



2023 Annual Report





Reflecting on 2023...

In our last annual, report written in April 2023, we commented on the state of the nation's health system, noting that it "is in crisis and our health workforce is under significant stress."

In the year since, the health system crisis has deepened, and the political landscape has changed dramatically. We addressed these issues in an article in our November 2023 Newsletter, discussing the health system reforms and where we were then, more than a year on from the passing of the Pae Ora (Healthy Futures) Act. We had:

- A 'new' health system that is not functional, equitable or whole.
- A 'new' half-renovated health system that is worse than what we already had.
- A health system, parts of which the National Party has said it will dismantle as well as rescinding some of the legislation that underpins it.

Since last November, the National-led coalition Government has disestablished Te Aka Whai Ora — the Māori Health Authority — without having given it a chance to address the intrenched disparities and inequities in Māori health and health outcomes. The concept of "by Māori for Māori" has been thrown out under the guise of "unifying" the country.

We are losing qualified health practitioners, particularly nurses, in droves and primary health care is so strained and "under the pump" that many New Zealanders have to wait weeks for appointments with GPs, and have no continuity of care as they see a different GP every time. Increasing numbers of New Zealanders are forced to attend hospital emergency departments because they can't access primary health care in a timely manner.

In our last report, we said that "Never has the ability of people to take responsibility for their own health and well-being been so important."

Not only has there been no improvement, but this observation becomes more pertinent as every week passes.

The pressure on the health system, and the uncertainty, inadequacies and failures that very many health consumers are experiencing within it, have increased the importance of NGOs such as the AWHC.

The consumer voice, consumer representation and advocacy have never been so important... and we know that it works, even if only in very slow, incremental ways. Health consumer/patient rights remain an issue and cultural changes in the system and among health professionals are also slow to change. New Zealanders need help and support, and access to quality independent, evidence-based information now as much as at any time in the past.

Since 1988, Auckland Women's Health Council has provided a strong voice on women's health issues for the greater Auckland region, and has been actively involved at a national level. It is tragic that our organisation is not only still needed, but that the issues that led to its foundation continue to be raised, often in barely changed forms, more than 35 years on.

A highlight of our year has been effective collaboration with some of our closest allies that has led to change, in particular calls for a suspension of mesh procedures for stress urinary incontinence. The value of our networks with other NGOs working to improve the experience of health consumers has been reinforced. We are committed to expanding those connections with others who are working towards ensuring that barriers to accessing affordable and available, as well as culturally appropriate, acceptable and beneficial health services are removed for our women/wāhine.

We remain a voice for women, and a voice for change.

Vision

All women/wāhine in Tāmaki Makaurau and across Aotearoa New Zealand have agency over their physical, mental, emotional and spiritual well-being and are fully informed of health services available and have access to them, particularly wāhine Māori.

Goal

To provide an independent feminist voice focused on women's/family health and health services in Tāmaki Makaurau.

The Council achieves its goal by:

 Contributing gender, women's health and consumer perspectives to the development of policies, including legislation, at a regional and national level.

• Collaborating with other appropriate entities.

 Ensuring consumer representation on appropriate policy advice and working groups, committees, etc.

 Maintaining a watching brief over changes to the health system and issues that affect women/wahine and their families/whānau as they arise.

• Disseminating evidence-based information using a range of media and forums.

Priorities

That the Council works towards becoming Tangata
 Tiriti as an organisation: to understand our re sponsibilities as a good Treaty partner; and to
 stand with tangata whenua in their language rights,
 their health rights, for the rights of their tamariki
 and wāhine. To find ways to honour the articles of
 Te Tiriti.



• That women/wāhine have the right to make informed decisions regarding their own health care and treatment.

• That women/wāhine participate in all decision-making processes for health care services.

• That women/wāhine have accessible, affordable, available, accountable and culturally appropriate health care services.

 That the work of the Council continues to be sustainable and to grow.

• Increasing our links and collaborations with other women's health related organisations.



Our Work

Newsletters

The Newsletter is an important link with women throughout the country, our collaborators (such as the Cartwright Collective, Federation of Women's Health Councils and Health Consumer Advocacy Alliance), other women's groups, several journalists and MPs, and a small number of academics and professionals in the health and disability sector.

The newsletters are freely available on the website and people can subscribe free of charge and have the Newsletters sent to their email inbox as soon as they are published. In the last year we have continued to produce a low vision accessible version of the Newsletter (posted on the website) with plans to extend the reach of the Newsletter to women living with disabilities.

The Council continues to receive very positive feedback on the Newsletter, including feedback from academics and students in the health sector, as well as readers who are consumers and consumer/patient advocates. Feedback has included women who have felt better able to make informed decisions about their health care and treatment and who feel able to share their stories and experiences in health.

In 2022, we published four *Newsletters* and these • the health system crisis and mismanagement included researched articles on:

- the Therapeutic Products Act;
- the Women's Health Strategy;
- the Five 'I's Framework; a consumer-centred co-designed health system;
- the lifelong health impacts of childhood poverty;
- how women's health is disproportionately impacted by pandemics and climate change;



- living with pelvic organ prolapse;
- continuing criticism of the Cartwright Inquiry;
- cervical and breast screening and the National Screening Unit;
- surgical mesh and work to have mesh procedures for stress urinary incontinence suspended;
- the harm caused by the Essure contraceptive device and a review of The Bleeding Edge documentary on medical devices;
- of health reforms;
- why the beauty industry is a women's health issue; and work on regulating professional skin therapists and have them placed under the Health Practitioners Competence Assurance Act to ensure client safety;
- medical injury, harm experienced by consumers in the health system and the Health Consumer Advocacy Alliance's report into the risk of harm in Aoteroa New Zealand.

Submissions

Making submissions on proposed legislation or legislative amendments, and other health related matters, continues to be some of our most important work. Submissions have a direct influence on health sector policy in Aotearoa New Zealand. For example, in our written and oral submissions on the Pae Ora (Healthy Futures) Bill we argued strongly for the inclusion of a women's health strategy and rural health strategy; it was hugely gratifying that the Government agreed with us, and other submitters, and added these two strategies to sit alongside the planned Māori, Pāsifika and disability strategies. Our submissions often have an impact beyond immediate changes in policy and legislation, and have been cited in reports and academic papers.

In the last year we have made the following submissions:

 written and oral submissions on the Therapeutic Products Bill (March);

- early input submission review of the Health and Disability Commissioner Act and Code of Health and Disability Services Consumers' Rights (March);
- written submission on the Women's Health Strategy (March);
- written submission on the Medical Council consultation on the Regulation of Physician Associates (July);
- review of and written support for the Health Coalition Aotearoa Prevention Brief (June).

On each occasion that oral submissions were offered we have been invited to present to select committees. Feedback from select committee members has been very positive and we have been commended on the quality of both our written and oral submissions.

From our submission on the Women's Health Strategy...

The Aotearoa New Zealand women's health strategy MUST focus on more than sexual and reproductive health. It MUST focus on the leading causes of loss of quality of life, death and disability for women and the factors that influence women's health.

The global discourse on health largely views women in terms of their reproductive capacity, a persisting myth reflecting gender bias that shifts the focus away from non-communicable diseases, violence, and other injuries. For example, gender bias results in women being asked fewer questions, and receiving fewer examinations and fewer diagnostic tests for coronary heart disease and other non-communicable diseases compared with men with similar symptoms.

Frustratingly this is an all too familiar issue in women's health; women are ignored or invisible, misunderstood and misdiagnosed. As a priority, the Expert Advisory Committee on Public Health must include gender experts, advisors in women's health and well-being, and lived experience consumers to ensure that this will no longer be the case in Aotearoa New Zealand.



Our Work

Advocacy and the Consumer Voice

Advocacy and consumer representation remains a vital aspect of our work. While submissions are a really important means of representing women on health issues, there are equally as important ways in which we ensure women's voices are heard and responded to. We continue to work in a collaborative way with other women's health organisations making our collective advocacy and voices all the more powerful.

In 2023, the power of advocacy and collaboration was epitomised by our joint work with three other non-profit organisations working for health consumers.

In July, we joined forces with the Health Consumer Advocacy Alliance, Federation of Women's Health Councils and Cartwright Collective, to demand that the Government and Ministry of Health | Manatū Hauora show some leadership and do what is necessary to stop the ongoing harm to hundreds of women/wāhine from surgical mesh procedures. We wrote a joint letter to the Director General of Health, Dr Diana Sarfati, asking her to impose an immediate suspension of surgical mesh procedures for stress urinary incontinence, at least until the considerable problems with the use of surgical mesh and the catastrophic harm that it can cause, are properly and adequately addressed.

We followed this up with a joint media release pointing out that the Government has the

legislative means to protect women from further harm from mesh procedures. We called on the Ministry of Health to take strong and decisive action to protect the lives and health of New Zealand women, and impose an immediate suspension of surgical mesh procedures for stress urinary incontinence.

In August, the combined lobbying of injured women, in particular Sally Walker and her Parliamentary petition, and the impact of our joint letter led to a suspension of surgical mesh procedures stress urinary incontinence at least until a number of planned measures to reduce harm, including the credentialling of surgeons, are put in place.

In 2023, we maintained our membership of the Health Coalition Aotearoa and Consumer Health Forum Aotearoa, and are represented on the Health Consumer Advocacy Alliance (HCAA) through our Communications Manager, Sue Claridge. All of these 'memberships' enable us to amplify our voice to ensure that women's health not only stays on the agenda, but that barriers to accessible, affordable, available, equitable, accountable and safe health care services for women are addressed.

We continue to provide one-on-one assistance to individuals who contact us for a variety of

reasons. These include seeking advice or information on personal health issues or where to seek help, journalists wanting information and comment, and occasional requests from students and health professionals requesting material or information.

Our *Newsletter* also provides a valuable forum for women to tell their stories. The sharing of

experiences with specific diseases and conditions, and in accessing health care services and treatment are vital in ensuring women do not feel alone and isolated in the health issues that they face, and in enabling other women to make more informed choices about their health and health care.

Amanda's Story

Published in the November 2023 Newsletter

"I am angry, frustrated and tired, and wish I had never ever heard of Essure. I really, really want my life back."

"I had the Essure contraceptive coils inserted in June 2013. I didn't want any more children and I asked about tubal ligation, but was advised that there was an extremely long waitlist. However, I was offered a new, nonsurgical, safe, quick and easy procedure. That day in hospital was the start of my decade long nightmare.

The procedure went well enough, and I had a small amount of bleeding and some abdominal pain for a few days, both of which had been expected. At my threemonth hysterosalpingogram it was confirmed that tubal occlusion had occurred; I could stop taking the pill and get on with life. Fabulous!

Little did I know that, within a few years, I would be living in a haze of brain fog and dealing with chronic abdominal and vaginal pain, not to mention horrendously sore breasts. What started as a great sex life, deteriorated to the point where there has been no intimacy for more than two years now. My periods go for weeks and are so heavy and clotty, sometimes I cannot even leave the house for fear it is going to flood everywhere, which has happened.

More recently I have been diagnosed with autoimmune conditions, including POTS (postural orthostatic tachycardia), Raynaud's and Sjogren's syndrome. Along with the constant pain and severe fatigue, I deal with ongoing corneal erosions and corneal ulcers, hives and rashes. My face itches and burns and I have developed sudden intolerances to food, which make the inside of my mouth

swell with painful bumps, and causes stomach cramps and bloating so severe it can be difficult to breathe. My teeth are cracking, my gums swell and bleed, and my hair falls out constantly.

I have been trying to get help for years, particularly recently as my health is deteriorating more and more. None of the doctors know about Essure, let alone the issues it has been causing. After a referral to the gynaecology department of a another hospital in June, I tried desperately to explain what Essure is and finally got an appointment for an ultrasound and a pelvic x-ray. However, the pelvic x-ray was cancelled four months later (apparently because they could see that the Essure was fine in the ultrasound). A referral to a different gynaecologist was cancelled, six different appointments were rescheduled, and I finally saw another gynaecologist, who told me that the coils are in the correct position but they can remove my tubes if that is what I want

My experience shows that nobody knows what they are dealing with and they haven't bothered to research the correct way to remove Essure, or even the correct imaging to ensure that fragments of the coils have not broken off and migrated, or that the PET fibres moved through the uterus and caused inflammation everywhere. I have zero trust in the health system that put these things in me and even less when it comes to removing them.

I just want the health system that implanted these substandard devices to give me a hysterectomy to remove the coils. I am angry, frustrated and tired, and wish I had never ever heard of Essure. I really, really want my life back. I feel like we have been tossed in a corner and forgotten."

The Website

We have continued throughout the year to work on our website adding information, articles, resources and links to external sources of valuable information. The AWHC website is currently the most comprehensive repository for information on the <u>Cartwright Inquiry</u> into allegations concerning the treatment of cervical cancer at National Women's Hospital, and the subsequent Gisborne Cervical Screening Inquiry.

In the last year we have added Newsletters and submissions to the website as they are completed; have regularly updated the surgical mesh pages; and have published new pages on the Essure contraceptive device and endometrial ablation, complete with women's stories. The endometrial ablation page includes an interesting history of society's attitudes to menstruation through the ages, and a history of the medical approach to

Netflix documentary, The Bleeding Edge, and a transcript of the documentary, have been added to the Medical Devices page.

Numbers of visitors to the website improved dramatically in 2023. Numbers had dropped off considerably with the launch of the new website in May 2022, which is typical, as it takes time for Google, the predominant online search tool, to recognise the new site, new webpages and the information it contains.

We had a total of 3253 visitors to the website over a total of 4089 sessions, meaning that 836 sessions were return visits to the website. The majority of visitors (an average of 59% over the year) found or arrived at the website as a result of an organic search using a search engine such as Google, while an average of 22% excessive menstrual bleeding. A review of the of visitors came directly to the site. The remainder came via social media or via links from other websites (20%)

The majority of visitors were from Aoteroa New Zealand (75%), followed by Australia (10%) and the US (7%). People from Canada, the UK, India, Germany, Fiji, China, Indonesia, France, Japan, Netherlands, and the Philippines combined made up a further 5% of visitors. People from a further 34 countries comprised the remaining 3% of visitors.

The most popular landing pages or subjects were (in order):

 Pages and articles about the Cartwright Inquiry and its history and legacy - 24% of views.

- Information about AWHC, our herstory and our people past and present — 9% of views.
- Newsletters 8% of views.
- Abortion, contraception and sterilisation 7% of views.
- The Health & Disability Commissioner, including if it has fulfilled it's promise and the Code of Rights — 7% of views
- Cervical cancer and cervical screening 5% of views
- Surgical mesh and medical devices in general - 4% of views

The home page of the website comprised 18% of views.

Website visitors, sessions and means by which visitors found/arrived at the website



Facebook



The AWHC Facebook page continues to engage with the community by providing feminist commentary and analysis of current health issues for women. In 2023, we made 28 posts and the metrics provided by Facebook for those posts are provided below. Not surprisingly the biggest group of followers are women — 95.8% — and from Auckland — 44.8%; 89% of followers are from Aotearoa New Zealand and 5% from Australia.



5,906 people were reached



1112 post engagements (reactions, comments and shares)



4454 post clicks



30 new page followers for a total of 476 followers



Our People

Cheryl Hamilton Treasurer and Founding Member

Deborah Payne Founding Member

Madeline Heron
Committee member (2000)

Pauline Proud Committee member (2007)

Katie Palmer du Preez Committee member (2014)

Sue Claridge Comms Manager, Committee member (2017)

Nikki Power Committee member (2022)

Erin Hanlon Committee member for parts of 2019 and 2023

The Executive Committee is the engine room of the Auckland Women's Health Council. We hold a general working meeting each month to: discuss the current projects the Council is working on; make decisions on particular health care and policy issues the Council is dealing with; discuss grant applications and financial matters pertaining to the operation of the Council; and to deal with the ongoing work of the organisation.

In 2023, we welcomed Erin Hanlon back to the Committee for a short time, before she announced that she was moving overseas and had to resign. We were thrilled to have Erin back with us for even a short period and valued her input and perspective on all women's health matters. Erin, we wish you well in this exciting new phase in your life.

During 2023, Committee members took responsibility for administrative duties on a voluntary basis, including the official Treasurer's role, meeting facilitation, minute taking and distribution, and meeting agendas. Committee members have also taken responsibility for other tasks including responding to phone calls, Council email, and *Newsletter* peer review. In total, Committee members contributed in the vicinity of 500 voluntary hours to the Council during the year.

The Council continues to establish *ad hoc* subgroups to work on issues as they arise, such as preparing submissions. At our monthly meetings detailed reports from the Treasurer, *Newsletter* editor, members and any current ad hoc subgroups are presented and discussed.

On the 5th of August we made our annual 'pilgrimage' to the *Spirit of Peace* statue outside the old National Women's Hospital at Greenlane:

to lay flowers in memory of the victims of the cervical cancer experiment in the 1960s and 70s; to commemorate the release of Judge Silvia Cartwright's Report; and to remember the 33 women who died as a consequence of receiving inadequate treatment. It was a beautiful day sunny day, and the special Pohutukawa that stands over the plaque honouring Drs Bill McIndoe and Malcolm (Jock) McLean who exposed the unethical research that had been carried out, was in flower. We followed up the visit to the *Spirit of Peace* with lunch in Cornwall Park.

The Executive Committee is enormously grateful to Cheryl Hamilton for her many years as Treasurer and for the work that she does managing the Council's finances.

Sincere thanks to Sue Claridge, Communications Manager, for her oversight and coordination of AWHC activities. For many years, the organisation has benefited from her skills, enthusiasm, and commitment. The committee acknowledges and is particularly grateful for the very high standard of research, content and writing in the AWHC *Newsletter* and submissions.





Funding and Finances



Without our collaborators our work would be harder and nowhere near as effective as it is. While the closeness of these relationships waxes and wanes depending on the issues we are responding to or advocating for, we value all the organisations with which we have close connections. We are all pulling in the same direction, fighting for the same things for all the women/wāhine in Aotearoa New Zealand - safe, accessible, effective, evidence-based, equitable and safe health care that enables women/wāhine to live their best, healthiest lives.

The Cartwright Collective













Consumer Council

Subscription to our Newsletter and membership of the Auckland Women's Health Council remain free of charge. People can subscribe to the Newsletter without becoming a member and receive the Newsletter directly into their email inbox. 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/wahine to have access to this without the burden of cost.



Without our funders our work wouldn't just be harder, it would be impossible. We acknowledge and thank our funders, Lottery Community and COGS. Without their ongoing funding and support we would not be able to continue our work.

We are also grateful to *numero* who host our website on a pro bono basis.



Char

Income and Expenditure

Income	2022	2023
Lottery Community	20,000	20,000
COGS	8,000	7,750
Subscriptions	-	_
Donations	700	_
Interest	70	255
Total Income	28,770	28,005
Expenditure	2022	2023
Communications Manager	16,020	11,243
Newsletter Production	10,220	8,944
Office Rent	2,180	2,220
Phone/Internet	848	914
Website	_	_
Travel	937	_
Dropbox	227	227
Zoom	163	163
narities Annual Report Fee	51	51
Total Expenditure	30,646	23,762



Looking Forward

We continue to value our relationships with our allies and collaborators, and look forward to joining forces with them to effect change in the coming months and years. We have formal memberships of health consumer forums and coalitions to which we contribute on behalf of women/wāhine, and will continue to keep the health issues that women face at the forefront of those discussions.

At the time of writing, the Health and Disability Commissioner has just launched public consultation on its review of the Code of Health and Disability Services Consumers' Rights and the Health and Disability Commissioner Act 1994. AWHC has had a sustained interest in the office of the Health and Disability Commissioner and the Code of Rights since its very first submission on the Health and Disability Commissioner Act 1994. In 2023 we were invited to provide early input on the HDC review and will also take part in the current public consultation.

These opportunities to be involved in consultation at many levels throughout the health system, and the legislation and policy that underpins it, are vital. They enable us to turn up the volume on women's health issues, and ensure that women are heard and can contribute to creating the sort of health system they want and need.

As is the case with very many non-profit organisations, we are always in need of more voices on our own Committee, and particularly more diversity. We welcome new members and eagerly look forward to more women joining us to help share the

load and bring their unique experiences and viewpoints to our table, so that we can continue to work towards providing a voice for all women/wāhine.

One of the issues that looms largest in the health system is that Māori and tagata Pāsifika continue to be disproportionately affected by inequities and disparities in access to and outcomes from health care. The current political landscape in Aoteroa New Zealand threatens to exacerbate this rather than improve it.

The Executive Committee of the Auckland Women's Health Council have had numerous discussions about what role we might play in addressing these issues. We are working towards being tangata tiriti — to stand in partnership and solidarity with Māori — and will continue to raise awareness and include commentary on the inequities and disparities in health and health outcomes for Māori, and racism in the health system, through our Newsletter articles, submissions and the website.

As difficult and dispiriting as the current situation in health in Aoteroa New Zealand is, we know that AWHC is not alone in our efforts to make a difference. We take heart from all the wāhine toa around the motu who work so hard behind the scenes, all of us pulling in the same direction to make Aoteroa New Zealand a healthier place for all our women/wāhine; a place where all women/wāhine have accessible, equitable, affordable, available, accountable and culturally appropriate health care services.





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