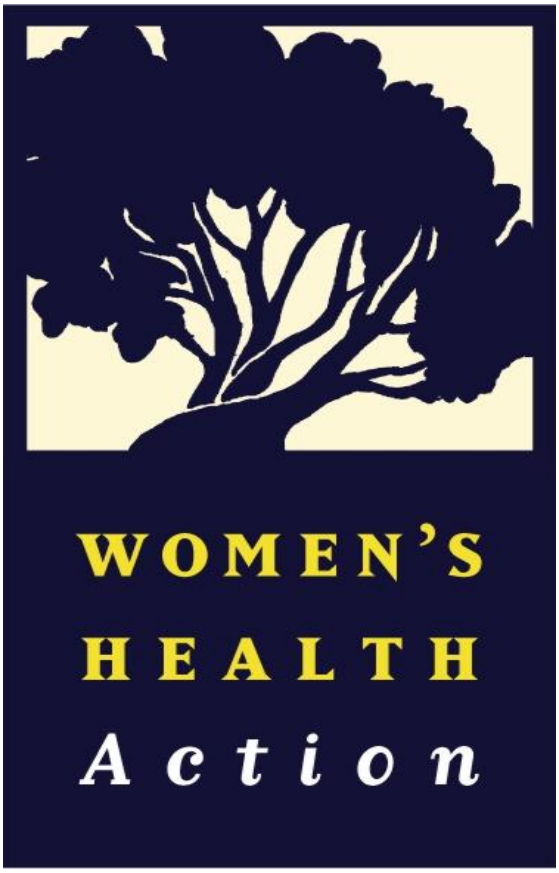

Women's Health Action Trust

Annual Report

April 2006 – March 2007

Women's Health Action Trust

Annual Report
for the year 1 April 2006 to 31 March 2007

Well Women Empowered in a Healthy World !

Introduction

Women's Health Action Trust grew out of the original Fertility Action, founded 23 years ago by Auckland women's health activist Sandra Coney, and is in its 19th year of operation. This Annual Report covers the period 1 April 2006 to 31 March 2007.

This has been a year of continuing consolidation for the Trust Board of Womens Health Action (WHA)[1]. We were pleased to support our Director Jo Fitzpatrick's nomination as chair of the Non-Government Organisations-Ministry of Health (NGO-MoH) Working Party, and onto the Organ Donation NZ Governance committee. Our chair Paulette Benton-Greig has helped strengthen the work of WHA, with Jesse Solomon continuing as Secretary, and Jenny Kirk as Treasurer. Other trustees are Maike Blackman, Lydia Sosene, Ginny Braun, with Karen Skinner seeking leave to travel overseas.

We accepted, with considerable regret, the resignation of our long-serving coordinator-administrator, Linda McKay. Linda resigned to concentrate on her own work, but has continued her involvement with WHA with oversight for our financial administration. Her office coordination role was filled by Jude Berman, who was a competent and welcome addition to our staff. Jude was known to Women's Health Action for her work with Louise James organising World Breastfeeding Week. Louise James our breastfeeding coordinator goes from strength to strength in this role, and is becoming a well-known media spokesperson and advisor on breastfeeding issues. World Breastfeeding Week gains more profile with each passing year. Irene Johnston our librarian took leave to travel overseas and has since returned, and Kristen Berger our policy analyst took maternity leave on January 12th and delivered her beautiful baby girl, Mika, on January 15th.

We lease our office premises on the second floor in 27 Gillies Road and share the floor with other public health NGO's - the Health Promotion Forum, ASH, and Alcohol Health Watch. We also lease a part of our office space to the Maternity Services Consumer Council - Lynda Williams and Jennie Valgre. We are also on the governing body of the Auckland Women's Health Council and make our space at Women's Health Action available for their monthly meetings.

[1] The use of acronyms in health can be confusing. Wherever possible we spell out the full name initially, and thereafter use the acronym.

Well Women Empowered in a Healthy World !

Our Vision

Our Vision – manifest by our Mission Statement above - is to ensure that gender remains on the public health agenda, and thereby ensuring women health consumers' needs are recognised, understood and met. We also provide women health consumers with up-to-date quality evidence-based information to assist them make informed health decisions for themselves and their families.

We 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 four main headings –

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

WHA Chairperson Paulette Benton-Greig with trustee Lydia Sosene at the Cartwright Lunch celebration

Director's Report

Womens Health Action Trust continues to be active in responding to requests for resources on women's health issues, making submissions from a consumer perspective on legislation relating to women's health issues and consumers generally, providing research linkages and references for others, and working alongside other agencies dealing with health matters affecting women and consumers.

August is a busy month for WHA and a highlight of our year. The month kicks off with World Breastfeeding Week, and we always produce a comprehensive report on the activities undertaken throughout New Zealand by breastfeeding mothers during WBW. This year we hosted two students from the School of Population Health to do a preliminary comparison and analysis of WBW activities for 2005 and 2006. Their powerpoint presentation and a full report is available on request.

The other annual event in the first week of August is the anniversary of the release of the Cartwright Report. Traditionally we hold a lunch dealing with some aspect of patient or consumer rights within health. This year we invited Dr Inga Hunter to present her pilot research on how consumers feel about the recording and dissemination of their health information. This was a well attended event which drew in the Privacy Officers from all the major hospitals in the region. It also went over its scheduled time as people got absorbed in the issue and the discussion and debate.

We have continued to seek a new direction for our website, and intend to undertake a major redevelopment project in late 2007. We continue to be concerned that two very popular pamphlets – Heavy Menstrual Bleeding and Fibroids – face an uncertain future and we are referring requests for these to the agencies directly responsible for the original publications.

Staff changes
Linda McKay who has been the Trust's office coordinator since its inception resigned in June to take up other work related to women's health issues, and a new coordinator Jude Berman was appointed. Linda continues to oversee the Trust's accounts on a part-time basis.

Kristen Berger, Policy Analyst has taken a years maternity leave. Mika was born on January 15th 2007 and Kristen and Simon were married in New York City in the summer. We extend our love and best wishes to them all. Joanne Adams, Gill Sanson and Jesse Solomon have all worked part-time to cover this position in the interim. Jude left the role of administrator in April to spend time with her young children. She continues to support Louise for WBW. The position has been filled by Catherine Farmer.

MoH/NGO Working Group
Jo Fitzpatrick, Director of WHA was elected as co-chair and deputy chair of the MoH/NGO Working Party late last year and in December was elected to the position of chairperson for this group.

WHA Director Jo Fitzpatrick with (clockwise from right) Librarian Irene Johnston, Breastfeeding Advocate Louise James and our outgoing Administrator, Linda McKay.

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 annual Suffrage function.

A Snapshot of our Work during the 2006-2007 Year

WHA provided information and assistance to individual women and health service providers	We responded to 572 phone calls, 531 email enquiries and 778 personal calls during the year from individuals, health professionals, students and women's groups. We also distributed information packs and data sheets to a number of women. Our Website www.womens-health.org.nz continues to be a major source of health information both here in New Zealand and internationally.
WHA ran a programme of seminars and events	Our seminars included two menopause seminars, a Direct-to-consumer advertising strategic planning coalition with other NGOs and ourselves, a presentation on the American Public Health Association Conference for other NGOs , our always popular annual Cartwright Lunch (August) and Suffrage Day Breakfast (September), breastfeeding stalls at the Parent & Child Show, and World Breastfeeding Week (August). WHA also ran a series of Young Women workshops to identify issues important to women in the 20-30 year cohort.
WHA published and distributed information for individual women, community groups and health professionals, and made public comments in the media on matters affecting womens health	Almost 15,000 Health **Update** newsletters were distributed at each publication date during the year – July and November 2006, January and May 2007. These are substantially funded by the Ministry of Health (MoH). We also published and distributed our own Health **Watch** newsletter in June and December 2006. We have updated our Information Packs, pamphlets, fact sheets and mailed out hundreds and thousands of these throughout the year. The subjects of these include – Vitamin K for Babies, Use of Ultrasound in Pregnancy, Fibroids, Heart Health, Hormone Replacement Therapy (HRT), the intrauterine contraceptive device (IUCD) Mirena, Polycystic Ovarian Syndrome (PCOS), hysterectomy, caesarean section, oral contraceptives, breast implants…. W continue to get many requests for the Heavy Menstrual Bleeding and Fibroids pamphlets. A new Code Watchers purse pack leaflet was developed for World Breastfeeding Week and sent out with comprehensive information on the Code for WBW activities.
WHA represented, and advocated, for women health consumers in a number of Forums, at seminars, events and conferences – including attendance and presentations at some international events	• MoH/NGO Working group meetings and Forums • HIV Screening in Pregnancy Implementation group • Epsom Day Hospital • NSU Consumer Reference Group • Health Information Standards (HISO) workshops, • Fertility Services Standards Group • NZ College of Midwives events • La Leche League, Auckland Breastfeeding Assn American Public Health Assn Conference • Disease-Mongering Conference, Australia • Womens Studies conference NZ • PHA Marketing symposium • Preventing Violence conference • HIV/AIDs in the Pacific Conference • UNIFEM Breakfast, International Womens Day • Fertility NZ Conference • DHBs and Regional Public Health Services meetings

1. Major Issues

1.1 Health Records, Cervical and Breast Screening, and Privacy

The Cartwright Inquiry in the late 1980s led to a major overhaul of health care in New Zealand. Ethics committees were formed, a Health & Disability Commissioner appointed, a Code of Rights for Patients drafted, and patient advocates established. The Cartwright Enquiry was a seminal event for WHA 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 issue of ownership and access to health records, the implications of the use of a unique identifier, the increasing vulnerability of health information provided by electronic records allowing data matching and the ability to transmit records at the push of a button. We maintain an ongoing interest in the rights of researchers and health professionals in relation to the records of female patients, and consumers generally

We have been disturbed at legislated changes to the National Cervical Screening Programme (NCSP) which provide the potential for all GP health information on women enrolled on the NCSP to be accessed by health researchers without the knowledge or approval of the woman concerned. We believe this has set a precedent and keep this issue under constant vigilance.

We are also concerned that people generally are unaware of the Memorandum of Understanding (MoU) between MoH and the NZ Police which allows access by the police to the country's historic store of Guthrie Cards (newborn metabolic tests). We are also watching the increasing research interest in this rich data source.

New technology allows for electronic health records, containing huge amounts of easily transmitted information, to be more widely used and available to a wider range of people. In Auckland the introduction of TestSafe, opening up laboratory information to health providers across the region, without consultation with consumers or key community providers, saw us being deluged by concerned women and NGO's. We met with Dwayne Crombie, who was leading the project, and the district health board (DHB) Privacy Officers to discuss ways to protect privacy and increase security of data management systems. We also looked at ways providing opportunities for consumer input, consultation and education in future.

This year's Cartwright lunch focused on this issue with Dr Inga Hunter's research presentation. There were over 50 people in attendance who found the subject fascinating. The discussion following the presentation was lively and went significantly beyond the allocated time. We believe this indicates a public interest in these issues and we look forward to hosting more debates on these matters. The study presented by Dr Hunter was a pilot and a larger study has now been commissioned.

We have ongoing involvement with population screening programmes in New Zealand, being represented on the NSU Consumer Reference Group, the HIV Screening in Pregnancy Implementation group and recently completing the detailed information booklet for women entering the Breastscreen Aotearoa programme.

1.2 Primary Health Organisations (PHOs) and NGOs

Most New Zealanders now belong to a PHO – a community grouping of doctors, nurses and other health professionals established to provide community based health services. The intention is that these should be available at a lower cost than previously and the government has introduced subsidies for doctors visits for most people. The primary health care strategy is a world leader in primary health care and designed to encourage a preventive, holistic approach to health at a community level.

There are, however, problems with integration of the work of current health-related Non-Government Organisations (NGOs) and that of PHOs which have still to be resolved. Among these concerns are the potential for PHOs to "take over" the work of NGOs without recognition of the specialist skills built up by NGOs, or the fact that NGOs grew out of and are rooted in community. This is developing as a particular problem for specialist services for women as DHB's and PHO's look to provide sexual abuse services, eating disorder services and cervical smears for difficult to reach populations.

1.3 The Hype over Herceptin

Over the last couple of years breast cancer lobby groups have placed pressure on PHARMAC (The Government Funding Agency for Pharmaceutical Drugs) to fund Herceptin for 12 month treatment of early HER-2 positive breast cancer. Herceptin (trastuzumab) is approved in New Zealand as a drug treatment for women with late stage (metastastic) HER2-positive breast cancer.

The increasing public pressure posed a significant challenge to New Zealand's public health system as 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 for early breast cancer. They cited the Finland Herceptin (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. This nine week treatment greatly lessens the high risks of heart disease and other adverse drug effects associated with the use of Herceptin.

However, the public pressure to fund the drug for 12 months has continued, and although the emotive personal stories of women with breast cancer make headlines, fuel petitions and feed public sympathy for those women unfortunate enough to have HER2-positive breast cancer, this does not make a sound and evidence based platform for health policy decisions.

Women's Health Action entered this debate reluctantly but felt that it was necessary given the unrealistic expectations these public campaigns were generating in women with early HER2 positive breast cancer. We also felt there were wider implications in the debate which deserved to come under public consideration.

Breast cancer advocacy groups have focused on the way current funding regimes ignore needy patients. What has not been addressed the inequities generated by the articulate few getting expensive drugs with limited efficacy while many people – particularly those who are poor and brown – don't get access to health services we know would benefit them based on strong and well established evidence.

Neither have these same groups nor the media questioned the high asking price of the drug by the pharmaceutical companies. 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 lifesustaining therapies, alongside the defense offered by pharmaceutical companies that they spend the bulk of their budgets on research and development. Recent investigations consistently reveal, however, that drug companies spend more on marketing drugs than on research and development.

We believe that private drug companies have a moral and ethical duty to resist the temptation of using vulnerable people with a terminal illness as their public face for endorsing and lobbying for highly expensive drugs of limited efficacy which come with a real danger of severe adverse reactions and without adequate evaluation over a period of years.

See the Women's Health Action Trust website for ongoing discussion and analysis of these issues.

1.4 Hormone Replacement Therapy (HRT) and Fosamax

New Zealand women responded well to information from the US Women's Health Initiative (WHI) studies in 2002 which found potential adverse health effects for women using HRT. Fewer New Zealand women are now taking HRT and US studies indicate that we can expect a drop heart disease and breast cancer rates in midlife women in New Zealand as a result.

Of particular interest, statistics presented at the 29th Annual San Antonio Breast Cancer Symposium in December 2006 suggest that a consequence of the drop-off in HRT use may have lead to a significant decrease in the rates of breast cancer. While the data is inferential, the most likely explanation for the drop is thought to be tumours stopping growth, shrinking or disappearing without HRT fuelling them. (See January 2007 Update)

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

The continuing "research" into the results of the early research such as the Womens' Health Initiative (WHI) seeks data to re-establish HRT as an effective treatment for midlife women. WHI continues to publish findings, and as yet there is no evidence to show that HRT is of use other than for extreme cases of severe menopausal hot flushes.

A recent trend among drug manufacturers has been a push for "oestrogen-only " HRT as having fewer negative side effects, conveniently forgetting that 'combined' HRT was introduced because of the increased likelihood of ovarian cancer with 'oestrogen-only' HRT use in women who had an intact uterus. With the drop in HRT, new drugs have emerged to fill the pharmaceutical gap. One which is particularly worrying is **Fosamax (**a type of drug called a bisphosphonate) for osteoporosis which has been increasing promoted as a 'bone saving' alternative to HRT. We have been concerned at the lifting of restrictions on the prescribing of this drug and the extensive Direct – To-Consumer advertising of it. This is yet another drug which has potentially serious 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. It is also a drug with a very long half life so it remains in the body for many years. The criteria for eligibility for this drug has widened, and we have found evidence that it is now becoming "routine" for older people who fracture. We have taken this issue up with the Minister of Health.

We continue to emphasise that menopause is a natural life transition rather than an illness or malady. We organise regular menopause seminars with experienced menopause educator, Gill Sanson, which attract large numbers of women and receive excellent evaluations. .

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

WHA has been actively opposed to 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, raises significant patient safety concerns, and lacks any evidence base demonstrating any claimed benefits of DTCA.

With the withdrawal of painkiller drug VIOXX, WHA again pointed out the need for New Zealand to discontinue the practice of allowing DTCA – particularly in relation to drugs which have not been fully tested for potential adverse side effects before going on the market. More recently, in the May 2007 Update, we pointed out that drug company Merck have been actively lobbying for the inclusion of Gardasil vaccination of young girls (aged 10 to 12 years) into the routine vaccination schedule to prevent cervical cancer, and that a more precautionary response is warranted.

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 potential 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 medicalisation of normal life experiences. The creation of "new diseases" by drug companies encourages consumers to think they have a problem which need conveniently developed new prescription drugs to "cure". These "new diseases" range from osteoporosis, pre-menstrual disorders, over-active bladder through to sexual dysfunction. In May 2005 our newsletter WATCH brought attention to Proctor & Gamble's new testosterone patch **Intrinsa** for use in treating women's "sexual dysfunction" (ie women deemed to have a low sex drive) without FDA approval for use of this patch. FDA's concerns about Intrinsa centre on the safety of long-term use and inadequate testing for its use.

Again, in September 2005 WATCH highlighted information sourced from the July 2005 seminar on "Evidence and Consumer Information" about the increasing medicalisation of these ordinary life processes and how drug companies can turn us all into patients.

Our Director, Jo Fitzpatrick attended the inaugural disease-mongering conference in Newcastle, Australia, to give a presentation on the use of DTCA in New Zealand and reported on the conference findings in the June 2006 WATCH. At the same time we continue being involved in the bi-annual consumer meetings of the Association of New Zealand Advertisers (ANZ) which not only gives us the opportunity to comment on the actual advertising, but also the opportunity to access industry information on DTCA campaigns and expenditure.

1.6 Trans-Tasman Agency to Regulate Therapeutic Products (ANZTPA – the Australia/NZ Therapeutic Products Agency)

WHA became involved in the creation of a trans-Tasman Agency to regulate therapeutic products as a consequence of our interest in and opposition to DTCA. We welcomed the opportunity it could provide to regulate therapeutic devices – especially breast implants and intra-uterine contraceptive devices which have not been subject to regulation in New Zealand. Initially we were appointed as consumer advocate on the Advertising committee, and then more recently we were appointed as alternates to consumer representative Jean Drage on the Advertising Implementation Steering group, and have continued to be involved in plans for this Agency's rollout. However the future of the Agency is uncertain as political parties in New Zealand pick up the concerns of lobby groups expressing opposition to the inclusion of complementary products in the scheme. The scheme is currently in abeyance.

1.7 Anti-depressant Use

Recent PHARMAC figures have confirmed the anecdotal reports we have had about increasing use of antidepressants in New Zealand. In September 2005, (GSK) GlaxoSmithKline issued a warning for popular anti-depressant Aropax after a new study had found increased risk of birth defects for pregnant women taking the drug in their first trimester. The study of over 3500 pregnant women in the US showed a 1% increase in the rate of birth defects (mostly heart defects) in the children of women taking Paroxetine. This drug is one of the top ten anti-depressants sold worldwide, and is the most popular type of anti-depressant in New Zealand taken by more than 54,000 people. These drugs have also been contra-indicated for use in children and teenagers as it is believed they increase the suicide risk for these populations.

1.9 Younger Women and Health Issues

WHA has worked successfully in the past to bring greater attention and responsiveness to women's health needs. We have noted, however, that there is little data available on younger women's health needs. We are particularly concerned about the dearth of information for young women in the 20 to 30 age group. This is a decade when women make many life transitions and face increasing pressures and expectations. We have had difficulty getting information on the health impacts of these pressures on women in this age cohort. This year we began to investigate ways to identify the health challenges for these women to ascertain ways in which WHA can effectively develop health information relevant to their needs.

Younger women often sit outside of formal systems. When they are considered at all, they are typically the focus of negative attention and morbidities such as the rising smoking, drinking and risk-taking behaviours. Another common public concern is fertility rates in younger women. If they are brown they are too fertile and if they are not, they are delaying fertility for too long.

The current WHA research organised focus groups among a diverse range of young women, using student researchers in the needs assessment process, with a focus on a holistic view of health. Our preliminary research with younger women indicates that their fertility concerns are – as they have always been – effective contraception. They prefer to keep themselves free of pregnancy in their teens and twenties, or to choose when they get pregnant.

Their universal concern was juggling the plethora of life choices and decisions they are faced with at this time and the impact these decisions will have on the course of their lives. Their dilemma is not a lack of choice, but the range of competing choices and expectations – around careers, life partnerships, children. They want to have it all but are at a loss to understand how this might be achieved. There is no generally understood heirarchy for managing these competing choices and expectations and no road map for negotiating one's way through them. This manifests itself in their health status as stress, depression and anxiety – and these impact on their emotional health and wellbeing. Efforts to reduce or relieve stress also may result in unhealthy and self defeating behaviours.

1.9 HIV Screening in Pregnancy

WHA is a consumer representative on the National Antenatal HIV Screening Implementation Advisory Group (NAHSIAG). This National Screening Unit Group meets quarterly and oversees the rollout of the national screening programme for Ante-Natal HIV. As a member of the advisory group WHA raise issues of informed consent, appropriate consumer resourcing and the medicalisation of pregnancy. Our principal concern is that HIV screening in pregnancy does not become one of the 'routine' ante-natal tests without proper, free and fully informed consent. As the programme is rolled out, the greatest challenge which is emerging is obtaining consent from women who don't speak English. This is a major obstacle as these women are more likely to be in the groups with high HIV risk - migrants from high HIV prevalence countries.

1.10 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. 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 harvesting of women's eggs – ova, ovum, oocytes – from 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.

1.11 The WHO Code on marketing of Breastmilk substitutes

It is almost 26 years since the International Code of the Marketing of Breastmilk Substitutes (the WHO Code) was adopted by the World Health Assembly in 1981. This remains a relatively unknown code in the public arena, and one that is often misinterpreted and misrepresented by infant formula manufacturers.

The Code is a set of marketing rules designed to protect both breastfed and artificially fed babies. It does not ban the sale of formula, the use of artificial feeding products or stop health workers from giving information about artificial feeding. It puts restrictions on the marketing of artificial baby milk (formulas), teats and bottles, and complementary food labelled for use by babies under six months.

We believe that increasing breastfeeding rates could reduce infant and young child illness and death more than any other health strategy. Implementation of the Code enables mothers to make informed decisions about how they should feed their babies and toddlers without commercial influence. Unethical marketing of breastmilk substitutes undermines breastfeeding and often contributes to early weaning from the breast which predisposes the child to undue health risks.

We have drawn up a small leaflet labelled "Code Watchers" which provides mothers, midwives, and other interested people with the information on who to complain to when they come across advertising which misrepresents the nutritional aspects of manufactured baby foods.

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Over 60 countries have legislated all or many provisions of the Code. However, New Zealand is not one of those countries.

We rely instead on a self-regulatory code of practice put in place in 1997 and recently revised with substantial industry input from infant formula manufacturers. WHA has been active in complaining about breaches of the Code and this year has seen some notable successes with the withdrawal of some advertisements. Women's Health Action welcomes the establishment in New Zealand of the Infant Feeding Action Coalition (IFANZ) which aims to monitor ongoing Code Compliance and Implementation. We look forward to working with them.

1.12 Media Activity, and Issues of Concern to WHA

We monitor newspapers, magazines, radio and television, providing media with comment and background on women's health topics , breastfeeding in the workplace and public areas, and women's health issues. Notable media-related activity for this year included -

- Opening the debate about the effectiveness and cost-benefit of Herceptin as a cure-all for early HER2 breast cancer.
- Querying the use of female research assistant and students donating their own eggs and body parts to participate in stem cell research
- On-going comment about DTCA as an educative tool for consumers.
- Complaining to the Censor about pornography in Pavement magazines teen birthday edition (Pavement has now ceased publication)
- 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 women's self-esteem,
- The use of very young, and/or very skinny, girls as fashion models

1.13 Lobbying and other Advocacy Initiatives

WHA is a consumer group and advocacy is part of our core business. We continue to keep a watching brief on a number of issues, and to advocate for women and health consumers. This is a legitimate activity for this organisation (and other NGOs) and is funded and resourced independently of our government contracts. We are perturbed with the threat of the withdrawal of government funding support for NGOs which undertake advocacy and lobbying activities as part of their core business.

The NZGG states [2] *"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"* [3] and that *"the contractual relationship should* ***not*** *be used to prevent the NGO commenting on public policy matters"*[4]

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

2. Other Breastfeeding Initiatives

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. 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. WHO estimates at least 1.5 million lives would be saved each year if all children were exclusively breastfed for six months. 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. It is of concern to us that an activity which is both natural to do and of proven benefit to mother and child, continues to receive controversial and adverse comments through the media and from the public and much of our work is aimed at reducing and eliminating these barriers.

Louise James, our breastfeeding advocate, initiates activities to celebrate and bring awareness to **World Breastfeeding Week** which occurs early in August each year. This years 'Latch-On' was an attempt to break the previous year's record for the most women breastfeeding simultaneously at one time. Petra Bagust fronted the publicity to advertise the event, and the poster was used to advertise numerous venues from North Cape to the Bluff. This event drew substantial media attention, but more importantly the participation of 742 mothers and 749 children across the land!

Two (or is it three!) generations participating in the 2006 Big Latch On!

3. WHA's Information and Education Services

3.1 Information

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

We continue to update our pamphlets and information packs we now offer include:

- Pregnancy and Childbirth
  - Vitamin K – Does my baby need it ?
  - Ultrasound Scans During Pregnancy
  - Caesarean Section
- Midlife Series
  - Osteoporosis
  - Hysterectomy
  - Hot Flushes
  - Menopause
- Women's Reproductive Health
  - Depo-Provera
  - The IUD – Mirena
  - Endometriosis
  - Cervical Cancer
  - Polycystic Ovarian Syndrome
  - Gardasil
- Cosmetic surgery
  - Breast Implants
- Action Pack
  - Code Watchers

Many of the inquiries we get from women require a 'tailored' response. We are committed to a response turnaround time of 24 hours and will often do evidence based searches for women – or give them the information so that they are able to access these themselves.

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 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 Newsletters

Women's Health UPDATE is distributed free to health professional service providers, women's groups and opinion leaders 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 July and November 2006, and January and May 2007. Articles during this year included:

- You are what you drink – women, identity and alcohol
- Summer Daze – drink, drugs and rape
- Why patients complain – research report
- An Eye on the Industry – Nutricia infant formula advertising
- National Health Index numbers
- Sacred Secrets meet Cyberspace
- White Ribbon Day – speaking out against Violence towards women
- Declining HRT use linked to fall in breast cancer
- Chlamydia Screening for New Zealand?
- Cervical Cancer vaccine and the need to continue screening
- Migrant women and consent for screening for HIV in pregnancy
- World Breastfeeding Week 2006
- Medical Council Guidelines for Patient Doctor Relationships
- NZ Medical Council looks at guidelines for cosmetic surgery

WHA's own newsletter, **Women's Health WATCH** provides us with an opportunity to research and discuss major topics concerning women. **WATCH** was published in June and December 2006. Articles this year included:

- Stem Cell Research – A women's issue
- The breastfeeding (week) poster fuss
- Health reforms and gender equity
- Unethical clinical trials
- Strange bedfellows – feminism, science and politics
- Abortion and Depression
- Disease-Mongering, DCTA and the proposed Trans-Tasman Agency
- The Hype over Herceptin
- Calcium supplements do not prevent hip fractures
- Maori Youth and Contraception
- Violence against Women
- The Menopause Industry fights back
- Breast Implants
- Chlamydia
- Pregnancy Police
- Skinny and young models
- National Womens' Annual Clinical Report 2005

Articles from both of these newsletters 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 enquiry into the treatment of women patients with carcinoma-in-situ at National Women's Hospital.

- **Inga Hunter**, from Massey University presented the findings of her recent research on patients' attitudes toward sharing health information via electronic medical records at our annual **Cartwright Lunch in August**.

WHA Director Jo Fitzpatrick (left) with Inga Hunter and former WHA trustee Christine Costley at the Cartwright Lunch in August 2006

- **Director at the World Health Organisation,** the United Nations specialist agency for health, and former trustee at Womens Health Action**, Ruth Bonita** spoke from a global perspective on women's health on her return to New Zealand, at our **Suffrage Breakfast celebration on 19 September.**

Guests at the 2006 Suffrage Breakfast – from left, Fiona Johnston and MPs Maryan Street and Darien Fenton

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. They are consistently highly rated by attendees.

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 have put 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. We receive invitations to submit from a number of agencies and professional bodies. Whether we respond, and our level of response, is determined by the importance of the issue, staff resources and priorities. Generally all relevant submissions that are sent to from health professional bodies (Medical Council, Midwifery Council etc) us are responded to. 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 have to search and download these from the internet.

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 are 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.

For some time, Women's Health Action has represented public health organisations on the Ministry of Health/NGO Working Group. This year, our Director was elected Chair of the Working Group. This has extended our networking into the wider Health and Disability sector with twice yearly Forums, weekly email newsletters to NGOs and organizations throughout the H&D sector.

4.3 Consultations, Working Parties, and Reviews on Women's 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 gave a presentation called "Science under Siege" from the American Public Health Assn Conference, and we are consumer representatives on Epsom Day Quality of Service Group. 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 (HISO) workshops, 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 Major Submissions

This year major submissions made include –

- MoH - Guidelines on Using Cells from established Human Embryonic stem cell lines for research, Service Delivery for National Cervical Screening Programme, Australia-NZ Therapeutic proposals re medicines, product licensing, medical devices, administration fees and charges ; Section 88 Maternity Service Notice ; DCTA of prescription medicines, National Drug Policy, Review of Smokefree Environments legislation, National framework for Eating Disorders
- National Screening Unit – Liquid-based Cytology Policy Statement
- Medical Council of NZ (MCNZ) Review of Patient Resources, Statement for Doctors Performing Cosmetic Procedures
- Health Select Committee – Obesity and Type 2 Diabetes in NZ, Human Tissue Organ donors, Gestational Diabetes, Human Tissue for Unspecified Research,
- Corrections Amendment Bill re mothers with babies in prison
- PHARMAC reviews/consultations – Herceptin, Fosamax
- Review of the Prostitution Reform Act by the Prostitution Committee
- Canterbury DHB – Breastfeeding policy consultation documents
- Statistics NZ – NGO Institutions satellite accounts
- NGO Working Group – Workforce Issues

4.6 Consumer Representation

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

- NZ Guidelines Group (NZGG) Consumer Forum
- Ministry of Consumer Affairs Consumer Forum
- MoH-NGO working group strategic planning committee meetings and activities including Forums held in Christchurch and Auckland
- HIV Screening in Pregnancy Implementation group
- Auckland branch PHA Conference Planning group
- WHO Code (for artificial baby milk)
- NZBA/National Breastfeeding Committee
- Public Health Association
- Epsom Day Hospital

The People at WHA and Our Supporters

Staff

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

- Jo Fitzpatrick — Director
- Louise James — Breastfeeding Advocate
- Linda McKay — Finance Controller
- Irene Johnson — Librarian
- Kristen Berger — Policy Analyst
- Joanne Adams — Policy Analyst
- Jude Berman — Office Coordinator
- Catherine Farmer — Office Coordinator

Trustees during the year were

- Paulette Benton-Greig — Chairperson
- Jesse Solomon — Secretary
- Jenny Kirk — Treasurer
- Dr Virginia Braun
- Lydia Sosene
- Maike Blackman
- Karen Skinner (on leave)

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

Gail Reichert	Sandra Coney	Gill Sanson
Avril Stott	Chris Bettany	Jesse Solomon
Jenny Kirk		

Our IT Consultant is Ross Fisher

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.

7. 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*