarian cancer before their diagnosis and most experienced significant difficulties in accessing the blood test and ultrasound required to find their cancer."<sup>48</sup>

Jane Ludemann requested the support of the AWHC for their submissions to the Health Select Committee and sent us the Cure Our Ovarian Cancer National Ovarian Cancer Report.<sup>3</sup> The *Report* paints a disturbing and depressing picture of the situation for women/wahine who develop ovarian cancer in this country. While there have been public awareness campaigns and screening programmes for breast and cervical cancer, awareness of ovarian cancer has barely seeped into the consciousness of the majority of New Zealanders. Twenty-five years of sufficient resourcing, awareness raising and a public screening programme for cervical cancer has resulted in a significant decline in the incidence of, and importantly, mortality from cervical cancer. Sadly, the same cannot be said for ovarian cancer, and as a result more than four times as many women die each year from this disease.

Researchers have identified a set of physical complaints that often occur in women who have ovarian cancer and may be early warning signs. While these symptoms are also common to other conditions, researchers believe that greater awareness will lead to earlier diagnosis and treatment, therefore reduced mortality.

All too often women presenting to their doctor with physical symptoms are fobbed off or diagnosed with functional or somatic disorders. Many common diseases and conditions take far too long to be diagnosed resulting in morbidity, disability, loss of quality of life, and in the case of diseases like ovarian cancer, a premature death. In a UK survey, 8% of women presenting with symptoms of ovarian cancer were told by their GP that their symptoms might be related to their mental health.<sup>49</sup> Another study found that diagnosis was impacted by "physicians' stereotypes, prejudices and their preconceived notions regarding women."<sup>14</sup>

We are far from a situation in which all women in this country have accessible, affordable, available, and culturally appropriate and acceptable healthcare. For women/wāhine who are Māori, Pāsifika, disabled or members of the LGBTQI+ community, the barriers

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and discrimination they face are multiplied. The statis-tics that Cure Our Ovarian Cancer present on ovarian cancer epitomise these issues.

The burden of undiagnosed, untreated ovarian cancer does not just fall on the woman who suffers considerable loss of quality of life and an avoidably premature death, but on their family/whānau and community. In addition, there is the loss of productive years, and a calculable burden on our health system when a woman/wāhine is diagnosed with advanced ovarian cancer.

In July 2023, the Ovarian Cancer Foundation NZ made an oral submission to the Parliamentary Health Select Committee and the Committee's report was published in August 2023.<sup>50</sup> The report acknowledged there are issues with the diagnosis, treatment and research of ovarian cancer. In the report, the Health Select Committee made the following two recommendations:

- that ovarian cancer and uterine cancer symptoms education be included in the National Cervical Screening Programme, and they strongly encouraged Te Whatu Ora Health | New Zealand to investigate this as a possibility.
- that Te Aho o Te Kahu (Cancer Control Agency) work with other agencies to explore how they can measure the effectiveness of detection, diagnosis and treatments in ovarian cancer.

The Ovarian Cancer Foundation NZ have requested a meeting with the Minister of Health, Dr Shane Reti, to determine the next steps, and are hopeful t hat Aotearoa New Zealand will become the first country in the world to implement gynaecological cancer symptoms education into the National Cervical Screening Programme.

There will always be deaths from ovarian cancer, but if this disease is prioritised the way the cervical cancer has been, Aotearoa New Zealand could see a substantial increase in the numbers of women/wāhine living longer than five years after diagnosis.

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## Annual General Meeting

The Auckland's Women's Health Council AGM will be held at **6.30 pm** on Wednesday the 1st of May 2024 at the AUT Northern Campus, Akoranga Drive, Northcote.

If you are interested in attending the AGM please RSVP by email to receive further details and directions for the venue.

awhc@womenshealthcouncil.org.nz

# **Free Period Products in Schools to Continue**

In February 2021, the then Labour Government announced the roll out of free period products in more than 1,600 schools and kura across Aotearoa New Zealand from June that year.

At the time, then Prime Minister, Jacinda Ardern, said "Young people should not miss out on their education because of something that is a normal part of life for half the population."<sup>1</sup>

"Removing barriers to healthy, active, educational outcomes for children and young people is an important part of the Government's Youth and Wellbeing Strategy."

The Government's commitment to providing free period products in schools was, in no small part, the result of lobbying by former AWHC Committee member and The Period Place Co-founder, Danika Revell, among other campaigners on period poverty.

The previous year, Danika, along with women from other organisations fighting period poverty, met with Jacinda Ardern and then Minister for Women, Julie Anne Genter, to advocate for period equity and ensure that students with periods no longer have to miss school because they can't afford period products.<sup>2, 3</sup>

At the time, research had found that 12 % of students in Years 9 to 13 who menstruate reported difficulty getting access to products due to cost and that one in 12 girls had missed school during their periods because they didn't have access to period products.<sup>4</sup>

With the change in Government and the National Party intent on repealing many pieces of legislation and reducing or removing funding for a number of the previous Labour Government's initiatives, there was a real fear in February that the free period products in schools would be a thing of the past.

Funding for free period products had only been guaranteed until June this year, as the Labour Government had committed around \$25 million on the initiative over three years.<sup>5</sup> In January this year, Education Minister Erica Stanford said any announcements on funding decisions for period products in schools would be made as part of this year's Budget, and would not say if the initiative was one the Government would like to continue.<sup>6</sup>



Period poverty campaigners discussing period equity and free period products in schools with then Prime Minister, Jacinda Ardern, and Minister for Women, Julie Anne Genter, in June 2020.



A Ministry of Education survey of the 2165 schools participating in the free period products programme found that "of the 119 secondary schools that responded, 45% said the access to period products reduced barriers to attendance, while 28% reported increased participation in sports, physical education or cultural activities."<sup>6</sup>

"Schools said the scheme had also had a significant positive impact on the well-being of students and their whānau."

"Nearly half of schools (49%) reported improved student well-being, while 71% reported whānau were benefitting from reduced expenses. Fiftynine per cent of schools reported reduced stigma around periods, too."<sup>6</sup>

So, it has been a huge relief to schools, students, whānau and those campaigning to end period poverty in Aotearoa New Zealand, that the Coalition Government has announced well ahead of the May Budget, that it has put aside \$2.9 million to continue providing period products in schools.<sup>7</sup>

In making the announcement Erica Stanford said "This is an issue of dignity and ensuring young women don't have to miss out on school because of something as simple as having access to period products."<sup>1</sup>

The University of Otago has estimated that up to 95,000 young New Zealand women could be missing school because of a lack of access to period products.

"All primary, intermediate, kura and secondary schools will continue to be able opt-in to the scheme, which will continue to benefit around 200,000 students," Ms Stanford said.<sup>1</sup>

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In a press release welcoming the Government's commitment to free period products, at least in the short term, Danika Revell says that <u>The Period Place</u> estimates that "each month 70,000 individuals experience the most severe period inequity in Aotearoa."<sup>8</sup>

"Addressing this requires \$4.2 million worth of period products to meet basic menstrual health needs over the same timeframe. This does not take into account individuals experiencing their menstrual cycle outside of the 'normal' range, nor does it cover any further associated costs for a menstrual cycle (such as overnight pads, pain

relief, purchasing of underwear or clothes to replace stained ones, etc.)."8

Revell also talks about the lack of knowledge about periods, the stigma around non-binary and trans individuals who also have menstrual cycles, normalising conversations about periods and ensuring age-appropriate menstrual health education is provided to everybody, whether they get a period or not.

She says that "while commendable, the school programme is one step forward in the journey to eliminating period poverty and period inequity in Aotearoa. Achieving this requires a shared commitment from all sectors of society alongside govern-ment, including businesses, healthcare providers, educational institutions, community groups, and individuals."<sup>8</sup>

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By Sue Claridge

The 8<sup>th</sup> of March every year is International Women's Day. It is the one day a year that aims to focus global attention on the state of women when it comes to gender equality, bias, stereotypes and discrimination.

Increasingly over the last few years, businesses and organisations in Aotearoa New Zealand have sought to celebrate International Women's Day, often by celebrating specific women or groups of women. To be honest, some of those public "celebrations" are a bit cringey and "mansplain-y".

For example, when Fonterra announced an all-male panel for a talk about "breaking the bias" as part of its International Women's Day celebrations.

Or when New Zealand Rugby Tweeted "Forever grateful to all the women in our lives that allow us to play the game we love. Partners, mothers, daughters, doctors, physios, referees, administrators and fans. Appreciate you every day #IWD2022 #internationalwomensday".

Completely forgetting to mention our five-time World Cup Winning Black Ferns! (And yes, that's more times than the men.)

At least when Fonterra and New Zealand Rugby were schooled in the error of their ways by outraged women/wāhine and men/tane, they responded — Fonterra changed the make up of their panel to two women and one man, and New Zealand Rugby took down the tweet and apologised.

However, what could possibly be better than women celebrating women?

Auckland Women's Health Council wants to celebrate Aotearoa New Zealand's wāhine toa all the time, not just on the 8<sup>th</sup> of March each year. There are so many women/wāhine around the motu who are making huge contributions to women's health. Every. Single. Day.

Some of them are women/wāhine who get little to no publicity, recognition or celebration of their contribution, commitment and dedication. Some of them are women/wāhine who are well known in the small circles they work in, and some are names many, if not all, our readers will be familiar with.

We are also all too aware that so much of what is published in our *Newsletter* is depressing, frustrating, angry and reactive. Who can blame us? There is a lot of talk out there in our health system and among our policy makers, law makers, MPs but not enough action... not anywhere near enough action! The inequity, bias and discrimination in women's health that has been around for centuries continues.

So, we want at least one small corner of the *Newsletter* to be a celebration of the women/wāhine in Aotearoa New Zealand who are doing their best to improve women's health and well-being, every edition, starting with this one.

## Sally Walker

I am writing this piece the morning after the Kiwibank New Zealander of the Year | Ngā Tohu Pou Kōhure o Aotearoa awards gala, held on the 27<sup>th</sup> of March; a black-tie, fancy schmancy awards gala that saw <u>Sally</u> <u>Walker win the New Zealand Local Hero award</u>.

In November 2023, 100 Local Hero Medallists were announced, Sally among them. On the 5<sup>th</sup> of March 2024 she was announced as one of 21 finalists across seven categories, and last night she won the Local Hero award!

#### Her nomination read:

"Sally Walker is an inspiring and dedicated advocate for women, whose remarkable efforts have driven fundamental changes in the health care sector by raising awareness around the impact of severe surgical mesh injuries. Having faced enormous, significant complications from her own surgical mesh implants, Sally has effectively influenced health professionals, government entities, and NGOs to prioritise patient safety and wellbeing. Her courage in sharing her personal journey has helped prevent others from enduring similar experiences. In addition to her advocacy work, Sally voluntarily manages a health and disability support network comprising 92 women who, like her, have faced similar challenges. Sally's relentless determination and the positive impact she has had on patient care have earned her numerous accolades. Notably, in August 2023, it was announced that all mesh surgeries in Aotearoa New Zealand would be halted because of safety concerns. Sally's impactful work continues to leave its mark, resonating with women worldwide who seek her guidance and assistance."

This is not the first award Sally has received for her advocacy for those injured by surgical mesh. In 2023 she was awarded the Urological Society of Australia and New Zealand (USANZ) New Zealand Urology Contribution Award.

In presenting the award, President of the New Zealand section of USANZ, Dr Leanne Shaw spoke about Sally providing "incredible consumer support and advocacy to patients undergoing cystectomy, as well



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as consumers with mesh complications. She supports them by telephone and in person and shares her own story. She visits their homes ... [and] supports them and visits them in hospital postoperatively. She does this as a voluntary service —she has no affiliation with any advocacy group".

Sally was also the recipient of Today FM Hero of the year Award in 2022.

In 2022, Sally submitted a petition to Parliament asking the Government to suspend the implantation of vaginally-inserted surgical mesh for stress urinary incontinence. A year later, and with the support of other mesh injured women/wāhine, and women's health organisations, Sally finally realised what she set out to achieve with her petition. In August 2023, the Director General of Health, Dr Diana Sarfati, announced that surgical mesh procedures for stress urinary incontinence would be suspended in Aotearoa New Zealand until a number of planned measures to reduce harm, including the credentialling of surgeons, were put in place.

Sally has achieved all this despite living with the devastating impacts of mesh injury. She was seriously injured by a surgical mesh procedure for urinary incontinence and prolapse. Her surgeon didn't tell her about the risks or the alternatives. Since the mesh surgery she has had multiple operations, has had to have her bladder removed, her vagina sewn shut and she lives with chronic pain and disability. You can read more about her personal journey with mesh <u>here</u>.

Celebrating Sally Walker – one of Aotearoa New Zealand's wāhine toa!



## **Worthy Causes – Current Petitions**

## Inquire into the Essure Contraceptive Device Recall and Compensate Women Harmed

Catrina McGregor has launched a <u>Parliamentary</u> <u>petition</u> asking the Government to initiate a full investigation into the promotion, funding, distribution and prescription of all Essure devices for New Zealand women; find, contact, and advise women who received these devices that they have been recalled; and offer full ACC coverage for any Essure-related care they may require.

In providing a reason for the petition, Catrina says:

"Essure devices are permanent contraceptive implants\*, recalled worldwide after women internationally suffered complications that I believe were catastrophic, life-threatening, and life-altering and included hysterectomies, agonising pain, bleeding, hair and tooth loss, and crippling immune system disorders, among other ill effects. While Essure has been recalled in New Zealand, women who received it have not been notified of the updated risks and ACC deny coverage for most Essurerelated care."

Many women/wāhine who had Essure implanted and have ongoing health issues may not realise that their symptoms are linked to the Essure device. Despite the device being withdrawn and Medsafe issuing a directive that gynaecologists and physicians monitor patients<sup>1</sup>, there is no evidence that any of the gynaecologists or physicians who implanted the devices have monitored or communicated with affected women at all.

The harm inflicted on many thousands of women by Essure worldwide makes painful reading. The devastating impacts of these devices was heavily featured in the documentary *The Bleeding Edge*<sup>2</sup>, and many women in Aotearoa New Zealand continue to suffer from the life changing harm that this device has caused them. Essure has featured in our *Newsletter* several times, most recently in the <u>November 2023 edition</u>, and these articles have been compiled into an <u>Essure page</u> under Health Topics on our website, including the personal stories of five women/wāhine.

It is simply not good enough that many women/ wāhine who have suffered the devastating impacts



of Essure have been left in the dark, on their own, with no accountability or even concern shown by their doctors. It is simply not good enough that the Government and health agencies in this country have not followed-up with women/ wāhine who had Essure implanted and advised them of the risks that the devices poses. They must do more to ensure that women/wāhine suffering the health impacts of this device are monitored and provided with the care they need, including in many cases Government/ACC funded surgery to remove the devices.

Support the women/wāhine living everyday with the harm caused by Essure – <u>sign Catrina McGregor's</u> <u>petition</u> that demands action on behalf of those women. The petition closes on the  $31^{st}$  of May 2024.

## References

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- 2. <u>Reviewed in the November 2023 AWHC Newsletter</u>

<sup>\*</sup> When correctly implanted the Essure devices sit in the fallopian tubes not the uterus.

## Stop the cuts - protect our free school lunches!

Sign the petition to save our school lunches

SIGN HERE

Many tamariki in Aotearoa New Zealand will go hungry!

The coalition Government plans to cut funding to Ka Ora, Ka Ako – a programme that aims to reduce food insecurity by providing access to a nutritious lunch every day.

"The name Ka Ora, Ka Ako is about being healthy and well in order to be in a good place to learn."<sup>1</sup>

Research indicates that reducing food insecurity for children and young people:

- improves well-being,
- supports child development and learning,
- improves learners' levels of concentration, behaviour and school achievement,
- reduces financial hardship amongst families and whānau,
- addresses barriers to children's participation in education and promotes attendance at school,
- boosts learners' overall health.

It is a no-brainer that hungry children won't learn as well — do as well — at school as those who have adequate healthy food to eat to fuel their growing bodies and minds. For whatever reason a child may go to school hungry or with no lunch, it is not their fault.

Around a million lunches are provided each week; in September 2023, lunches were provided to over 230,000 learners in 998 schools and kura.

Health Coalition Aotearoa (HCA), of which AWHC are members, <u>have launched a petition</u> calling on the Government NOT to cut the free school lunches programme.

Associate Education Minister and ACT leader, David Seymour, is reviewing the free school lunches programme ahead of Budget 2024 in May and has stated he wants to cut the programme by up to 50 per cent.

HCA co-chairs, Professor Boyd Swinburn and

Professor Lisa Te Moregna, say that Seymour's plan "would be outrageously mean and a complete tragedy as Ka Ora, Ka Ako is a crucial safety net for students from the growing problems of food poverty and poor nutrition."

In fact, HCA believe that the programme needs to be expanded to reach more children.

Research from the Program for International Student Achievement shows that students who miss meals due to lack of money are two to four years behind their peers who never miss meals, in educational achievement.<sup>2</sup>

The provision of lunches to students has helped families financially and reduced their food bill and encouraged children to make healthier food choices,<sup>3</sup> and has reduced the number of children/rangatahi who have to work to help their family pay for the basics.<sup>4</sup>

Find out more about the HCA petition here, or sign the petition on Our Action Station here.

The petition closes in early April and the HCA are aiming for 100,000 signatures. At the time of going to press the petition had 25,286 signatures.

Delays to publication of the *Newsletter* have resulted in very limited time in which to add your signature, so if you would like to support this, <u>please do it now</u>!

## References

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- 2. McKelvie-Sibeleau P and Swinburn B, 2024: Food poverty for NZ teens creating an achievement lag of up to four years, The Briefing, Public Health Communication Centre Aotearoa.
- 3. McKelvie-Sibeleau P et al., 2023: Health, wellbeing and nutritional impacts after 2 years of free school meals in New Zealand, Health Promotion International, Volume 38, Issue 4, August 2023.
- 4. TVNZ, 2024: 'No doubt' free lunches programme has helped results principal, OneNews, 5 March 2024.