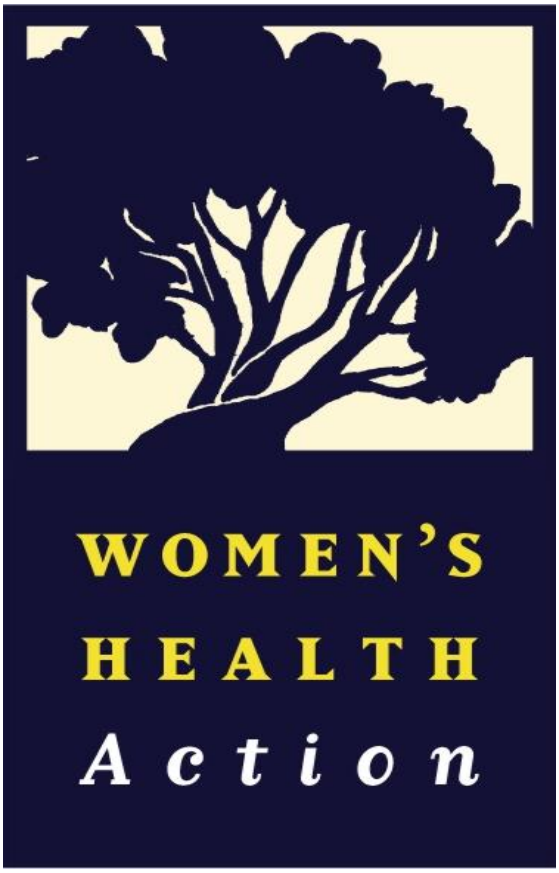

Women's Health Action Trust

Annual Report

April 2007 – March 2008

Women's Health Action Trust

Annual Report
for the year 1 April 2007 – 31st March 2008

Well Women Empowered in a Healthy World!

Introduction

The Women's Health Action Trust, which grew out of the original Fertility Action founded 22 years ago by women's health activist Sandra Coney, is now in its 19th year of operation. This Annual Report covers the period 1 April 2007 to 31 March 2008

We are a nationwide women's health consumer and advocacy organisation. There are a number of streams to our work but the two main streams involve health information and advocacy services for women and consumers across a range of topics and current health issues; and the promotion, protection and support of breastfeeding, particularly focusing on the workplace. Our work providing evidence-based information to meet the needs of women health consumers is extensive. We have a range of publications covering the lifespan – from pregnancy to menopause. These include pamphlets and information packs, which are regularly updated. New resources are developed as the need arises and our Women's Health Update raises current issues and helps to inform the medical profession, Government agencies, pharmaceutical and medical research communities and women and community organisations. We also submit regularly on the health needs of New Zealand women consumers to legislation and to Parliamentary select committees ; and we provide a women's health consumer point-of-view on various bodies set up to oversee such matters. Our website is an additional resource providing up-to-date information to the 100,000 people who access it every three months.

Our support, promotion and protection for breastfeeding involves us in the production of resources and materials and we also work with the Ministry of Health and other breastfeeding organisations to reinforce and support their work. Our particular area of current interest is the transition back into the workplace for breastfeeding women and we have updated our employer pack and put together support material and programmes for employers who wish to be breastfeeding friendly. This work was facilitated and assisted by the active participation of key stakeholders.

We lease our office premises on the second floor in 27 Gillies Road alongside the Health Promotion Forum, ASH, and Alcohol Health Watch. We also lease a part of our office space to Lynda Williams for Maternity Services Consumer Council.

Well Women Empowered in a Healthy World !

Our Vision

Our Vision – manifest by our Mission Statement above - is to ensure that issues relating to gender remain on the public health agenda, thereby ensuring women health consumers' needs are recognised, understood and met, and to provide women health consumers with up-to-date quality evidence-based information to assist them to make informed decisions around their health and the health of their family.

We will achieve our Vision by -

1) Stimulating debate to strengthen the ability of the public health and non-government organisational (NGO) communities to contribute to the wellbeing of all women in Aotearoa-New Zealand
2) Promoting women's interests and providing a woman's voice in research, education and policy where there are implications for women's health
3) Providing women with information and evidence based resources to enable them to make informed choices and decisions around their own health needs
4) Ensuring the viability and increasing the future capacity of WHA

We categorise the work we do to achieve our Vision under three main headings –

1) Major Issues of Concern to Womens Health, including Breastfeeding
2) Education Services and Information
3) Consumer Representation and Networking

WHA Trustee Jesse Solomon with son Arlo

Director's Report

Introduction

The 2007/08 year has been a challenging one for Women's Health Action Trust. Most of the period has been dominated by staff difficulties (see below) but, despite this, we have maintained our profile and outputs. Thanks for this are due to core long term staff, who worked under duress to maintain performance and quality. We are also extremely grateful to contract Policy Analysts – Gill Sanson and Jesse Solomon – who increased their hours and extended their workloads to ensure that the work was done. We start the 2008/09 year in much better shape and are pleased to start the year by welcoming Christy Parker to the staff as Policy Analyst.

Highlights of the 2007/08 year were once again a very successful series of events in the second half of 2007 – World Breastfeeding Week, the Cartwright lunch and the Suffrage breakfast. World Breastfeeding Week saw an increase in the number of participants and in the number of venues. There was also much more 'local ownership' of the event with consequent increased local media coverage. World Breastfeeding Week has become a signature event for Women's Health Action Trust and embodies many of our fundamental principles of community development and empowerment. It is also valuable in bringing a whole new generation of young women exposure to the organisation and our work. We owe this recognition to the solid and consistent work of breastfeeding advocate, Louise James.

A significant contributor to a turnaround of our beleagured fortunes in the latter half of this year has been the recruitment of Isis Mckay -Smith as our office co-ordinator. Isis has taken to her job with optimism, enthusiasm and alacrity. The most tangible evidence of this has been the outstanding increases in resources distributed. Information Packs distributed for all of 2007 numbered 34. In the quarter relevant to this report (January to March 2008) Information Pack distribution jumped to 53. This followed active promotion generated and organized by Isis. Isis has also streamlined many of the office systems and processes and her manner of operating has lifted our profile across the health community and with many of the organisations we work alongside. Isis is an active and enthusiastic networker.

This year got off to a challenging start with the loss of two valued staff members and with Director, Jo Fitzpatrick, assuming the Chair of the Ministry of Health NGO Working Group. Two new staff appointment were effective from March 2007 but the second half of 2007 was particularly difficult for Women's Health Action Trust. The new employees put an incredible strain on the organisation as the second half of the year – with World Breastfeeding Week, our Cartwright activities and our Suffrage breakfast makes this a busy time. This, with increasing responsibilities on the Director as Chair of the MoH/NGO Working group made for a challenging 2007. Women's Health Action has proved resilient in challenging times. Thanks are due to the steady stewardship from a committed Trust governance group and to all staff and supporters for maintaining outputs and morale under incredibly difficult circumstances.

Staff changes

This has been a difficult year for staff at Women's Health Action Trust. The two new recruitments to staff – the Office Co-ordinator and the Policy Analyst proved challenging for different reasons and the second half of 2007 was dominated by activity to deal with these challenges. The Policy Analyst left the staff temporarily to go onto a sickness benefit in early August – after a protracted period of non-delivery and absence from work due to her multiple morbidities. She was offered the opportunity to return in the New Year but has since found employment elsewhere. We increased work hours for our contracted part–time Policy Analyst staff. Particular thanks are due to Jesse Solomon and Gill Sanson, who increased their hours and their workloads to cover Policy Analyst work.

The Office Co-ordinator left in October after an extensive period of training and orientation which saw no appreciable improvement in her performance. In a small organisation, dysfunctional staff and non-delivery from staff puts a huge strain on all staff and the organisation. A staff workshop in October was necessary to deal with the aftermath of the disruption caused and to help prevent further erosion of valued staff. To cover to the end of the year, we employed a temp for the Office Co-ordinator position. Emma Kelly was a welcome addition to the staff and we are grateful to her for stepping in at short notice and doing a great job. We also contracted Sheffield Consultants for advice on future recruitment.The new office co-ordinator, Isis Mckay Smith started the year with us in 2008 and she has proved an excellent addition to the staff.

The last quarter of this year was without Policy Analyst support as we undertook a comprehensive recruitment process for this position. It was a process which was time and resource intensive. Over 60 people applied for the position and a shortlist of seven were interviewed. We were delighted with the choice and quality of candidates and are delighted to welcome Christy Parker to the position at the start of the 2008/09 year

WHA Director Jo Fitzpatrick with Policy Analyst Christy Parker and fellow health activists at the "Sprit of Peace" on the 5th of August

WHA Staff- Louise James (Breastfeeding Advocate) and Jude Berman (Office Coordinator) with Trustees Dr Virginia Braun and Maike Blackman

Women's Health Action appreciates the support given by the Ministry of Health through funding contracts, ongoing contact and encouragement in our work. We gratefully acknowledge funding from the ASB Community Trust, J R McKenzie Trust, Lottery Welfare, and Smokefree. Donations and grants from these organisations enable us to continue to provide independent information and advocacy services. We also appreciate the support of our sponsors and the individuals who donate gifts for the raffles at our two annual functions.

A Snapshot of our Work during the 2007-2008 Year

WHA provided information and assistance to individual women and health service providers	We responded to almost 800 phone calls, 700 fax and email enquiries and a number of personal calls during the year from individuals, health professionals, students and women's groups. Our Website www.womens-health.org.nz continues to be a major source of health information both in New Zealand and internationally, and this year we have started to re-build and update it. We expect to launch a new website later in the 2008.
WHA ran a programme of seminars and events	Our seminars include two 'Managing menopause' educational seminars in May and November 2007, our always popular annual Cartwright Lunch (August) and Suffrage Day Breakfast (September), and we organised the NZ World Breastfeeding Week in August – with the big "latch on" of breastfeeding mothers simultaneously putting baby to breast at 10am on 8 August 2007. With the highest participation rates internationally we took the title as 'Breastfeeding Champions of the World'.
WHA published and distributed information for individual women, community groups and health professionals, and made public comments in the media on matters affecting women's health	Over 10,000 Women's Health **Update** newsletters were distributed at each publication date during the year – May, August and November in 2007 and January 2008. These are funded by the Ministry of Health (MoH). We have updated our Information Packs, pamphlets, fact sheets and mailed out hundreds of these throughout the year. These include topics such as – Vitamin K for Babies (over 10,000 posted out) Use of Ultrasound in Pregnancy (3750 posted out), Fibroids, Heart Health, HIV Reports, HRT, the intrauterine contraceptive device (IUCD) Mirena, Polycystic Ovarian Syndrome (PCOS), hysterectomy, caesarean section, oral contraceptives, breast implants, etc Although we get many requests for the Heavy Menstrual Bleeding and Fibroid pamphlets, we have not yet been able to source funding to reprint this. We also sent out numerous Employers' Breastfeeding Packs, and Toddler, General and Maori Breastfeeding Posters . A new resource is the 'Breastfeeding Controversies' poster.
WHA represented, and advocated, for women health consumers at a number of seminars and events – including attendance at some international events	• MoH/NGO Working group • HIV Screening in Pregnancy Implementation group • Food Standards NZ • Epsom Day hospital • Auckland District Council of Social Services • Womens Studies Association conference • Auckland Coalition against Violence Network • Consumer Collaboration of NZ • UNIFEM Breakfast, International Womens Day • NSU Consumer Reference Group • DHBs and Regional Public Health Services meetings • Infant Feeding Association of NZ • Organ Donation NZ • Advertising Standards reviews • UN Convention on the Rights of the Child Working group • Health Information Standards Organisation (HISO) • NZ College of Midwives events • La Leche League, Auckland Breastfeeding Assn

1. Breastfeeding

1.1 World Breastfeeding Week 2007: We are the Champions of the World!

Louise James, our breastfeeding advocate initiates activities to celebrate and bring awareness and publicity for breastfeeding during **World Breastfeeding Week** which occurs early in August each year. This year the campaign went international with an extremely successful "**World Wide Latch On**". In total, 9825 mothers in 14 countries took part in the event at 325 different sites worldwide.

New Zealand lead the way as the first country to start so at 10am on 8 August 2007, 937 breastfeeding mothers at 118 locations from Kaitaia to Invercargill, in the Chatham Islands and even in an aeroplane above Auckland Airport all put their babies to the breast for a world record-breaking simultaneous breastfeeding event.

After the event, the Phillipines organiser's went looking for the Champions of the World by calculating the participation rates using the ratio of participants compared to the number of babies born. New Zealand emerged as the clear winner and we were declared the breastfeeding champions of the world.

Research shows breastfeeding is extremely beneficial to both mothers and babies – positively influencing the future health of both and increasing the intellectual and emotional development of children.

WHA believes that having full information on the benefits of breastfeeding is important for women in helping them make an informed choice which will benefit themselves and their children. More importantly, we believe that women need a facilitative social climate in order to make breastfeeding a comfortable choice for them, particularly in the workplace.

Information from the World Alliance for Breastfeeding Action (WABA) suggests if babies worldwide were exclusively breastfed for six months, and then introduced to appropriate solids while breastfeeding continued until the child is two years, almost 2.5 million babies per year worldwide would be prevented from dying.

Breastmilk provides –

- **ü** 100% of energy intake for a baby from 0 to 6 months
- **ü** 70% of energy intake for a baby from 6 to 8 months
- **ü** 55% of energy intake from a toddler from 9 to 12 months
- **ü** and 40% of energy intake for a toddler from 1 to 2 years

  Fresh foods complement continued breastfeeding for toddlers.

1.2 Breastfeeding and Work

Research indicates that returning to work is a major barrier for women in the initiation and continuance of breastfeeding beyond the period of Paid Parental Leave.

We have worked extensively with employers and their representative groups to promote breastfeeding friendly workplaces. We also work with official government agencies with an interest in these areas – Human Rights Commission; EEO Trust; Department of Labour, State Services Commission and with organisations representing labour – the Council of Trade Unions (CTU) and their women's committee; individual unions and the Auckland Working Women's Resource Centre.

A new and developing area of work is with the District Health Board HEHA managers who have been given breastfeeding friendly workplaces as one of their priorities. We have established good relationships with many of them and provided material for their intranet – where we are listed as a resource.

We have also been involved with research in the area as part of a Centre for Midwifery and Women's Studies research project. This has been submitted for publication to the Australian Lactation Journal

1.3 Parent and Child Shows

We are now participating regularly in Parent and Child Shows nationwide. We use our networks and resources to liaise with La Leche league and local breastfeeding advocates for stalls at Parent and Child Shows in Auckland, Wellington and Christchurch. Our breastfeeding advocate, Louise James, organises posters, handouts and stall furnishing and set up – attending all shows. She also liaises with locals to ensure that stalls are well staffed for the duration of the show. We also use the opportunity to run 'questionnaires' and extend our knowledge around areas of breastfeeding where information is scarce.
This year, we also worked with local breastfeeding advocates at the Waikato Wyeth Child and Parenting Show. After significant lobbying, this campaign was successful with Wyeth pulling their exhibit from the show.

WHA, stall at the Auckland Parent and Child Show 2007

The WHO Code

It is almost 28 years since the International Code of the Marketing of Breastmilk Substitutes (the WHO Code) was adopted by the World Health Assembly in 1981.

Over 118 countries (including the USA) have legislated all or many provisions of the Code. New Zealand is not one of those countries. We rely instead on an unsatisfactory self-regulatory code of practice put in place in 1997.

This voluntary code of practice is inadequate, and easily broken by infant formula manufacturers. This occurs on a regular basis in New Zealand.

Our 'Codewatchers' purse pack provides mothers, midwives, and other interested people with the information on what constitutes code breaches and how to complain when they come across breaches of the Code. This has been picked up internationally and adapted for use in other countries.

The WHO Code prohibits certain aggressive infant formula marketing strategies, such as:

1. Promoting infant formula through health care facilities
2. Lobbying health care personnel with free gifts
3. Providing free formula samples to new mothers
4. Using words or pictures in advertising which idealise bottle feeding

The Code also insists that formula advertising and labels include the facts about the benefits of breastfeeding, and the hazards associated with formula feeding.

The Code does not prohibit the existence of infant formula nor the choice to bottle feed. Instead, it seeks to give all women facts about feeding their babies free of marketing influence, so that they can make free and informed choices. The Code tries to level the playing field so that the superiority of breastmilk is not lost in the landslide of formula marketing.

The introduction of 'new' products often mean New Zealand mothers are subjected to an intense advertising campaign. This year Nutricia added a supplement to its Karicare Toddler Gold Plus "claiming that it made it more like breastmilk. The new ingredient caused problems. Following complaints to the NZ Food Safety Authority (NZFSA) which found that Nutricia had added an untested ingredient to its formula, Nutricia launched an aggressive campaign – essentially advertising the product. (See August 2007 Update article)

Protesting in Hamilton against formula company sponsorship of Child and Parenting Show

1.4 Other

New resources
New resources have been added to our information resources for breastfeeding include: the 2007 World Breastfeeding Week poster; the 'Breastfeeding Controversies' poster and the Skin-to-Skin leaflet.

Networks
Our breastfeeding networks are comprehensive and extensive. We are represented on the governance board for the New Zealand Breastfeeding Authority by Jude Berman. We are the secretariat for the Auckland Breastfeeding Network and Louise James, our breastfeeding advocate is also a founding member of the Infant Feeding Association of New Zealand. We also work with general networks in the area of infant feeding and child health – Plunket, Well Child providers, NZ College of Midwives, Parent's Centre, Childbirth Educators, La Leche League, Agencies for Nutrition Action, Food Standards Authority of Australia and NZ (FSANZ), and the Auckland District Council of Social Services. We are on the Infant feeding Advisory group for FSANZ and our work there this year resulted in the initiation of a research project on infant formula in a contested environment.

This year, we also wrote to all the District Health Board newly appointed Healthy Eating/Healthy Action (HEHA) mangers congratulating them on their appointment and offering our support for their breastfeeding initiatives. We attended and supported all relevant workshop areas for a series of seminars around the Pan HEHA review initiated by Auckland District Health Board.

Social Marketing
Women's Health Action has attracted attention for its successful social marketing around breastfeeding and we were invited to present at the NZ Social Marketing conference on our work.

2. Women's Health Issues

2.1 Electronic Health Records and Privacy Issues

The Cartwright Inquiry in the late 1980s led to a major overhaul of health care delivery in New Zealand. Ethics committees were formed, a Health & Disability Commissioner was appointed, a Code of Rights drafted, and patient advocates were established. The Cartwright Enquiry was also a seminal event in that it led to the establishment of Fertility Action which later became Women's Health Action Trust.

We continue to take particular interest in the ownership and management of personal health records, the implications of the use of a unique identifier, links between records, and the rights of researchers and health professionals in relation to those of female patients. We remain concerned about the lack of public knowledge on the National Health Index (NHI) and its implications.

We have been disturbed at legislated changes to the National Cervical Screening Programme (NCSP) which provided the potential for all health information on women who are enrolled on the NCSP currently held by their GPs, to be accessed by health researchers without the knowledge or approval of the woman concerned. This appears to have had a 'flow-on' effect where ethics committee's and others are changing their orientation towards research and patient rights. Increasingly we believe that they see their role as facilitating research rather than protecting participants.

We are also concerned that people generally may be unaware of the Memorandum of Understanding (MoU) between MoH and the NZ Police which would allow access by the police to the country's historic store of Guthrie Cards (newborn metabolic tests).

With new technology allowing for increasing access and mobility for electronic health records, we have been involved with the district health boards (DHBs) in seeking ways to improve the need for greater transparency, consumer information and consultation, and the need for retaining privacy – especially with the introduction of the TestSafe database in the Auckland region. We strongly believe that consumers have a right to know what is happening with their records and deserve the security of knowing that there are measures in place to protect their personal health information.

The emerging issue in this area is the increasing availability of genetic testing and its implications. The Guthrie cards are an unregulated source of rich genetic information which is attracting attention from macchiavellian researchers keen to get access to them.

2.2 Gardasil

In July 2006, Medsafe approved the use of a vaccine (Gardasil) against human papilloma virus (HPV) which can lead to cervical cancer, and since then the New Zealand Government has approved a budget to fund vaccination of all young New Zealand women aged from 11 years to 16.

Cervical cancer is caused by human papilloma virus (HPV), a common, sexually transmitted infection. There are many types of HPV (possibly as many as 200) and only a few “high risk” types can lead to abnormal precancerous cells. However, all women who have been sexually active will continue to need to have regular cervical smears, whether they are vaccinated or not. This is because the vaccine only protects against two types of HPV associated with cervical cancer and it is unknown at this stage how long protection will last. Booster doses may also be required in the future.

Cervical cancer is one of the most preventable of all cancers. A woman’s best protection against developing cervical cancer is having regular cervical smear tests, between the ages of 20 and 69 years, which can reduce her risk of developing cervical cancer by 90 percent.

Womens Health Action has considerable concerns about Gardasil. Its makers, Merck, lobbied the Government intensely to have the vaccine included on the national immunisation schedule, and yet there is currently only enough research to show that the vaccine is effective for five years, nor are its long-term effects and efficacy known. Internationally concern is growing over the side effects. While there may be a role for this vaccine among populations which are not well served by screening programmes, we question whether a country such as New Zealand – with a well established screening programme, and low incidence of cervical cancer – requires such a widespread vaccination among its young women.

We remain concerned about the official attitude to vaccination in general. There is an underlying assumption that ‘informed consent’ does not allow for people to refuse vaccination – on the basis that given sufficient information, then the only informed decision is to be vaccinated. This puts health professionals under enormous pressure as high refusal rates are seen as indicators of defective practice.

2.3 Herceptin

Over recent years public pressure has been placed on PHARMAC (the government funding agency for pharmaceutical drugs) to fund Herceptin in early treatment of HER-2 positive breast cancer for at least 12 months. This drug, Herceptin was previously approved in New Zealand for the treatment women with the late stages of (metastastic) breast cancer (HER2-positive).

Herceptin is one of the most expensive medications on the current market – coming at a cost of at least $30 million. PHARMAC eventually reached the conclusion that funding Herceptin for nine weeks along with chemotherapy medicines would be the most effective use of this expensive drug. They cite the Finland Herceptin trial (FinHer trial) which found that after three years, in 90 out of 100 women with HER2, breast cancer had not come back in women who were treated with chemotherapy plus Herceptin for nine weeks. The nine week treatment greatly lessens the high risk of heart damage and other adverse effects from the drug.

The PHARMAC decision and its process was challenged in the High Court by a breast cancer advocacy group. Women's Health Action was asked to submit an affidavit on Pharmac's consultation with us – which we did. The case was mostly rejected but the High Court did request that Pharmac reconsult on the issue. From April to July 2008, PHARMAC went through a thorough consultation and decision making process which went beyond that directed by the High Court. This included seeking new advice from PTAC and its cancer treatments sub-committee, revising the budget impact and the cost-utility model for Herceptin (both concurrent 9 weeks and 12 months), as well as undertaking wide consultation which included face to face meetings with breast cancer patients and oncologists.

Having gone through that process, PHARMAC's confirmed its view that funding for 12 month treatments cannot be justified. They do subsidise a concurrent 9 week treatment of Herceptin with chemotherapy as an effective, complete and fully funded treatment for women with HER2-positive early breast cancer.

WHA has supported PHARMAC in its work, and questions the way in which breast cancer advocacy groups have focused on the current public funding regimes rather than questioning the high pricing of the drug by the pharmaceutical companies. We have also commented extensively on these issues in the media.

Herceptin, produced by Roche costs up to $100,000 for 12 months, per individual treated. This extraordinary cost is justified by Roche (whose total net profit last year was $US 5.25 billion) as part of the inherent value of life-sustaining therapies, alongside the defence offered by pharmaceutical companies that they spend the bulk of their budgets on research and development. Recent investigations have revealed, however, that most of these companies spend more on the marketing drugs than on research and development.

2.4 HRT and What's Replacing It

New Zealand women responded well to information about the US Women's Health Initiative (WHI) studies which found potential adverse health effects for women using Hormone Replacement Therapy (HRT) including increased heart disease and the increased possibility of breast cancer. Fewer New Zealand women are now taking HRT.

However, there is evidence of an ongoing international campaign to re-evaluate the WHI studies and "rehabilitate" HRT which is a cause for concern. There are also worrying trends with new medications seeking to treat the so-called "diseases" of the middle years for women.

A recent trend among drug manufactuers has been a push for "oestrogen-only " HRT as having fewer negative side effects, but again, little long-term research has been done into these claims. For instance, with the drop in HRT, sales of Fosamax **(**a type of drug called a bisphosphonate) has been increasing as an alternative to HRT, and again – our research indicates that this is yet another drug being marketed which might have adverse effects on women who take it for any length of time. There are growing concerns that because Fosamax and other bisphosphonate drugs suppress normal bone remodelling, long-term use may result in brittle bones that fracture more easily.

The benefits to bone of calcium supplementation are also now showing emerging risks. A five-year Auckland University study was recently halted when it was found that supplementing with 1000mg of calcium a day increased the incidence of heart attack by 40% of women over 70 years of age.

We cannot emphasise enough the fact that HRT should be used only for the treatment of severe menopause-related hot flushes in the lowest dose for the shortest time possible. We continue to urge women to use natural means to assist with menopause symptoms.

2.5 Mirena

Mirena is a T-shaped intrauterine contraceptive device (IUCD) which is inserted into the womb. The vertical arm or stem of the device contains a small storage system of a hormone called levonorgestrel which is slowly released over a period of five years to the living of the womb. Two removal threads are tied to the loop at the lower end of the vertical arm. Mirena is effective (almost 100%) at preventing pregnancy with only one or two pregnancies per year for every 1000 women using it. It is usually recommended for women who have had at least one child, and have no history of pelvic inflammatory disease, or of ectopic pregnancy or of conditions that would predispose them to an ectopic pregnancy.

Mirena has been put on the 'free' list of medications for the control of heavy periods and use has increased exponentially across a number of indications. When initially released, it was placed on the Intensive Medicines Monitoring Programme because of concerns about it. However, while patients initially enrolled are subject to limited followup, no new patients are being enrolled and no reports are publicly available on the findings from the initial cohort of women enrolled. Mirena is advertised directly to consumers regularly – both on television and through the Family Health Diary.

Women's health groups, however, have reservations about Mirena, citing side effects lasting several months including severe pain, headaches, heavy bleeding, depression and decreased libido. Some women describe the first few months as their body adjusts to Mirena as one long PMT episode.

2.6 Direct to Consumer Advertising (DTCA), and new "diseases"

WHA has been actively opposed to Direct to Consumer Advertising (DTCA) since it emerged in New Zealand in the early 1990s. New Zealand is virtually isolated in its permissive stance towards DTCA with the USA being the only other country in the developed world allowing DTCA, although there are on-going strenuous efforts being made by pharmaceutical companies to have it introduced in the European Union, Canada and Australia.

In 2003, a report to the Minister of Health found that DTCA did not provide appropriate and balanced information to the health consumer, can have deleterious effects on public health funding and resources, has negative effects on patient-clinician relationships, that there are significant patient safety concerns, and there is a lack of evidence demonstrating any claimed benefits of DTCA.

We have a further concern that following DTCA, certain drugs such as Xenical are allowed to become available as "over the counter" medicines and are able to be purchased by consumers without them knowing much about potentially severe side-effects, nor with the approval of a GP which may be necessary if the consumer is taking other prescription drugs, or has health problems other than weight concerns.

We also believe DTCA leads directly to the formation of "new diseases" which encourage consumers to think they need prescription drugs to "cure" the problem. These "new diseases" range from osteoporosis, pre-menstrual disorders, over-active bladder through to sexual dysfunction. We are consistently highlighting information about the increasing medicalisation of

these ordinary life processes and how drug companies can turn us all into patients.

2.7 Trans-Tasman Agency to Regulate Therapeutic Products (TTARP)

WHA became involved in the TTARP as an offshoot of our interest and opposition to DTCA. We also welcomed the opportunity it could provide to regulate therapeutic devices – especially breast implants and interuterine contraceptive devices which are again being advertised widely. Initially we were appointed as consumer advocate on the TTARP Advertising committee, and then more recently we were appointed as alternate consumer advocates to the Advertising Implementation Steering group. However the planned Trans Tasman Agency for the regulation of therapeutic products has been put on hold after the Government failed to get support for it in Parliament. Instead, a Medicines Strategy for New Zealand has been developed which adds a different dimension to the discussion.

2.8 Depo-Provera, Young Women, and Birth Control "Patches"

Womens Health Action continues to be concerned that the use of Depo-Provera contraceptive injections for teenagers and young women can lead to loss of bone density. The USA Food & Drug Administration (FDA) issued warnings about the longterm use of Depo-Provera – warnings also taken up by the United kingdom Committee on Safety of Medicines.

WHA has updated its Depo-Provera Fact Sheet to provide information on the uses and action of the drug, its advantages, side effects and disadvantages as well as examining some of the social and safety issues that have arisen with it.

We have also noted concerns being raised in the USA that the use of the birth control patch **Ortho Eva** may be leading to strokes, blood clots and deaths in young women who were thought to be at low risk for blood clots. An analysis of reports filed with the American Food & Drug Administration (FDA) appear to indicate that the risk of blood clots is three times greater for women using the patch than for women using contraceptive pills.

2.9 HIV Screening in Pregnancy

A programme proposing that HIV Screening be offered to women in pregnancy is now being implemented throughout the country. This does not mean that all pregnant women will be routinely screened for HIV, but that they will be offered HIV screening which they are entitled to refuse.

WHA is one of the consumer representatives on the National Antenatal HIV Screening Implementation Advisory Group (NAHSIAG). This Group is administered by the National Screening Unit and meets quarterly.

We have long been concerned about the implementation of national screening for Ante-Natal HIV, and as a member of the advisory group WHA has been able to raise issues of informed consent, accurate consumer resourcing and the medicalisation of pregnancy. As many women who are a high risk for HIV infection are migrants to New Zealand, difficulties with language can be a significant barrier for true understanding and informed consent. Non-English speaking women need to be made aware of their right to ask for a professional interpreter, and members of Primary Health Organisations (PHOs) also need to be aware they can draw on "access funding" for such costs. There is a danger though that non-English speaking women will not use interpreters because the PHO may charge them for this.

2.10 Stem Cell Research

Genetic technology is presented as the new miracle cure, a way to eradicate disease and prolong life, a technology with the ability to control the creation of life itself, a tool for health management. Research and use of genetic technology continues to expand worldwide including the use in biotechnology, genetic engineering and genetically modified food. Some of the wider issues around gene technology concerns embryonic stem cell research, and the use of women's eggs – ova, ovum, oocytes – from actual women following hyperstimulation of her ovaries. We are concerned at the very real possibility of potential abuse of women in such research, and have joined calls for international regulation of embryonic research.

2.11 Pesticides and Breast Cancer

New Zealand has one of the highest rates of breast cancer in the world, and it has been estimated that 80% of breast cancer cases are associated with environmental factors that include lifestyle, diet and exposure to contaminants. New Zealander Dr Meriel Watts set out to identify what synthetic chemicals may be contributing to breast cancer. Her research took three years, and resulted in the book "Pesticides and Breast Cancer : A Wake Up Call" which WHA helped to launch this year. One pertinent fact in it is : there may be as many as 42 pesticides still in use in this country which could be contributing to the risk of breast cancer of NZ women.

2.12 Media Activity, and Issues of Concern to WHA

We monitor newspapers, magazines, radio and television, providing all media with positive comment on topics of women's health, or on other issues that arise. In addition to the normal everyday work of our staff in relating to the media on breastfeeding in the workplace and public areas, and women's health issues, other media-related activity arose on a number of issues of concern to women generally.
These included -

- Countering the public pressure that 12 months use of Herceptin is of more benefit than the nine weeks plus chemotherapy provided by PHARMAC.
- On-going comment about DTCA which we believe preys on the vulnerability of people who are desperately ill.
- Using the Code of Marketing of Breastmilk Substitutes to complain, and have withdrawn, advertising of infant formula which breach the Code
- Actively seeking ways to highlight the continuation of violence and abuse against women and children in domestic situations
- Commenting about the negative impact sexism in advertising has on womens' self-esteem,
- the frivolity of articles in womens magazines and their prurient concentration on the private lives of so-called "celebrities".

2.13 Lobbying and other Advocacy Initiatives

WHA is a consumer advocacy service, and advocacy is an everyday part of the Trust's business. We continue to keep a watching brief on a number of issues, and to advocate for the voice of women and health consumers to be heard, and heeded.

We believe this is a legitimate activity for this organisation (and other NGOs) to undertake, and we are perturbed that there may be some difficulty with the concept of government funding support for NGOs which undertake advocacy and lobbying activities as part of their core business.

The NZGG states [1] "*It was clear from the international evidence that this role is largely accepted in the other countries studied. For example, the Canadian Women's Health Network is funded specifically to alert the government to emerging issues"*

We note also from The Treasury Guidelines for Contracting with Non-Government Organisations that the Principles of Good Contract Management include "*respecting the autonomy of the voluntary sector"* [2] and that *"the contractual relationship should* ***not*** *be used to prevent the NGO commenting on public policy matters"*[3]

[1] NZ Guidelines Group October 2004 "Effective Consumer voice and Participation for New Zealand' discussion document
[2] Executive Summary, Treasury Guidelines
[3] Selecting A Provider, Chapter 2, Treasury Guidelines

3. WHA's Information and Education Services

3.1 Information

We receive most requests for information from individual women health consumers and others come by phone, fax or email, with the occasional letter or a visit in person. We get other requests for assistance and researched information from health professionals as follow-ups to conferences, seminars, submissions and networking with health, womens groups and educational institutions.

We continue to update our pamphlets and information packs and have now completed

- Help for Hot Flushes
- Cervical Cancer
- Depo-Provera
- Breast Implants
- Caesarean Section
- The IUD – Mirena
- Ultrasound Scans During Pregnancy
- WHO Code Watchers
- HRT New Information
- Move It or Lose It
- Menopause
- Hysterectomy
- Endometriosis
- Osteoporosis
- Polycystic Ovarian Syndrome
- Vitamin K – Does my baby need it ?
- Fibroids
- Heart Health for Women

Our Information Packs cost $10 each, and the Fact Sheets are $1, and we mail out hundreds of these each year to individual women and to groups of women. (In the last year we have mailed out over 3750 Ultrasound Scans and over 10,000 Vitamin K Pamphlets).

3.2 Website

Our website continues to grow and receives excellent feedback. Outdated material is archived, and there are additional documents or pdf files available for downloading.

The website now contains almost 200 pages, receives an average of about 100,000 hits every three months, and maintenance of the website continues on a regular basis.
There are at least 350 other sites linking to www.womens-health.org.nz.

We put all our submissions on the website after the closing date and work with other interested organisations to develop our submissions and encourage them to submit their own. This is a service appreciated by other groups.

We have obtained funds from the ASB Community Trust to re-develop and update the website, and are planning a database structured site which will allow staff members to add pages to it without mediation from the web person. This will allow the site to be more interactive and we will have the facility to post material which is topical and current, along with updating the health strategies section of the site which is intended to be a major resource for New Zealand researchers and health professionals.

3.3 Women's Health Update Newsletter

Women's Health UPDATE is distributed free to health professional service providers and women's groups courtesy of funding from the Ministry of Health. Current funding allows us to distribute 8000 copies per time, but requests this year for the newsletter are now almost 10,000 per publication which has created some limitations in circulation. **UPDATE** was published in May, August and November in 2007, and in January 2008. Articles during this year included:

- Cervical Cancer Vaccine doesn't rule out Need for Screening
- Screening for HIV in Pregnancy
- Medical Council guidelines – Cosmetic Surgery
- Formula company flouts food safety boundaries
- Drug, Device and Therapeutic Products Agency on "hold"
- HRT Rollercoaster leaves women confused Again
- World Breastfeeding Week 2007
- The Burden of Osteoporosis
- Update on Gardasil
- Global Safe Abortion Conference Report
- World Breastfeeding Champions
- NZ Research on Place of Birth
- Home Birth Renaissance
- The First National Breast Cancer Conference
- Pesticides and Breast Cancer

Articles from Update appear on our website *www.womens-health.org.nz*

We are frequently approached by groups wishing to use articles from our publications in their newsletters. We allow this but do ask that our authorship is acknowledged in the reproduction. Many groups are alerted to the issues we raise, and access the articles, through our website.

3.4 Annual Events

Each year we hold two major public events - celebrating Womens Suffrage Day and the publication of the Cartwright Report following the Inquiry into the treatment of women patients with carcinoma-in-situ at National Womens Hospital.

- **Judge Patrick Mahony and Katharine Greig** spoke on Truth and Reconciliation in the Twilight Zone – the story of a confidential forum for former psychiatric hospital inpatients at our annual **Cartwright Lunch** on 9 August held at Ferndale House in Mt Albert.
- **Lawyer and Director of Stop Demand, Denise Ritchie** presented images of women in New Zealand's sports media with excerpts from sports chat shows such as Sport's Café and Game of Two Halves which graphically illustrated the continuation of public humiliation to women in New Zealand, at our **Suffrage Breakfast celebration on 19 September 2007.**

Speakers, Judge Patrick Mahony and Katharine Greig with WHA Director and Chair at the Cartwright Lunch 2007

College Students at the WHA 2007 Suffrage Breakfast

3.5 WHA Menopause Seminars

WHA runs two menopause seminars each year – known as the Spring and Autumn workshops. They are advertised as regular WHA events on our website and in publications. We advertise in community newspapers and also send out flyers and email alerts, and we continually get a good response at each seminar.

Courses cover the biology and chemistry of menopause, attitudes to menopause, the experiences of course participants, information on lifestyle changes, evaluation of treatment options, latest information on HRT and its patterns of use, and practical information on osteoporosis risk, prevention and treatment. The one night format is popular but it does make for an "intensive" course which seems to suit the women attending. The workshop is facilitated by health educator, Gill Sanson, who ran menopause seminars for the Family Planning Association (FPA) for many years. Women who attend the course are given one of our Menopause Packs, and all seminars are evaluated.

4. Consumer Representation & Networking

4.1 Policy Analysis, Discussions and Advice

Most of the formal work WHA does in this area is by way of submissions to relevant legislation. With the addition of a policy analyst onto our staff, we have increased submission numbers. We are putting together a system to record the number of submissions sent to us for comment, the number we search out for ourselves, and what action we take with respect to these. Standards NZ send submission information but we are only able to respond to a small percentage of these. Some MoH ones are sent to us, but most are not and we search for and download these from the internet.

We completed 35 submissions throughout the year – the details of which are :

Ministry of Health

- Family Violence Death Reviews *May*
- Primary Health care Strategy: Key Directions for the Information Environment *May*
- Future Directions for the care, management and treatment for service users with eating disorders in NZ *June*
- New Born Blood Spot cards *June*
- Preferred Options for Changes to the Well Child/Tamariki Ora Framework *August*
- Food and Nutrition Guidelines for Healthy Infants and Toddlers *September*
- Temporary removal of restricted activity: Psychosocial interventions and mental illness *October*
- Let's Get Real consultation *October*
- The Health NZ Proposal *February 2008*

Ministers

Letter to Ministers of Justice, Health and Women's Affairs re Abortion Supervisory Committee *June*

NACEW (National Advisory Council on the Employment of Women)

- Priority improvements to Paid Parental Leave *June*

NZ Medical Council

- Proposal to review the vocational scope of breast medicine *December 06*
- Statement on Cosmetic procedures *May*
- Statement on Cosmetic procedures *July*

National Screening Unit

- National Cervical Screening Programme Laboratory Strategy *June*
- National Cervical Screening Programme Laboratory Strategy (2nd consultation) *October*

Health & Disability Commissioner

Review of Policy on Naming Providers in Public HDC Reports – *January 2008*

ANZTPA

- Improving access to Consumer medicine Information and Product Information *March*
- Medicines Labelling *March*
- Regulation of human cellular and tissue therapies under ANZTPA *June*
- In vitro devices regulatory Scheme *June*

NZ Food Safety Authority

- Domestic Food Review *February*
- Maximum residue limits of agricultural compounds *June*

Privacy Commissioner

- Proposed Amendments to the Health Information Privacy Code *May*

Midwifery Council

- Second Scope of Practice: Midwifery Assistant *October*
- Recertification of the Midwifery Council *December*

Select Committees

- Government Administration**:** Gambling Amendment (No 2) Bill *October*

Waitemata DHB

- PHO policy; After hours Primary Care *October*

ACART

- Advice on Aspects of Assisted Reproductive Technology *August*

Food Safety Authority NZ

- Proposals to amend the New Zealand maximum residue Limits *October*
- Assessment of Report Proposal P306 Addition on Inulin/FOS & GOS to Food and Initial Assessment Report Application A609 Addition of GOS, Long

Ministry of Justice

- Review of the operation of the Prostitution Review Act 2003 *August*

PHARMAC

- Proposal to list a wider range of condoms on the Pharmaceutical Schedule *November*
- Submission in support of PHARMAC on Herceptin

New Zealand Breastfeeding Authority

- Breastfeeding Training Standards Submissions Form – *February 2008*

World Alliance for Breastfeeding Action

- WBW 2008 – Action Folder Review – *February 2008*

Select Committees

- Submission on the Public Health Bill – *March 2008*
- Chain to Infant Formula and Infant food. – *February 2008*

4.2 Networking with Women's groups and Key Health Agencies

Networking continues to be integral to the work of WHA. We have established extensive links and collaborations with other agencies and information flows between our organisations is constant and issues based. We share information with other NGOs interested in women's health, speak with other women's groups regularly and compare notes at least once a month with the FPA policy analyst.

Our networking also covers a wide range of health professionals and related activities, and these have included meetings with NZ Endometriosis Foundation; HDC Commissioner, Ron Paterson ; School of Population Health re Advertising ; Visiting Chinese Women about domestic violence ; Kerry Chamberlain, Massey University re DCTA and disease-mongering ; Screening and management of diabetes in Pregnancy programmes ; PHA Conference programming committee, attendance at Conference ; NGO Working Group forum planning; BSA Auckland & Northland Configuration Steering Group ; Meeting UNICEF, La Leche League and others re involvement in WBW ; NZ Food Safety Consumer Forum ; NAHSIG – HIV Screening in Pregnancy; and so on.

4.3 Consultations, Working Parties, and Reviews on Womens Health Issues

We have attended, and participated in, a large number of working parties on issues to do with women's health in the widest possible sense – including violence against women, prostitution bylaws, endometriosis, privacy issues and workplace matters.

We are consumer representatives on, and we attend as many DHB and Regional Public Health Services planning and programming meetings as possible, Fertility NZ Conference and meetings, Alcohol marketing symposiums, Health Information Standards Organisation – Security and Authentication Subcommittee (HISO), NZ College of Midwives events, Breastfeeding groups and La Leche League, trade union and workplace meetings, and so on.

We also support other groups and NGOs by circulating notes and discussion papers around significant topics published for public debate.

4.4 National Women's Health Database

The database continues to expand with over 1500 groups including around 160 Maori and 47 Pasifika health care providers. There are also more than 10,000 individuals on the database. We are constantly adding and deleting individuals and groups as they come and go, and receive requests daily from people wanting to be added to the database for **Update**, or notification of events and activities. The database is both current, and dynamic

4.5 Consumer Representation

WHA provides a consumer's voice as members of the following committees and working parties:

- Epsom Day Service Quality Group (ongoing)
- NZ Consumer Collaboration (NZGG)
- MoH-NGO working group (Chair) including Forums held in Christchurch and Auckland
- HIV Screening in Pregnancy Implementation group
- Food Standards Authority of Australia and NZ
- NZBA/National Breastfeeding Committee
- Public Health Association
- Auckland District Council of Social Services
- National Screening Unit Consumer Reference Group
- Standards NZ Fertility Services Standard
- Infant Feeding Association of NZ
- NZCOM Midwifery Review Panel
- UN Convention on the Rights of the Child Working Group
- TAPS six monthly review of DTC advertising (hosted by the Association of NZ Advertisers)
- Auckland Women's Health Council
- Roche – consumer views consultation

The People at Womens Health Action, and Our Supporters

Staff

The staff at Womens Health Action during the past year were –

• Jo Fitzpatrick	Director
• Louise James	Breastfeeding Advocate
• Irene Johnson	Librarian
• Linda Mckay	Financial Controller
• Joanne Adams	Policy Analyst
• Catherine Farmer	Office Coordinator
• Isis Mckay – Smith	Office Coordinator
• Gill Sanson	Policy Analyst
• Jesse Solomon	Policy Analyst

Trustees during the year were

• Paulette Benton-Greig	Chairperson
• Jesse Solomon	Secretary
• Jenny Kirk	Treasurer
• Dr Virginia Braun	
• Lydia Sosene	
• Maike Blackman	

WHA Consultants

WHA uses the services and expertise of many women in different ways, and we greatly appreciate the contributions they all make to our work. During this year the following women in particular have regularly contributed to our activities

Linda McKay	Gill Sanson
Gail Reichert	Avril Stott
Kristen Berger	Sandra Coney

Auditors **BDO Spicers**

We also appreciate and acknowledge the support shown by our partners and families – particularly during the busy times of media campaigns and deadlines.

The History of Women's Health Action

Women's Health Action started life as Fertility Action in 1984, when it helped New Zealand women wanting to take claims for Dalkon Shield damage to the United States Courts. FA worked with the YWCA and West Auckland Women's Centre to set up support groups for women injured by the Dalkon Shield.

In 1987 FA members Sandra Coney and Phillida Bunkle wrote an article The Unfortunate Experiment which led to the Cartwright Inquiry into the treatment of patients with carcinoma in situ at National Women's Hospital. The immense amount of work for the inquiry, the high media profile developed during the inquiry, and the follow-up work placed an additional and great demand on what was essentially a volunteer organisation. The inquiry led to a continuing workload for the organisation and a need for monitoring the issues raised by Judge Cartwright in her report, particularly around cervical screening, patient's rights, the Health Commissioner Bill and patient advocacy, informed consent and the need for information on health issues.

A private donation received in May 1989 enabled Fertility Action to set up an office, and make our service better organised and more accessible. Fertility Action was re-named and re-constituted as Women's Health Action Trust and the office is now centrally located in Newmarket – close to bus and train transport. Other community health advocacy groups occupy offices on the same floor of the building, and we have been able to be cost-effective in sharing some of our equipment with these other groups.

Among highlights in the work of WHA over the years have been –

- *Working with women damaged by the Dalkon Shield IUD to get their cases into the US Courts for compensation, and the subsequent major re-examination of IUD use*

- *Broadening the focus on consumer rights which gave people permission to question ethical conduct in the health sector, led to the formation of ethics committees and eventually to the establishment of the Office of the Health and Disability Commissioner*

- *Bringing to public prominence the issue of life-threatening blood clots in young women using third generation contraceptive pills, resulting in a dramatic reduction in the use of such pills*

- *The HRT campaign when we made sure good quality information on the US research studies was quickly available to New Zealand women, again resulting in reduction in the use of such medication by NZ women.*

- *Our continuing advocacy for breastfeeding of babies by their mothers especially in public places and workplaces.*

- *And continuing to seek the removal of direct-to-consumer advertising by drug manufacturers*