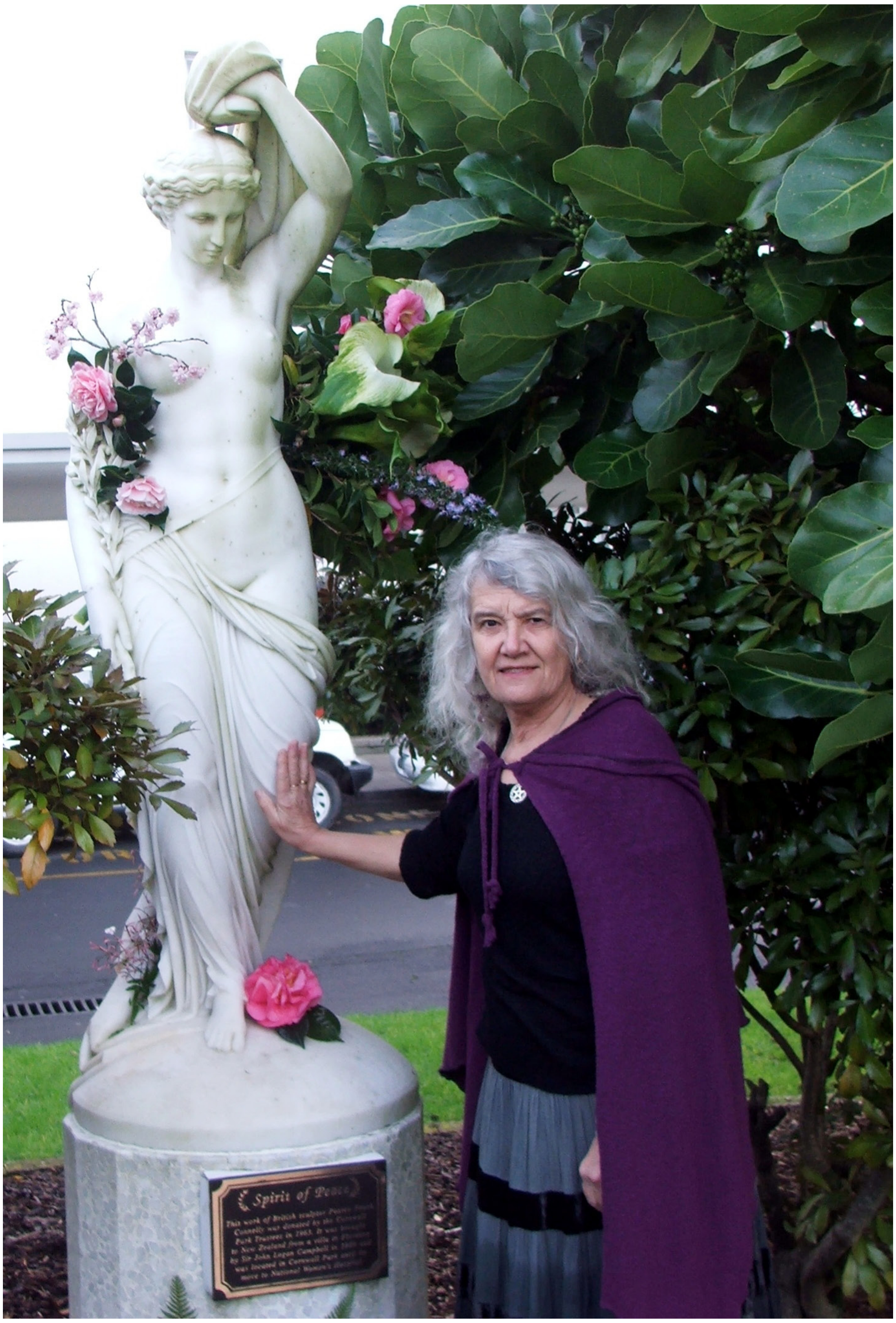
AUCKLAND WOMEN'S HEALTH COUNCIL

NEWSLETTER

SEPTEMBER • 2017

a voice for women's health



Lynda Williams

11 March 1950 ~ 6 July 2017

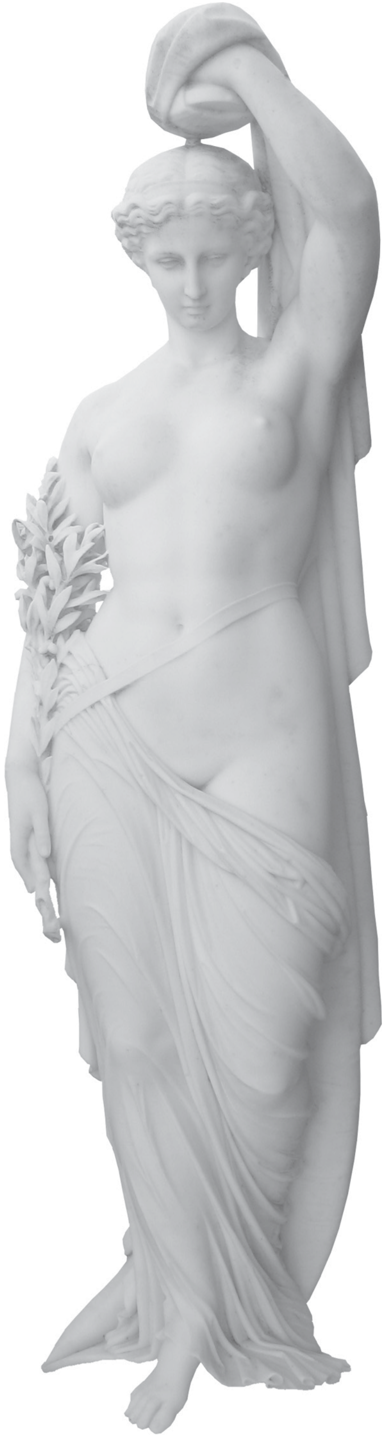
Welcome to this edition of the AWHC Newsletter, which is dedicated to Lynda Williams and her contribution to women's health.

Lynda's feminist principles and history of advocating and lobbying for women's rights over birthing choices called her to be one of the founding members of AWHC. She was involved in several of the working groups set up following the release of Judge Cartwright's Cervical Cancer Inquiry Report and was appointed as the first patient advocate at National Women's Hospital, fulfilling one of the key recommendations from the inquiry.

In 1995 Lynda took up the role of AWHC's co-ordinator. This was a role to which she brought transparency, scholarship and rigour. To each executive meeting she would bring a record of the work she had done, the meetings she had attended, and the phone calls and emails she had responded to. Her scholarship and rigour were made evident in the monthly newsletter she produced. Lynda stirred our emotions and called us to action through the use of literature, facts and figures showing how and what the situation was. Her concern was evident but not easy to dismiss. That the newsletters were subscribed to by academics and politicians shows how well thought of and useful her writing was. She was sought after by both national and international reporters for the AWHC's views on health issues.

Lynda was also generous in her commitment to AWHC. In times when we were waiting for the results of another funding grant application, Lynda would literally pay herself by loaning monies to the AWHC. She maintained a steadfast belief that AWHC would survive. When she was diagnosed with cancer, Lynda's commitment to AWHC's future survival was evident too. She wanted to ensure that she safely passed the mantle on to our new co-ordinator and pushed us to begin this process (sooner rather than later). We recognise that this was not an easy thing for Lynda to do and one of the many things that she had to grieve for.

Lynda always kept us on track as an organisation. She was mindful of the key issues and principles that were our history, present and future, such as the right to informed consent and quality screening programmes. She kept institutions on track and mindful of these principles as well. Her consistent attendance at the Auckland region's DHB and Health & Disability ethics meetings was noted by the board and committee members. Her attendance and astuteness at these meetings allowed AWHC to stay alert to the changes and potential threats to patients' rights, and to voice our concerns.



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Indeed, AWHC would not have survived had it not been for Lynda. It was through her work and efforts that AWHC was seen as a credible organisation to fund. It was through all the qualities that she had, her persistence, courage and commitment to social justice that AWHC was and is what it is.

What Lynda also made evident to us was the delight, love and pride she felt for her children and grandchildren. She would bring photos and relate stories to us of their weddings and births. It was for her children and grandchildren that Lynda agreed to accept a Member of the New Zealand Order of Merit honour. As Lynda noted in her blog on the investiture ceremony "It will be something for them all to remember me by." (lyndasletters.nz Blog Post February 11, 2017)

Lynda was also deeply spiritual. The beaches and the bush of West Auckland played a hugely important part in her life as did Trounson Kauri Park and the Waipoua Forest. Lynda's blog telling of a return trip to visit to her favourite kauri trees (lyndasletters.nz blog post February 4, 2016) brought back memories of the times Lynda shared her sacred places with us on AWHC retreats in the earlier days of the organisation. Typically, Lynda, always brought her whole self to whatever she was doing. She persuaded Canada's CBC, here filming for a "fifth estate" programme on the high cost of pharmaceutical drugs in Canada and the establishment of a Canadian "PHARMAC" as a possible solution to the problem (lyndasletters.nz Blog Post January 22, 2017), to film her on the beach at Te Henga, her most spiritual home, instead of the visual they had suggested – picking up her meds from the pharmacy.

Resigning after 22 years as AWHC co-ordinator Lynda wrote in her blog (lyndasletters.nz Blog Post March 6, 2017) "I am not at all sure what lies beyond the door I have just stepped through. I have mixed feelings about it, and my dreams are currently providing proof of my distress over the loss of this aspect of my identity." For the next four months what lay beyond that door continued to demonstrate Lynda's commitment to women's health as all encompassing, a passion and an integral part of her lifeblood that was with her to the end. Events that brought her great satisfaction and a sense of completion during that time included the launch of Ron Jones' book, *Doctors in Denial: the forgotten women in the 'unfortunate experiment'* (lyndasletters.nz Blog Post February 18, 2017); writing her final submission on the Health and Disability Commissioner's consultation on research involving adult participants who are unable to provide informed consent to being enrolled in research (lyndasletters.nz Blog Post May 4, 2017); and, just two weeks before she died, attending Professor Jo Manning's inaugural lecture on "Compensation for research related injury in the UK, Australia and New Zealand: a legal and ethical audit".


Lynda with other AWHC members at the Spirit of Peace statue outside the old National Women's Hospital on the 5th of August 2008.

We are grateful to Ron Jones and Jo Manning, and to former Health and Disability Commissioner Ron Paterson, for their contributions to this special edition of the AWHC newsletter. We also thank Sandra Coney and Caroline Young, as well as Maternity Services Consumer Council, where Lynda was also co-ordinator for almost 25 years. There would not be many women's health organisations of the last three or so decades that Lynda was not involved with – Fertility Action/Women's Health Action, Maternity Services Consumer Council, Save the Midwives, Maternity Action, Federation of Women's Health Councils, and the Cartwright Collective are just some that come to mind. Lynda's legacy is huge, and while she would be the first to say that nobody is indispensable, those of us who are left behind are very conscious of the gap she has left and later in this newsletter as a reminder of Lynda's uniqueness we are including some of her own words from previous newsletters to speak to us one last time.

Remembering Lynda

Lynda Williams died at home on the 6th of July 2017 surrounded by her children; Luke, Taare, Samantha, Ariel and Tristan. The life of this remarkable woman was celebrated at a service at Landsendt in Oratia where the esteem in which she was held was echoed in a diversity of eulogies acknowledging her as a devoted mother and grandmother, loving daughter and sister, dearly valued friend and life-long health activist.

As a health activist, Lynda was very much the Warrior Queen but a Warrior Queen who also had the ability to listen, to consider and to immediately change stance if it was indicated. Her tenacity in her pursuit of what was fair and just was unrelenting, as was her insistence that women not only had a voice, but that their voice should be heard and respected. Nothing could vouch for this commitment more than her consistent attendance at every DHB meeting; even for those obligated to be there this would be a daunting record to have maintained.

Lynda unhesitatingly took on challenging roles, such as that of patient advocate after the Cartwright Inquiry, when such a concept called for integrity and grit in sailing into such an uncharted territory still being buffeted by storms. This same passion for ethical care saw her taking on roles within Fertility Action, which later became Women's Health Action, being the co-ordinator of the Maternity Services Consumer Council and the Auckland Women's Health Council. Lynda was always about justice for others. I well remember that intake of breath when confronted with a situation where this had not been upheld and the silence that followed during which plans to address this were being rapidly formulated. This year Lynda was deservedly awarded the New Zealand Order of Merit for services to women's health, something she took more delight in for her children's sake than her own. New Zealand midwives and women owe her a debt of gratitude for her role in the Women's Health Action group, which had a significant role in the movement that won back the right for midwives to care for women independently of doctors.

Lynda's life as a health activist speaks for itself as a life well lived, one which needs no accolades from me. Instead I will speak of Lynda as a mother and as a friend. We first met in the 1980s when she began working as a childbirth educator and made an approach to me regarding what she was offering as I was the local midwife. I confess to being stand-offish seeing this as a business overture. Lynda never did 'stand-offish' and inevitably it was easier to capitulate and meet with her rather than leave the country. We soon discovered we were pushing the same wagon and heading in the same direction; thus began our friendship. This was to see me taking on the role of her midwife in due course, and to see her taking on the role of my birth supporter when I myself had children.

Lynda with Governor General, Dame Patsy Reddy

Lynda's children were the jewels in her crown. I believe that the children of mothers who are innovators and movers and shakers need acknowledging for letting us borrow their mothers as they are growing up, to help bring about those much needed changes. On behalf of us all I thank Luke, Taare, Samantha, Ariel and Tristan for the times when Lynda went out to attend meetings, perhaps didn't make the sports event or the fancy dress costume was safety pinned together, because of all the things that mattered in Lynda's life you mattered the most.

We had a very easy friendship. It never needed dusting, or weeding or polishing, it just was. No matter the time lapse between meetings, it was always as nothing in the delight of reconnecting. Sometimes this was at restaurants, with the lights being brightened, heaters dimmed and even once the floor starting to be swept in a clear signal it was time we went home; sometimes it was a chance meeting in a hall or under an umbrella as we passed on our way to somewhere else. As many of Lynda's friends commented at her funeral, she had an enormous capacity for joy and delight that was impossible to resist, just as was her bottomless resource for showing compassion and empathy.

Lynda will be sadly missed by so many across so many sectors, but her work and Lynda herself will never be forgotten.

— *Carolyn Young*

A Full Moon, A Thunderstorm, A Shooting Star

I met Lynda through the Cartwright Inquiry. The Inquiry drew together women who wanted to change the health system and the relationship of health professionals with women. With her background in maternity issues, Lynda was a natural fit and put huge energy into the groups that came out of the Cartwright Inquiry.

You could call these the "glory days" of the women's health movement. The Cartwright Report legitimated what women, through their health groups, had been saying for years. It created a climate in which the Ministry of Health, medical professionals and health managers had to listen, had to include women, and many gains were made.

One of the gains was that the women's health movement grew in size and strength. Lynda was highly instrumental in getting the Auckland Women's Health Council off the ground, and in the formation of the Federation of Women's Health Councils as a national network.

She had two periods with Women's Health Action, and I spent many hours working closely with Lynda. She devoted years to these and other groups, but as the Cartwright Inquiry became more distant, that became tougher. The health system went through repeated profound changes, the people changed as managers left and new ones who lacked the same experiences came on the scene.

Lynda was a constant. If there was ever anyone who was in for the long haul, it was Lynda. While others of us took new paths or put less in, Lynda was the rock. She put her life into it.

That is not to say Lynda did not move with the times. Lynda was a true intellectual. She embraced new knowledge, new ways of thinking. Her newsletters provided wonderful critiques of new science. With Lynda's passing we have lost an enormous repository of first-hand experience, knowledge, memory and just plain guts.

She also did all this while bringing up five children. Part of my Women's Health Action experience with Lynda involved Tristan in a carry cot. Lynda juggled all this with great grace, even made it look easy.

There are other words that need to be said about Lynda. Forthright, courageous; I don't know anyone who was braver than Lynda. There was no health manager, politician, doctor, or committee, to whom Lynda would not say it like it was. She was never intimidated or over-awed. I am on my third term on Waitemata DHB. Lynda attended every meeting of WDHB and other DHB boards over years and years. The information she gathered through her attendance she digested, analysed, put out there and turned into action.

When I think about Lynda's contribution, I realise she was often in the situation of holding the flag alone. While many of us supported her work, and thought like her, Lynda often put herself in positions where she had to speak up for women, and more widely for patients, in uncomfortable situations, where the interests of the public relied on her speaking up.

Perhaps no role that Lynda played drew more on her inner strength than when she was the first and only patient advocate at National Women's soon after the Cartwright Inquiry.

It is another example of the great courage that Lynda displayed all her life, down to the wire. I think she was really pleased that some of us in the last few years came together as the Cartwright Collective and continued to work collectively on outstanding Cartwright issues. Lynda was a key member of this group and we will miss her badly.

Lynda could be quite challenging. She did not hold back. But one of the things I found about Lynda was, if she got a reasonable answer back, or something that required her to rethink, she did. She did not harbour grudges and was not personal in her advocacy. I think she could do this because she did not operate from her ego.

Lynda took on a cause because the world needed to change; she did it for the people she served, the mothers, the babies, the people getting a raw deal in the health system. It was not ego driven. That made Lynda a very honourable and unusual person.

Not just unusual, actually, Lynda was a complete one-off. Linda drove around in a car with a "witch" number plate. She loved babies, mothers, trees, the wild West Coast and Waitakere.

I liken Lynda to a force of nature: a full moon, a thunder storm or a shooting star. It is really impossible to think of Lynda not being here. Those of us who were her friends have known an unforgettable woman.

— Sandra Coney

Lynda's Law: "Without Legal Commitment"

Compensation for injury in pharmaceutically funded trials in New Zealand

I don't know exactly when it was – maybe about two years ago – when Lynda said to me that she had learned from a meeting on research ethics she had attended in Dunedin, about the case of a man, a builder, who had suffered some kind of injury to his heart in a pharmaceutical drug trial, such that he could no longer work. The drug company had successfully resisted paying him any compensation for his injury to that point (they later did reach a confidential settlement with him).

"I can't get him out of my head", she said.

She confided that she hated attending ethics committee meetings, because the applications she heard being discussed often left her profoundly worried. But she had to continue to stay effective. This immediate empathetic response was typical of Lynda. She truly put herself in the shoes of patients and research subjects, and "felt their pain."

Lynda urged me (being an academic medical lawyer) to research the legal and ethical issues relating to the compensation rights of people who are injured in medical research trials. In the relatively short few years that I had known and worked with Lynda on the Cartwright Collective, I had learned to pay close attention when she voiced a strong sense that there was something wrong in relation to a matter, and so I did so in this case. What I was to find shocked us both, more so than either of us expected.

Members of the Cartwright Collective at a one-day conference, in 2013

At the back: Lynda Williams, Phillida Bunkle, Betsy Marshall
Front: Julie Radford Poupard, Jo Manning, Jo Fitzpatrick, Sandra Coney, Ruth Bonita

My research revealed a profoundly unsatisfactory legal and ethical situation. Despite a consensus among bioethicists that society owes an ethical obligation to compensate for research-related injury, and that no-fault is the best ethical response, an assessment of the compensation arrangements in place in New Zealand showed that the arrangements fell below this ethical expectation. New Zealand's Accident Compensation Act was amended in 1992 to provide that people, who agree to participate in a clinical trial funded by the New Zealand taxpayer (a publicly-funded trial), and are injured as a result of their participation in it, are covered by our no-fault accident compensation scheme (ACC), and so have access to legally enforceable and reasonably appropriate compensation without having to prove that the trial funder or researchers were negligent. But the amendment also provided that those injured in clinical trials funded by pharmaceutical companies were not thenceforth covered by the ACC scheme, but must instead prove such negligence in a court before they have any legal right to compensation. This is notoriously difficult to do, usually because injury is caused by an unforeseen risk of the trial medicine eventuating – often something the research is designed to discover. Also proving a causative link between the person's injury and the medicine being trialled, as opposed to a comparison medicine or their underlying health condition, can be a major challenge for the injured person.

Since 1993 Medicines New Zealand, the organisation which represents the interests of the pharmaceutical industry, has been permitted by Government to use voluntary Compensation Guidelines, which state that a pharmaceutical company's obligation to pay compensation to an injured participant is "without legal commitment." This amounts to, therefore, an unenforceable assurance to the injured participant of payment of compensation in the event of injury. The unequal treatment and relative disadvantage of injured subjects in industry trials, compared to those in publically-funded trials, is inequitable and discriminatory. Once injured, the source of funding for the trial in which they participated, pharmaceutical or otherwise, is immaterial to the subject.

The information about the compensation arrangement in place for pharmaceutically funded trials contained in the standard template for a Participant Information Sheet recommended by the Health Research Ethics Committees for use by companies and researchers is seriously misleading. It does not state that an injured participant's right to compensation is legally unenforceable. Instead it states the opposite: "compensation would be available from the study's sponsor if something was to go wrong." Accordingly, it is overwhelmingly likely that subjects only find out about their financial exposure in the event of injury when they make a claim for compensation.

Lynda and I were in agreement that the best and simplest response was to extend ACC cover to the small group of research subjects injured in pharmaceutically sponsored clinical trials, by repealing the provision in the Accident Compensation Act which excludes them from ACC cover, so that all injured research subjects are treated equally. Unfortunately, Government ministers have not responded positively to the case for reform I have pressed, but I will stay on it! I made a commitment to Lynda that I would continue to push for this law change. I told her that, if successful, I would think of the law change as "Lynda's law," in recognition of her raising this important issue and of her work and advocacy in relation to it. She was not overly impressed by this suggestion, it has to be said, being much more interested in the right result!

— Joanna Manning
Cartwright Collective

An Unexpected Friend

I never expected to become a friend of Lynda's. During my decade as Health and Disability Commissioner, Lynda was often a thorn in my side, never hesitating to publicly and privately challenge and criticise my views. We had lots of vigorous debates. Sometimes I found Lynda infuriating, which I think she rather enjoyed. But I always engaged with her – and Lynda once told me she thought I had a sixth sense, as I would frequently phone her just as she was penning another furious letter or email to me.

I never doubted Lynda's passion and commitment for consumers' rights. Over time, I developed a lot of respect for her insights and her ability to research and write. We grew to like each other and, in recent years, through our shared friendship with Judi Strid, we became good friends. We worked together to try to improve continuity and co-ordination of care for cancer patients in Auckland, so that other patients won't face the obstacles Judi and Lynda faced.

Lynda wanted me to see her home, her sanctuary in Waitakere, and my partner Greg and I enjoyed lunch with her there in March. Later that month, Lynda came to talk to my class of third year medical students, about why the Cartwright Inquiry and the Code of Consumers' Rights are so important. The students were totally captivated.

Lynda's death leaves a huge gap – for her family and friends, but also for the community. Lynda's contribution to consumers' rights in New Zealand has been enormous; countless hours of largely unpaid labour. Her monthly Auckland Women's Health Council newsletter was always a must read. Lynda was an expert in so many fields: informed consent, screening, maternity care, evidence-based public funding of medicines, proper ethics committee review of research.

We all benefitted from her research and advocacy, and marvelled at her energy and commitment. We have lost a leading health activist, a strong and powerful advocate for consumers.

I have lost a friend.

Arohanui

— Ron Paterson

Lynda Williams: An Unusual Friendship

I learned of Lynda Williams at the time of her appointment as the first patient advocate at the National Women's Hospital following the Cartwright Inquiry. The hospital was depressed, angry and broken; no one wanted an outside feminist health advocate to be imposed on them. At that time I was a broken man – *persona non grata* with my colleagues, and my wife was battling cancer. I kept my head down, did my clinical duties and opted out of hospital politics. This didn't entirely separate me from grumblings about this difficult, stroppy woman who couldn't possibly understand how 'the' National Women's Hospital worked. The medical profession saw Lynda as a rabble-rouser and a threat – this didn't bother Lynda.

Some years later this formidable woman made contact with me in order to discuss issues of common interest – this was the beginning of a professional relationship. Understandably our respective backgrounds meant we had quite different perspectives – we educated each other and frequently we needed to agree to disagree. In our early days we probably regarded each other with a degree of suspicion.

Although Lynda was widely seen as a feminist health advocate, the questions we debated focussed more on the issue than on gender. Perhaps we both mellowed over time – our perspectives began, on occasion to merge and we increasingly saw each other's point of view.

Following her cancer diagnosis we had regular coffee mornings in Newmarket and later at her home. She told me the only thing on her bucket list was to be around for the publication of my book – *Doctors in Denial*. She attended the launch where she was delighted to be surrounded by many old friends.

Over her last 18 months our professional relationship morphed into a personal friendship – an unlikely mix of a feminist health advocate and a 'perceived' conservative older male obstetrician and gynaecologist. Of course we discussed her terminal illness but we spent more time discussing our families, friends, the mess the world is in, our regrets, our wins and our losses. Not long before she died I asked her whether she thought health consumers were in a stronger position today than when she began her crusades many years before. After some thought she agreed they were – but with a caveat that there is still a long way to go.

Thank you Lynda for being a feisty, formidable feminist and especially an advocate for all of us who at some time may need to use our health system.

— Dr Ron Jones

This page and opposite: Lynda with Auckland Women's Health Council members celebrating the 20th anniversary of the AWHC in Glenorchy in 2008 (this page) and the 25th anniversary in 2013 (opposite).

Lynda's Other "Baby" – the MSCC

Lynda was appointed as the co-ordinator of the Auckland Maternity Services Consumer Council in 1992, and not until her health demanded it did she resign in March 2016. Lynda will always remain synonymous with the organisation.

Lynda started the Auckland Caesarean Support Group in 1984, after having a birth experience over which she felt she had little control. During this time, Lynda joined up with other women to form a number of new groups such as Save the Midwives, Maternity Action, Obstetric Watch, the Direct Entry Midwifery Taskforce, and the Auckland Women's Health Council. She started teaching childbirth education classes in her home, and over the next 15 years Lynda attended the births of many babies of the couples who had attended her antenatal classes and had subsequently asked her to be a support person.

Lynda became the first patient advocate at National Women's Hospital, a job she started in 1989, resigning in September 1991. She said that in this role she felt constantly undermined, sometimes in subtle ways and at other times it was more obvious. This patient advocacy role was created in the wake of the Cartwright Inquiry, as was the Health and Disability Commission Act and the office of the Health and Disability Commissioner.

However, Lynda's experience as the first patient advocate at National Women's Hospital did not dim her enthusiasm for helping women negotiate their own health care, and subsequently she took on the co-ordinator role at the MSCC.

During her time at MSCC she helped shape the changes made to the Nurses Amendment Act of 1990, lobbied for a new primary unit in West Auckland after Waitakere maternity hospital was upgraded to a level two unit, made numerous submissions to parliament, and attended ADHB and WDHB board meetings. In 2008, Lynda was appointed to the ADHB Community and Public Health and Hospital Advisory committees and served for three years. As co-ordinator for both MSCC and AWHC, Lynda put everything she had into helping women understand the health care system.

Lynda's passion and energy is sorely missed.

— Holly Nielson,
Maternity Services
Consumer Council

In Lynda's Own Words

WHAT PRICE A FREE DINNER?

On a wild wet windy evening in late June that made crossing the Auckland harbour bridge no mean feat, an event took place in the Spencer on Byron hotel in Takapuna that made even the most hardened cynics amongst us turn ashen-faced.

As the storm raged outside complete with thunder and lightning and a tornado or two waiting in the wings, inside it was all cosy and warm, with immaculately-clad waiters handing out free drinks and delectable nibbles as the guests drifted in and mingled with their colleagues.

The guests were nearly all GPs who at the end of May had received a letter from the drug company Bayer inviting them to a presentation by a senior paediatrician and a drug company representative, after which dinner would be served. The invitation was attractive enough to bring out over 100 GPs on such an inclement night.

The topic of what the letter described as "a dinner presentation" was *Feeding Options for Women Not Fully Breast Feeding*. After half an hour or so of "arrival drinks and canapé" we were ushered into a room and seated at tables set for dinner. Paediatrician Peter Nobbs was introduced and began his presentation on the history and politics of breastfeeding. He began setting the scene for the message he was there to give by focusing on an aspect of the environment that some new mothers in New Zealand 100 years ago were subjected to. The Plunket Society was put under the spotlight as Peter Nobbs described their staunch support for breastfeeding, their objections to an advertisement for an early version of what was then known as "humanised milk mixture" that appeared in the *Otago Witness* in the first decade of last century, and the two-faced behaviour of Plunket Nurses who, according to a letter that appeared in the *Otago Daily Times* in 1915, were telling mothers to breastfeed while they themselves were bringing up their babies on Glaxo.

We were told Plunket Society's founder, Sir Truby King's Melrose property in Wellington is listed as a category 1 Heritage Building, and that it was here that the earliest attempts to make "humanised milk mixture" or infant formula in New Zealand began. Vegetable oil, cod liver oil and dextrose were added to cow's milk and this humanised milk mixture was marketed by the Plunket Society under the name of Karilac along with "Plunket cream" known as Kariol.

Following a bit more history Peter Nobbs showed a slide documenting the falling breastfeeding rates in the middle of last century – it was recorded as being 91.5% in 1939, 82.1% in 1945, and 74.4% in 1952.

By now it was clear that the message we were being given was that not fully breastfeeding was normal and natural, that health authorities were often hypocritical about the advice they were required to give to new mothers about breastfeeding and what they actually said and did, and that the pro-breastfeeding stance was just a lot of politically-correct behaviour. Along with this were some subtle and not so subtle messages about the problems and risks of breastfeeding.

Turning his attention to the politics of breastfeeding, Peter Nobbs went on to talk about the WHO Code on the International Marketing of Breast-Milk Substitutes, the advice given to new mothers in hospital, and the argument around whether complementary feeding with a bottle does have any effect on breastfeeding.

He referred to the erroneous perceptions of groups like La Leche League and quoted from one of the group's 2007 newsletters in which the sentence "Formula companies' only aim is to make money" appeared. He assured the audience that formula companies in New Zealand do comply with the WHO Code and therefore see themselves as providing a complementary service.

NZ Breastfeeding Authority

The next organisation to come under attack was the NZ Breastfeeding Authority. He described their website, their current proposals around the Baby Friendly Hospital Initiative, and the accreditation of the hospitals in the Auckland region in critical terms. The NZBA website refers to the benefits of breastfeeding but not the risks, and risks of infant formulas but not the benefits. He cited as an example the fact that the website mentioned bacterial contamination of infant formulas. He was very critical of how ridiculous this was when the incidence is less than one in a million.

Bottles and Pacifiers

The issues surrounding the use of pacifiers and bottles featured next with Peter Nobbs referring to some of the evidence about their supposed effects on breastfeeding. Studies on the use of pacifiers show no consistent results, he said. The effects of supplementary bottle-feeding had been studied in two studies from the USA and one from Switzerland. One showed an effect on breastfeeding and one did not. The duration of breastfeeding in both groups was the same.

No RCTs

The lack of randomised controlled trials was something Peter referred to several times during his presentation.

Peter ended his presentation with a list of the five most common conditions that mothers and babies present with at the doctor's office. They included reflux, colic, poor weight gain, allergies, and diarrhoea. As he talked about each condition he showed a slide with the image of the appropriate Bayer Infant Formula (brand name is Novalac) product – Novalac Reflux, Novalac Colic, Novalac Hypoallergenic, Novalac Diarrhoea. There was even a Novalac Sweet Dreams! With the exception of Novalac Diarrhoea, all products are suitable for use from birth onwards and are described as a "nutritionally complete formula suitable for long-term everyday use." Given that each of these special formulas costs around $30 a tin (almost double that of ordinary infant formula), the statement that the aim of the drug company is to make money does not seem at all unreasonable.

Bayer Consumer Care

The presentation by Ayumi Uyeda, the young female drug company rep was unremarkable in that it was clearly her job to promote the wonders of the Novalac range of specialised infant formulas. She consistently described them as "premium products', and the higher cost was simply "a price differential."

Ayumi Uyeda referred to the EDEN study of 3,500 babies, "an observational study of what happens in private practice" that was firstly an epidemiological study on presenting problems, and secondly the effects of Novalac on the problem. However, there was no mention of RCTs!

Her slides showed the "scientifically developed" range of specialised infant formulas and how they differed from each other. The slick marketing of solutions to "problems" such as reflux, colic and constipation, the expansion of the diagnostic criteria used to identify such commonplace events as spilling or spitting up, periods of prolonged crying and distress, and constipation and diarrhoea, along with the supply of free drinks and good food, was both impressive and incredibly dishonest.

Needless to say, I left after the presentations – before dinner was served – because I suddenly found I had completely lost my appetite. I went instead to the bar and bought a spiced tomato juice and sat mulling over what I had just witnessed with a health professional friend.

Lynda Williams (aka Linda Watson)

(Originally published in the June 2008 AWHC Newsletter.)

AUCKLAND WOMEN'S HEALTH COUNCIL

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AWHC GENERAL MEETINGS July, August & September 2017

Detailed minutes of this meeting are available on request. Matters discussed included:

- Financial & Corodinator's reports
- Grant applications and funding
- DHB and Ethics committee meetings

The next general meeting will be held at 4pm, 26th of October, 2017.

AWHC NEWSLETTER SUBSCRIPTION

The newsletter of the AWHC is published monthly.

COST:

$30 waged/affiliated group

$20 unwaged/part waged

$45-95 supporting subscription

If you would prefer to have the newsletter emailed to you, email awhc@womenshealthcouncil.org.nz

Send your cheque to the AWHC, PO Box 32-445, Devonport, Auckland 0744, or contact us to obtain bank account details.

My Last Submission

by Lynda | May 4, 2017 | Blog |

Last week I spent a considerable amount of time working on a submission. This time it was my own personal submission. The Auckland Women's Health Council's new co-ordinator was also busy working on her first submission for the AWHC on the same consultation document – the Health and Disability Commissioner's consultation on research involving adult participants who are unable to provide informed consent to being enrolled in research.

Producing this submission gave me a great feeling of satisfaction and a sense of completion as the fact that vulnerable populations of people, including unconscious patients in intensive care units, young adults with Down syndrome, patients with dementia, prisoners, etc, are being enrolled in clinical trials and other forms of research without their prior consent has outraged me for some years. A front-page article in the *NZ Herald* three years ago about the practice had not resulted in action from either the Ministry of Health who oversee the Health and Disability ethics committees or an inquiry by the Health and Disability Commissioner (HDC). Three years of writing letters and emails to the Commissioner finally resulted in some action – the production of a consultation document. Last year as the months ticked by I felt an increasing sense of despair as the promised consultation failed to eventuate. Finally, at the end of February, the HDC released the long-awaited consultation document and I counted my lucky stars that I had survived long enough to not only produce a submission, but was still capable of being able to go all out on my own submission. This was no mean feat as the submission had to be completed online and it proved to be a very time-consuming and clunky process. I felt a profound sense of completion once I had pressed the "submit" button. Whether it makes any difference is not as important as my being able to call upon my eight years of experience attending ethics committee meetings and exercise my democratic right to contribute a consumer/ patient perspective on a practice that I had thought was ended by the 1987/88 Cartwright Inquiry and the release of Judge Silvia Cartwright's report in August 1988. The fact that the New Zealand government allows it to continue is against not only international agreements we have signed, but is also unethical and illegal.

Changes to the New Zealand Cervical Screening Programme

There is a synergy in reprinting these partly abridged articles of Lynda's from the last couple of years. Cervical screening has been a critical issue for the AWHC since the early days of the organisation, and still is. The proposal two years ago to change the cervical screening programme is one that concerns many women involved in a number of women's health organisations; Lynda, as a member of the Cartwright Collective and in her role as co-ordinator of the AWHC was one of the most vocal and articulate opponents of this change.

Misinformation from Minister's Office on Cervical Screening

(October 2015 AWHC Newsletter)

On 29 September 2015, the Minister of Health announced via a press release that there would be public consultation on the National Cervical Screening Programme's proposal to change the primary laboratory test for cervical screening from a cervical smear test to an HPV (Human papillomavirus) test.

The press release contained some confusing and totally misleading statements about cervical screening, which revealed a complete lack of understanding about the purpose and the process of cervical screening.[1]

"The protection offered by the HPV vaccination programme and the HPV test would ensure screening can provide a greater level of reassurance of finding cancer early, resulting in better health outcomes for New Zealand women," the Minister stated.

Actually, Minister, the cervical screening programme does not test for cervical cancer. It is one of the few, if not the only, cancer screening programmes that can prevent the development of cancer by a screening test that identifies changes to cells well before they develop into cervical cancer. Likewise the new HPV test cannot and will not provide "a greater level of reassurance of finding cancer early" because it aims to identify the high risk infections – HPV16 and HPV18 – that may eventually result in the development of pre-cancer cervical lesions.

Given the huge amount of misleading information there is about the benefits and risks associated with all cancer screening programmes, it is alarming to find press releases emanating from the Minister of Health's office that contribute to the confusion and lack of evidence-based information around cancer screening tests.

Several women's health groups contacted the Minister's office with their concerns about the press release, and received a "Thanks for your email. I will pass it on" response. The AWHC asked that the Minister retract his press release and issue a statement acknowledging the misleading information about cervical screening that it contained. "The women of New Zealand have a right to receive clear and accurate information from authoritative sources about cervical screening and about the proposed changes to the cervical screening test," we wrote.

However, the Minister is probably unaware of our concerns as, when we contacted his office we were advised that our email was passed on to the Ministry – who of course wrote his press release. This is even more alarming.

Primary HPV Testing

There are several important issues that need to be addressed before we head off down the path of HPV testing and five-yearly cervical smears.

The most important of these is the effect that HPV testing may have on the women who have an HPV test and are found to have one of the two most common high risk HPV types that may lead to the development of cervical cancer. What is not mentioned in the Minister's press release, and what is glossed over in one sentence in the consultation document, is the fact that the vast majority of women will clear the HPV infection without the need for any treatment. Between 80% and 90% of women will clear HPV infections within one to two years without even knowing that they were infected. The consultation document puts it this way: "Often the body's immune system will clear the infection before the woman notices any symptoms. However, for a small number of women, persistent hrHPV infection *can* lead to cervical cell changes; if these changes are not treated, they *may* cause cancer." [Italics added]

What the introduction of the new HPV test will do is inform thousands of women that they have one of the high risk HPVs – HPV16 or HPV18 – when there is every likelihood that it would not have caused them any problems. Instead these women will be told they have a high risk infection and will be referred straight to colposcopy for further assessment. Imagine the anxiety this will cause.

There are also major issues around the impact the switch to HPV screening will have on the cervical screening workforce.

The Consultation Document

In the meantime, the deadline for providing considered and researched comment on the consultation document is fast approaching.[2] Consultation meetings are being held in Wellington, Auckland on Christchurch between 14–16 October and submissions are due in by 23 October 2015.

References

1. https://www.beehive.govt.nz/release/consultation-changing-cervical-screening-test
2. https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/new-and-future-developments/primary-hpv#document links

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The Switch to HPV Primary Screening

(February 2016 AWHC Newsletter)

The National Screening Unit (NSU)is in the process of making the switch to HPV primary screening, and during October 2015 undertook a consultation process that involved holding 12 public meetings around the country. The NSU reported that they received 87 submissions from individuals and organisations.[1]

Doubts about the wisdom and evidence base for changing from three-year cervical screening with a cervical smear test, to HPV primary screening with an extended screening interval were raised by a number of those making submissions, including the AWHC.

A letter to the editor published in *Cytopathology* in November 2015, that was written in response to an editorial by H.C. Kitchener, "HPV primary cervical screening: time for a change," raised further questions about the evidence base for this change. R. Marshall Austin, at the Department of Pathology at the Women's Hospital of University of Pittsburgh Medical Center, USA wrote:

"Although this editorial acknowledges the UK Cervical Screening Programme as 'an exemplar,' one which has reduced cervical cancer deaths between 1988 and 2014 by almost two-thirds, discordant data which should raise questions about the ability of primary HPV screening at extended intervals to effectively sustain the accomplishments of cytology-based screening are not acknowledged."[2]

Dr Austin makes several observations about the UK ARTISTIC (A Randomised Trial in Screening to Improve Cytology) trial[3] and points out that protection against invasive cervical cancer is the most relevant endpoint in efforts to optimise cervical screening. "CIN3 and CIN3+ end-points can be significantly misleading in this regard, as most CIN3 cases will not develop into invasive cervical cancers over extended follow-up."[2]

A one-size fits all cervical screening programme that is based on HPV primary screening will also not address the inequities that exist in the current screening programme. Only a publicly-funded cervical screening programme will do that.

References

1. http://www.nsu.govt.nz/news/screening-matters-issue-54-november-2015/update-transition-hpv-screening-consultation
2. R. Marshall Austin. "HPV primary screening: unanswered questions." *Cytopathology*. 24 November 2015 DOI:10.1111/cyt.12279
3. http://www.journalslibrary.nihr.ac.uk/__data/assets/pdf_file/0015/60090/ExecutiveSummary-hta13510.pdf

Changes to Cervical Screening

(May 2016 AWHC Newsletter)

Despite the serious reservations that continue to be raised about the NSU's plan to change the primary cervical screening test from the current liquid-based cytology test to primary HPV screening, the NSU recently announced that it will make the switch to HPV primary screening in 2018.[1, 2]

New Zealand currently has one of the best cervical screening programmes in the world. It was established in 1990 in the wake of the Cartwright Inquiry into the treatment of cervical cancer at National Women's Hospital. Since then the numbers of women who get cervical cancer and the number of women who die from it have reduced by 60%.[3] MOH statistics reveal that there are now 150 – 160 women who are diagnosed with cervical cancer each year, and about 50 women who die from it.

Many women's health groups are therefore understandably anxious at the thought of the NSU making changes to New Zealand's excellent screening programme, and question whether the HPV test will actually be of much benefit to those women who are currently not being regularly screened.

Māori Women

Women who are un-screened and under-screened feature highly in those diagnosed with cervical cancer, and Māori women are disproportionately represented in these statistics. Māori women have a registration rate for cervical cancer twice that of non-Māori women, and a mortality rate about 2.5 times that of non-Māori.[4]

The most efficient and effective way of increasing the rate of regular cervical screening for Māori women and for other under-screened women is to introduce free cervical screening. The AWHC has been actively lobbying for this for some years, as we are often contacted by women who do not understand why breast cancer screening is publicly funded, but cervical screening is not.

Use of International Statistics

When discussing cervical screening the MoH and NSU usually begin by announcing that around 275,000 women die from cervical cancer each year and continue to provide international statistics, but do not mention the actual figures for women living in New Zealand. Of course, New Zealand health agencies are not alone in doing this, but that does not make it acceptable to set the scene for discussions about proposed changes to cervical screening by overdramatising the incidence of cervical cancer in this way.

The facts are that over 85% of cervical cancer cases are found in low-resource countries, with

the incidence and death rates being the highest in sub-Saharan Africa, Central America, South-Central Asia and Melanesia.[5] Most of these countries do not have organised cervical screening programmes, nor do they have the necessary follow-up diagnostic and treatment services.

Information about cervical screening, and HPV and cervical cancer on the NSU website states that “about 80 percent of sexually active women will become infected with HPV at some point in their lives. Most HPV infections have no symptoms, and in nearly all cases (especially in women under 30) the infection will clear on its own in 6-24 months, without the woman even knowing she had it,”[6] yet the information in the pamphlets on cervical screening does not mention this important fact.[7]

New Website

The March issue of the NSU newsletter features an article about the new consumer-friendly website that the NSU is developing on cervical and breast screening which is due to be rolled out in mid-2016.[8]

The article states that “the website will also be accompanied by a social marketing campaign and new consumer resources to help increase screening rates especially for under-screened and unscreened women. The new website, social media and consumer resources are being designed with the help of advertising agency FCB.”

This is not good news. The experience of women’s health groups is that advertising agencies are often not good at producing health information for consumers, as they do not understand the Code of Consumers’ Rights or the need for informed decision-making. They see their brief as being promotional resources rather than providing evidence-based information on the benefits and risks of cervical and breast cancer screening.

The Elephant in the Room

The elephant in the room is the influence of big pharma. At the NSU/MOH consultation meeting the AWHC attended in October last year there were more representatives from Roche in the room than consumer representatives.

It was also obvious from some of the 87 submissions the NSU received that the drug company was behind some of the statements that, when the switch to HPV screening is made, New Zealand women must have access to Roche’s FDA-approved HPV test, as other tests were inferior, or not FDA-approved. For example, one submitter, who of course wished to remain anonymous, wrote:

“I strongly recommend that the Cobas® HPV test is considered for use in New Zealand because it is the only clinically validated, FDA-approved and CE-IVD marked assay for first-line, primary screening of cervical cancer.”[9] Another anonymous submitter even described women’s right to have access to Roche’s test as an equity issue.

It is difficult to know exactly who or what is behind the NSU’s rushed move to adopt an HPV test as the primary cervical screening test. And only time will tell whether it will save money and/or save lives.

References

1. www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/primary-hpv-screening
2. www.nsu.govt.nz/news/screening-matters-issue-55-march-2016/planned-changes-cervical-screening-test-2018
3. www.nsu.govt.nz/national-cervical-screening-programme/about-cervical-screening-programme
4. http://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/cancer
5. http://annonc.oxfordjournals.org/content/early/2014/01/19/annonc.mdt538.full
6. www.nsu.govt.nz/national-cervical-screening-programme/hpv-and-cervical-cancer
7. www.nsu.govt.nz/national-cervical-screening-programme/national-cervical-screening-programme-resources
8. www.nsu.govt.nz/news/screening-matters-issue-55-march-2016/new-consumer-website-development-cervical-and-breast
9. www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/primary-hpv-screening

The Government's New Screening Strategy – Get Rid of the Messenger

(August 2016 AWHC Newsletter)

At the Cartwright Forum held on Friday 5 August, those attending the Forum learned that Associate Professor Brian Cox, one of the speakers at the Forum, had been dismissed from the National Screening Advisory Committee (NSAC) as a result of voicing his concerns about proposed changes to the National Cervical Screening Programme (NCSP).

Given his long involvement and considerable expertise in screening programmes Brian Cox's knowledge is a valuable resource. His inclusion on NSAC also provided an independent voice, but this proved to be unacceptable to the MoH and the current government who want their advisory committees to rubber stamp their decisions, not question them.

In March 2016, the *New Zealand Medical Journal* featured an editorial that recommended caution before making the change from liquid-based cytology (LBC) to the HPV test in 2018.[1] Brian Cox was one of the five authors of the editorial, and after refusing to back down or change his position on the proposed change he was fired.

The editorial stated: "We believe that while primary HPV screening shows promise, particularly in *de novo* screening programs, implementation in New Zealand in 2018 is premature and wrong. This decision could reduce the current level of cervical cancer protection and increase unnecessary referrals for assessment and treatment. The potential physical and psychological cost to women is unknown. Financial projections suggesting savings for the government are optimistic and the proposed change may cost more. The public sector colposcopy services are currently stressed and unlikely to meet further demand without considerable extra resourcing."

Brian Cox was not happy when the NSAC endorsed the proposed change at its November 2015 meeting. He did not agree with them and the committee was supposed to operate by consensus, he said in an interview with the *Otago Daily Times*. "I don't think the Ministry have been as interested in differing views as they should have been."[2]

Professor Marshall Austin, a pathology specialist from the University of Pittsburgh, USA was one of the keynote speakers at the Cartwright Forum. He described the new HPV test as being relatively unproven technology in a number of areas and said New Zealand should be very cautious about changing its world class cervical screening program. Although there are a few countries thinking about changing to an HPV test none of them have actually started doing it yet.

He also clearly explained why it was not safe for New Zealand to base the proposed changes on international clinical trial evidence and population-based modelling. Much of the international evidence is based on conventional cytology, rather than the superior semi-automated LBC that New Zealand has adopted. It is important to note here that the NSU's consultation document repeatedly referred to the Australian program, which unlike New Zealand's, is not based on LBC.

As the *NZMJ* editorial stated:

"Four large European clinical trials provide much of the data used for modelling primary HPV screening. In these clinical trials, 8 of 19 invasive carcinomas tested were negative for HPV 2.5-8 years prior to the diagnosis of invasive carcinoma – a false negative rate for invasive carcinoma of 42%. Three of the four European studies used conventional cytology not LBC, and so their cytology performance is not applicable to New Zealand, where LBC has been the standard since 2008."[1]

Professor Austin went on to draw a parallel between "the unfortunate experiment" at National Women's Hospital and the change to an HPV test. "The irony, in a way, is that they are really proposing an experiment, and that has special meaning in New Zealand because everybody knows that there was another experiment in New Zealand," he said, referring to the Cartwright Inquiry into the treatment of cervical cancer at National Women's Hospital.

He also refuted the claim that HPV is a more accurate screening test than the current cytology test. It is simply not true to say that the HPV test must be more sensitive than cytology as it actually depends on the quality of the cytology.

Furthermore, there are also the issues of over-diagnosis and over-treatment. "Primary HPV screening may harm women through excessive referral to colposcopy and consequent over treatment. HPV screening will detect high-grade squamous intraepithelial lesions (HSIL) earlier, but this will not necessarily reduce overall invasive cancer, as persistent HSIL would have been detected later by cytology before it became invasive. Because the HPV test is less specific than cytology, more women without any identifiable cervical cancer precursor must be sent to colposcopy to find each HSIL. The likelihood of over treatment will be highest in women less than 30 years of age."[1]

Reference

1. www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2016/vol-129-no-1431-11-march-2016
2. www.odt.co.nz/news/dunedin/health/screening-editorial-costs-cox-position